THE UNIVERSITY OF HULL

Understanding the help seeking behaviour of cardiac patients with erectile dysfunction:

An exploratory study

Being a dissertation submitted in partial fulfillment of the requirements for the Degree of Doctor of Clinical Psychology in the University of Hull

By

Adam Orchard BSc (Hons)

July 2008
Acknowledgments

I would like to begin by thanking the eight men that gave up their time to talk to me about their personal experience of help seeking for ED. I truly hope that I have done them justice by accurately conveying the meaning of their stories in this study.

Thank you to the staff of the cardiac rehabilitation service through which these participants were contacted. In particular, Anita Trotman-Beasty and the staff of the physiotherapy department headed up by Nicola Beaumont. Thank you also to Peter Nicholas (Chair of the support group for patients with Implantable Cardiac Defibrillators).

I would like to thank both Dr Dorothy Frizelle and Patricia Ross for their wisdom, patience and understanding. Their calm, supportive and approachable personalities have kept me going throughout this research and the ClinPsyD course.

Thank you to Fr. Jim O’Brien for welcoming me into his chaplaincy and providing me with much needed sanctuary whenever I’ve needed it.

Thanks of course must also go to my mother and father for their lifelong support of me.

Finally, I close with my biggest thanks to Emma Joyce, someone who has had more faith in me than I will ever believe. Her presence in my life has been inspiring and she has supported me “through thick and thin.” Her unwavering patience and sunny disposition have made what at times has been an horrendous experience, more bearable than she or I could ever fathom.
Erectile dysfunction (ED) is defined by the World Health Organisation as “a continuous or repetitive inability to achieve or maintain an erection sufficient for satisfying sexual activity”. It is a sexual disorder that affects many men and is particularly prevalent in cardiac populations. Since the release of Viagra in 1998, there has been an increased awareness of ED and arguably with it a reduction in the stigma attached to the condition. Despite this, ED remains significantly undertreated.

Sexual dysfunction is an important determinant of a person’s quality of life and subjective well-being. Left untreated sexual dysfunction can have an adverse effect on a person’s mood, well-being and interpersonal functioning. Some have proposed ED to serve as a marker for occult cardiovascular disease and it is therefore vital that men with ED seek treatment promptly in order that they can be assessed for further cardiac risk factors so that preventative or corrective measures can be put in place as necessary to minimise the chances of chronic illness developing.

Researchers have proposed that men’s reluctance to seek help is due to masculine attitudes and beliefs they hold. It has been suggested that help seeking may conflict with men’s socialization of what it is to be a man i.e. being self-reliant, physically tough and emotionally inexpressive. The extent to which masculinity affects men’s help seeking for ED is not yet clear.

In order to increase the number of men coming forward for treatment of ED, we must understand the help seeking behaviour associated with it. Whilst there has been much
research on the prevalence, aetiology, pathophysiology, diagnosis and treatment of ED, very little is known about help seeking for it.

The primary focus of this research portfolio thesis is on men’s help seeking for erectile dysfunction. The specific aim of the research activity is identifying common factors in cardiac patients’ experiences of seeking help for ED; highlighting key drivers and barriers to help seeking for the disorder; and elucidating the extent to which masculinity influences such behaviour.

This portfolio is arranged in three parts. The first comprises a systemic literature review examining the existing research on men’s help seeking for erectile dysfunction. The review attempts to evaluate and synthesise current knowledge about key factors influencing men’s decisions to seek help (or not) for ED. The results of the review highlight the paucity of knowledge in this area and explain why qualitative research is necessary to deepen our understanding.

Part two of the portfolio comprises an empirical study investigating the experiences of eight cardiac patients with erectile dysfunction. The study involved conducting and recording individual semi-structured interviews with participants. All interviews were fully transcribed and analysed utilising Interpretative Phenomenological Analysis. Two super-ordinate themes and five sub-themes are described in the results section. The discussion relates findings to existing theoretical models of health behaviour, and suggests a preliminary model of help seeking for ED.

Part three of this portfolio is Appendixes that provide supporting material to accompany the systematic literature review and empirical research paper.
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PART ONE:

Help seeking behaviour for erectile dysfunction: a systematic review of published research

This paper is written in the format for submission to the Journal of Clinical Psychology

Please see Appendix 2 for Guidelines for authors

Word Count: 7,563 including references (6,187 excluding)
Help seeking behaviour for erectile dysfunction: a systematic review of published research

Abstract

Introduction: Erectile dysfunction (ED) is a highly prevalent disorder that remains largely undertreated. Much is known about the prevalence, aetiology and treatment of ED yet little is known about help seeking behaviour (HSB) related to the disorder.

Aim: To systematically evaluate research on HSB for ED to identifying what is currently known about why some men seek help for ED whilst others do not.

Methods: Five key electronic databases were searched: CINAHL; MEDLINE; EMBASE, PsychINFO; Cochrane Library.

Results: Nineteen papers identified numerous factors involved in help seeking for ED. All studies reviewed utilised quantitative methods. Current understanding of potential interactions between influential factors is lacking.

Conclusions: Qualitative research examining help seeking for ED is highly recommended.

Keywords: help seeking; treatment seeking; erectile dysfunction; impotence; systematic review
Introduction

Erectile dysfunction (ED) is a sexual disorder affecting more than 30% of men aged 40-70 years (de-Boer, Bots, Nijeholt, Moors & Verheij, 2005). The worldwide prevalence of ED is expected to double by 2025 due to the ageing population (Aytac & Krane, 1999).

Since the launch of “Viagra” in 1998, there has been an increased awareness of ED. Whilst this has arguably brought with it a reduction in stigma attached to the condition, ED remains significantly undertreated - just 30% of men with ED seek help (Shabsigh, Perelman, Laumann & Lockhart, 2004). Low treatment-seeking rates have been described as “an important obstacle in improving men’s health” (Banks, 2001, p.1058). Minimal visits to the physician and delays in seeking help attenuate men’s chances of early detection, treatment and prevention of disease (O'Brien, Hunt & Hart, 2005).

Sexual function has been shown to be an important determinant of quality of life and subjective well-being. Left untreated sexual dysfunction can adversely affect mood, well-being and interpersonal functioning (De Busk et al., 2000). Researchers have proposed ED as a marker for occult cardiovascular disease (Feldman, Goldstein, Hatzichristou, Krane & McKinlay, 1994). It is therefore imperative that men with ED are promptly assessed for other cardiac risk factors so that preventative or corrective measures can be taken.

Men however are notoriously bad at seeking help for a whole range of health problems (O’Brien et al., 2005). As a group, men of different ages, nationalities, and racial backgrounds, seek professional help much less frequently than women for a range of problems [Addis & Mahalik, 2003].

If ED associated morbidity and mortality is to be reduced, efforts must be made to increase the number of men seeking help. To do this, we first need to understand men’s help seeking behaviour (HSB) for ED. Whilst there has been much research on prevalence, aetiology, diagnosis and treatment of ED, little is known about help seeking.
The purpose of this review was to systematically evaluate research on HSB of men with ED. Particular attention was paid to highlighting factors that have been identified as influential in HSB for ED and what is currently known about men who do and do not seek help for this disorder.

[See Appendix 3 for a definition of help seeking used in this dissertation]

Method

Data sources and search strategy

A systematic search of the literature was carried out informed by the guidelines from the Centre for Reviews and Dissemination (2001). Key electronic databases were searched: CINAHL, MEDLINE, EMBASE, PsychINFO and Cochrane Library. Databases were selected to ensure that a range of medical, social science, psychological and general reference journals were included. All were searched using the following terms (accompanied by truncation symbols applicable to each database – denoted as “$” here): help seek$ and erect$; health service utilisation and erect$; treatment seek$ and erect$; help seek$ and impot$; health service utilisation and impot$; treatment seek$ and impot$; help-seek$ and erect$; help-seek$ and impot$ (“impot” denotes impotence – a name formerly given to ED). All terms were applied to the “whole document.” Dates searched are shown in Table 1. On-line abstracts were reviewed and reprints of papers potentially eligible for inclusion were obtained. Reference lists of retrieved articles were further searched for relevant articles.
Table 1. Database search dates

<table>
<thead>
<tr>
<th>Database</th>
<th>Period Searched*</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL</td>
<td>1982 – 20th April 2008</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>1950 – 23rd April 2008</td>
</tr>
<tr>
<td>EMBASE</td>
<td>1996 – 23rd April 2008</td>
</tr>
<tr>
<td>PsychINFO</td>
<td>1806 – 23rd March 2008</td>
</tr>
<tr>
<td>Cochrane</td>
<td>1800 – 23rd April 2008</td>
</tr>
</tbody>
</table>

*All databases searched from earliest date available

Selection Criteria

Studies were eligible for inclusion if they provided information on factors associated with men’s (>18 years old) HSB for ED of any causation. Where a study reported help-seeking for sexual disorders in general, stand-alone data for ED had to be reported. Included studies were qualitative, quantitative or mixed methodology and samples could be drawn from clinical and/or non-clinical populations. Searches were limited to English language and human studies. Data reported in grey literature (e.g. unpublished theses, non-peer reviewed papers), secondary sources (e.g. review articles and books) and papers consisting of abstracts only, were excluded. Papers that were not freely available on the worldwide web or directly from authors were excluded due to resource constraints.

Data extraction

Data relating to the aims of the review were collected using a data extraction form specifically created for this study. This structured proforma recorded eligibility and relevant data such as study sample characteristics, the proportion of men who sought help and factors associated with seeking help, or not, for ED. As suggested by Khan, Riet, Popay, Nixon & Kleijnen (2001) it also included items from the quality appraisal tool (discussed below).

[See Appendix 4 for a copy of the data extraction form]
**Appraisal of study quality**

According to Prins, Blanker, Bohmen, Thomas and Bosch (2002), two aspects of validity are important in the assessment of methodological quality: external validity (generalisability) and internal validity (bias and confounding).

For the purpose of the current review, a number of published evaluation instruments were considered and included: the CONSORT statement (Moher, Schulz & Altman, 2001); the TREND statement (Des Jarlais, Lyles, and Crepaz, 2004); the QUOROM statement (Moher, Cook, Eastwood, Olkin, Rennie & Stroup, 1999); the STROBE statement (von Elm, Altman, Egger, Pocock, Gotzsche & Vandenbroucke (2008); and the criteria for the methodological assessment of prevalence studies (Prins et al., 2002).

None of the existing instruments alone however, seemed appropriate for the scope of the review. This was because they did not provide a single tool that could: 1) be applied to different types of methodologies (qualitative and quantitative, experimental and observational, randomised and non-randomised); 2) produce a profile of scores as well as an overall quality score for individual studies; and 3) did not adequately assess external as well as internal validity.

A bespoke tool was thus created to address the aims of this review. In its creation Prins et al.’s (2002) criteria were adapted to include issues specific to ED research as well as the more generic methodological issues (Khan et al., 2001).

Face validity of the tool was maximised via consultation with a qualified clinical psychologist with experience of reviewing and publishing research within health domains.

Test-retest reliability was assessed by blind scoring of five research papers, on two separate occasions, four weeks apart. On both occasions and in all cases, scores were identical on both testing sessions, indicating good test-retest reliability.

[See Appendix 5 for a copy of the quality assessment tool]
Results

Included and excluded studies

Figure 1 illustrates the article selection process for the review. Four hundred and ninety three studies were identified. Initial screening of titles and abstracts eliminated 451 articles that were duplications or clearly not relevant or eligible for the review. Reprints of the remaining 42 articles were ordered for further scrutiny. Of these, 37 were obtained as 5 were not freely available either on the worldwide web or direct from the published author details. Applying the inclusion and exclusion criteria, led to the rejection of 18 articles based on: 1) data on ED indistinguishable from other disorders; 2) participants under 18 years old; 3) no information provided on help seeking; 4) not published in English. Thus 19 articles became the focus of the review.

[See Appendix 6 for details of excluded studies]

![Figure 1. Flowchart of selection process](image)

Findings of the review:

Data are summarized in Table 2. and reviewed below.
<table>
<thead>
<tr>
<th>Paper No.</th>
<th>Author(s)</th>
<th>Publication Date</th>
<th>Country/Continent</th>
<th>Design</th>
<th>No. Of Participants</th>
<th>Mean Age in years (Range)</th>
<th>Marital Status %</th>
<th>% with ED</th>
<th>% who sought help</th>
<th>Main Findings</th>
<th>Quality score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ansong et al.</td>
<td>1998 (Nov 1996 - June 1997)</td>
<td>Rural New York</td>
<td>Descriptive, Questionnaire</td>
<td>1438 (Not Specified)</td>
<td>64.5 (50-76)</td>
<td>Married/Living with partner = 82.9; remainder not specified</td>
<td>46.2</td>
<td>31.6</td>
<td>Confusion over effective treatments; no difference between age groups in help-seeking; mostly primary care workers and urologist seen first; high dissatisfaction with response to help-seeking.</td>
<td>16</td>
</tr>
<tr>
<td>2</td>
<td>Ansong et al.</td>
<td>2000 (Not Specified)</td>
<td>Rural New York</td>
<td>Descriptive (Epidemiological) &amp; Correlational, Questionnaire</td>
<td>1438 (44.7)</td>
<td>64.5 (50-76)</td>
<td>Not Specified</td>
<td>46.3</td>
<td>31.6</td>
<td>Participants reporting ED were significantly older than those not reporting ED; Socioeconomic status, age, marital status and perceived health did not predict help-seeking</td>
<td>15</td>
</tr>
<tr>
<td>3</td>
<td>Mirone et al.</td>
<td>2002 (1997-1999)</td>
<td>Italy</td>
<td>Descriptive and correlational (Cross-sectional), Questionnaire</td>
<td>12761 (Not Specified)</td>
<td>44.5 but based on N=7981 - reason not specified (&lt;30 - &gt;60)</td>
<td>Total Not Specified; &lt;6 months = 17.5; 6 months - 1 year = 22.4; 1-3 years = 26.1; &gt;3 years = 34.0</td>
<td>Total Not Specified; &lt;6 months = 33.6; 6 months - 1 year = 68.3; 1-3 years = 57.4; &gt;3 years = 57.9%</td>
<td>Range of concomitant diseases in men with ED; Approx. 50% discussed ED with their partner (increased with severity) or physician (increased with duration); help initially sought from an andrologist/urologist. Age no effect on number of discussing ED with others. Concomitant disease associated with discussion of ED with physician.</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Kitai et al.</td>
<td>2002 (Not Specified)</td>
<td>Not Specified</td>
<td>Non-randomised (quasi-experimental), Questionnaire</td>
<td>2x250 (41.5)</td>
<td>66.9 (40+)</td>
<td>Married = 83.5; remainder not specified</td>
<td>42.5</td>
<td>Pre-questionnaire = 6.8; post-questionnaire = 9.3</td>
<td>Most men not seen any physicians; Urologist or a family doctor most commonly seen; oral treatment preferred; questionnaire increased discussion of ED with physician.</td>
<td>7</td>
</tr>
<tr>
<td>5</td>
<td>Berrada et al.</td>
<td>2003 (Not Specified)</td>
<td>Morocco</td>
<td>Descriptive Epidemiological &amp; Correlational (Cross-sectional), Questionnaire</td>
<td>646 (81.9)</td>
<td>40 (25-85)</td>
<td>Single = 45.0; Married = 44.6; Separated/ Widowed/ Divorced = 5.1</td>
<td>Total = 53.6; Mild = 37.5; Moderate = 15.0; Severe = 1.1</td>
<td>ED positively associated with age in most. ED correlated with diabetes, hypertension and heart disease; Inverse effect of education and socioeconomic status on help-seeking.</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Shabsigh et al.</td>
<td>2004 (Mar-Sept 2000)</td>
<td>US, UK, France, Germany, Italy, Spain</td>
<td>Correlational, Questionnaire</td>
<td>33644 (Not Specified)</td>
<td>20-75</td>
<td>Single/Never married = 9.0; Married/Living with a partner = 77.0; Divorced/ Separated = 12.0; Widow ed = 3.2</td>
<td>14.0</td>
<td>46.0</td>
<td>ED increased with age; range of drivers, barriers and predictors of help-seeking found; ED alone not sufficient motivation to seek help.</td>
<td>15</td>
</tr>
<tr>
<td>Paper No.</td>
<td>Author(s)</td>
<td>Publication Date (study period)</td>
<td>Country/ Continent</td>
<td>Design</td>
<td>No. Of Participants (% Response Rate)</td>
<td>Mean Age in years (Range)</td>
<td>Marital Status %</td>
<td>% with ED</td>
<td>% who sought help</td>
<td>Main Findings</td>
<td>Quality score</td>
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<td>7</td>
<td>Schover et al.</td>
<td>2004 (Not Specified)</td>
<td>US</td>
<td>Correlational, Questionnaire</td>
<td>1188 (49.0)</td>
<td>68.1 (42-87)</td>
<td>Married = 86.0; In a committed relationship = 6.0; remainder not specified</td>
<td>100</td>
<td>Previously = 46.0; Intend to this year = 44.0</td>
<td>Higher distress about post-cancer ED associated with increased help-seeking; positive attitudes towards help-seeking associated with previous help-seeking for ED and future intent: more men sought help for ED post-cancer diagnosis.</td>
<td>11</td>
</tr>
<tr>
<td>8</td>
<td>Perelman et al.</td>
<td>2005 (2000)</td>
<td>US, UK, France, Germany, Italy, Spain</td>
<td>Descriptive, Questionnaire</td>
<td>2829 (Not Specified)</td>
<td>57 (20-75)</td>
<td>Single/Never married = 9.0; Married/Living with a partner = 77.0; remainder not specified</td>
<td>100</td>
<td>Not Specified</td>
<td>Variation in extent that ED felt as source of great sadness, willingness to accept ED, perceptions of aging, link to partner, and extent to which ED physical or psychological.</td>
<td>10</td>
</tr>
<tr>
<td>9</td>
<td>Fisher et al.</td>
<td>2005 (Not Specified)</td>
<td>US, UK, France, Germany, Italy, Spain, Mexico, Brazil</td>
<td>Descriptive, Questionnaire</td>
<td>449* (Not Specified)</td>
<td>Not Specified</td>
<td>Not Specified</td>
<td>100</td>
<td>66.4</td>
<td>Range of drivers and barriers to help-seeking identified and the experiences of men who had sought help described; possible future motivators for help-seeking elucidated.</td>
<td>6</td>
</tr>
<tr>
<td>10</td>
<td>de Boer et al.</td>
<td>2005 (Not Specified)</td>
<td>Netherlands</td>
<td>Descriptive (Epidemiological), Questionnaire</td>
<td>1481 (44.0)</td>
<td>Not Specified</td>
<td>Not Specified</td>
<td>14.2</td>
<td>10.4</td>
<td>Many men reported need for help, were bothered by ED, and could not accept having it; need for help clearly related to age (declined as years increased); few men given help.</td>
<td>16</td>
</tr>
<tr>
<td>11</td>
<td>Haro et al.</td>
<td>2006 (Apr 2003 - Apr 2004)</td>
<td>Europe (Belgium, Denmark, Germany, Greece, Italy, Norway, Spain, UK)</td>
<td>Prospective, Descriptive (with 3 time points) Questionnaire</td>
<td>8055 (Not Specified)</td>
<td>56.5 (18-90)</td>
<td>In a relationship = 92.7 (80.2 Married/ Cohabiting)</td>
<td>Total Not Specified; Experienced ED 1-5 years = 52.9</td>
<td>Not Specified</td>
<td>Characteristics of men with ED highlighted (substance use, weight, severity of ED, concomitant illness); reasons for switching or cessation of medication were expounded.</td>
<td>16</td>
</tr>
<tr>
<td>12</td>
<td>Holden et al.</td>
<td>2006 (Sept - Dec 2003)</td>
<td>Australia</td>
<td>Correlational, Questionnaire</td>
<td>5990 (78.0)</td>
<td>Not Specified</td>
<td>Moderate/ Severe = 21.0</td>
<td>Moderate/ Severe = 38.0</td>
<td>Being young, living in a remote location, not speaking English, and having never been married were associated with a reduced likelihood of discussing ED with a health professional.</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Paper No.</td>
<td>Author(s)</td>
<td>Publication Date (study period)</td>
<td>Country/Continent</td>
<td>Design</td>
<td>No. Of Participants (%Response Rate)</td>
<td>Mean Age in years (Range)</td>
<td>Marital Status %</td>
<td>% with ED</td>
<td>% who sought help</td>
<td>Main Findings</td>
<td>Quality score</td>
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<tr>
<td>13</td>
<td>May et al.</td>
<td>2007 (Mar - June 2005)</td>
<td>Germany</td>
<td>Descriptive (Epidemiological) &amp; Correlational, Questionnaire</td>
<td>2499 (31.2)</td>
<td>50.4 (18-79)</td>
<td>Single = 0.0; Married = 80.4; Living in established relationship = 19.6</td>
<td>40.1</td>
<td>Not Specified</td>
<td>Belief ED could be treated successfully; good awareness of the oral treatments but little usage; preference for oral treatments; explicit refusal of penile injection. Viagra scored highly.</td>
<td>15</td>
</tr>
<tr>
<td>14</td>
<td>Tan et al.</td>
<td>2007 (Sept 2004 - Sept 2005)</td>
<td>Asia (China, Japan, Korea, Malaysia, Taiwan)</td>
<td>Descriptive epidemiological &amp; Correlational, Questionnaire</td>
<td>Not Specified</td>
<td>Not Specified</td>
<td>Phase I: Single = 33.3; Married/living with partner = 65.4; Divorced/ Separated = 1.2</td>
<td>Phase I: 10934 - China = 18.8, Japan = 17.2, Korea = 18.3, Malaysia = 27.4, Taiwan = 18.3. Phase II: 1286 - China = 17.5, Japan = 17.7, Korea = 17.5, Malaysia = 29.5, Taiwan = 17.7.</td>
<td>Phase II: 100</td>
<td>Total Not Specified; Japan = 43; Korea = 33; Malaysia = 33; Taiwan = 30; China = 17</td>
<td>Higher rates of concomitant illness in men with ED; greater general dissatisfaction in men with ED; proportion of men who sought help varied by region; high proportion of men influenced by their partners, friends or relatives.</td>
</tr>
<tr>
<td>15</td>
<td>Sookdeb</td>
<td>2007 (3 months in 1996)</td>
<td>UK</td>
<td>Descriptive, Questionnaire</td>
<td>37 (Not Specified)</td>
<td>Not Specified</td>
<td>Single = 16; Married = 68; Cohabiting = 16</td>
<td>100</td>
<td>100</td>
<td>Time delay in seeking help varied; time intervals between consulting GP and specialist appointments varied; reactions to time delay reported.</td>
<td>8</td>
</tr>
<tr>
<td>16</td>
<td>Eardley et al.</td>
<td>2007 (Feb - Apr 2001)</td>
<td>US, UK, France, Germany, Italy, Spain, Mexico, Brazil</td>
<td>Descriptive &amp; Correlational, Questionnaire</td>
<td>2912 (Not Specified)</td>
<td>Not Specified</td>
<td>Total = 58.0; Men with diabetes = 72.0; Men without diabetes = 55.0</td>
<td>100</td>
<td>100</td>
<td>Men with diabetes and ED were more likely to perceive ED as severe, permanent and seek help. A range of sources are consulted by men for further information on ED. Treatment (l)disatisfaction was reported with reasons. Differing effects of medication were observed.</td>
<td>16</td>
</tr>
<tr>
<td>17</td>
<td>McCabe &amp; Mitic</td>
<td>2007 (Not Specified)</td>
<td>Australia</td>
<td>Correlational, Questionnaire</td>
<td>410 (Not Specified)</td>
<td>55 (Not Specified)</td>
<td>In a sexual relationship (heterosexual only) = 85.6</td>
<td>100; Mild = 11.5; Moderate = 42.4; Severe = 46.1</td>
<td>76.3</td>
<td>Men reactions to ED were reported along with the sources of further information consulted. Reasons for not seeking help were expounded and the professionals approached described.</td>
<td>12</td>
</tr>
<tr>
<td>Paper No.</td>
<td>Author(s)</td>
<td>Publication Date (study period)</td>
<td>Country/Continent</td>
<td>Design</td>
<td>No. Of Participants</td>
<td>Mean Age in years (Range)</td>
<td>Marital Status %</td>
<td>% with ED</td>
<td>% who sought help</td>
<td>Main Findings</td>
<td>Quality score</td>
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<td>18</td>
<td>Sand et al.</td>
<td>2008 (Feb - Apr 2001)</td>
<td>US, UK, France, Germany, Italy, Spain, Mexico, Brazil</td>
<td>Descriptive, Questionnaire</td>
<td>27839 (Not Specified)</td>
<td>20-75</td>
<td>Single = 28.0; Married/Living with partner = 62.0; Divorced = 8.0; Widowed = 2.0</td>
<td>16.0</td>
<td>Not Specified</td>
<td>Constructs of masculinity differed across countries; attributes involving self-respect more often most important and not focused on sexuality; no effect of age; constructs of masculinity did not differ between men with ED and men without, or between men who had sought help and those who had not.</td>
<td>15</td>
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<td>19</td>
<td>Matic &amp; McCabe</td>
<td>2008 (Not Specified)</td>
<td>Australia</td>
<td>Correlational, Questionnaire</td>
<td>409 (Not Specified)</td>
<td>45-75</td>
<td>In a sexual relationship = 85.8</td>
<td>100</td>
<td>76.5</td>
<td>Men's reactions to ED reported alongside severity and duration of ED; characteristics of men who had discussed ED with others highlighted.</td>
<td>12</td>
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Note. *Excludes participants who were partners of men with ED and physicians treating men with ED.
1. **Percentage with ED**

The proportion of men with ED varied between papers with seven papers solely recruiting men with ED (Total study sample n=37 to n=2912 [Eardley, Fisher, Rosen, Niederberger, Nadel & Sand, 2007; Fisher, Meryn & Sand, 2005; Matic & McCabe, 2008; McCabe & Matic, 2007; Perelman, Shabsigh, Seftel, Althof & Lockhart, 2005; Schover et al., 2004; Sookdeb, 2007]). In the eleven papers that included men with and without ED, the proportion of men with the disorder ranged from 14.0% to 53.6% (study sample range n=500-n=32644). One study (Tan et al., 2007) was a two phase study - phase one contained a mixed sample (total study sample N= 10934; 6.4% with ED) and phase two solely men with ED (total study sample N=1286).

2. **Percentage help seekers**

Twelve papers reported the total number of men seeking help for ED in their study sample with proportions ranging from 6.8% to 100% (Ansong, Lewis, Jenkins & Bell 1998, 2000; Berrada, Kadri, Mechakra-Tahiri & Nejjari, 2003; de Boer et al., 2005; Eardley et al., 2007; Fisher et al., 2005; Kitai, Vinker, Kijner & Lustman, 2002; Matic & McCabe, 2008; McCabe & Matic, 2007; Schover et al., 2004; Shabsigh et al., 2004; Sookdeb, 2007). Three articles reported proportions of men seeking help by duration or severity of ED or sample nationality, whereas four reported no proportions of help-seekers at all (Haro et al., 2006; Holden et al., 2006; May et al., 2007; Mirone, Gentile, Zizzo, Terry, Longo & Parazzini, 2002; Perelman et al., 2005; Sand, Fisher, Rosen, Heiman & Eardley, 2008; Tan et al., 2007). One study reported the proportion of men seeking help before and after an anonymous questionnaire (6.8% and 9.3% respectively); one detailed the proportion of men who had sought help alongside the proportion who intended to seek help (46.0% and 44.0% respectively); and one study stated the proportion of men with or without diabetes seeking help for ED (72.0% and 55.0% respectively [Eardley et al., 2007; Kitai et al., 2002; Schover et al., 2004]).
Eight studies highlighted men’s reactions to having ED. Study 17 elucidated that as perceived severity of ED increased, men increasingly believed that their ED was permanent (McCabe & Matic, 2007). Study 4 reported a clear negative association between ED and satisfaction with sex life (Kitai et al., 2002). This was corroborated by study 5 reporting a positive correlation between ED and disturbed sex life (as measured by the frequency of sexual encounters per month [Berrada et al., 2003]). Study 14 indicated men with ED compared to men without ED, exhibited significantly greater dissatisfaction with all aspects of life including family, work, relationships, sex life, health, general happiness, and “overall contentment” (Tan et al., 2007). Study 10 identified that 67.3% of men with ED were “bothered” by it; 85.3% perceived a need for help; and 19.4% could not accept having ED. Despite these negative consequences, only one man (0.56%) had received help for ED. In addition, the majority of men who were not “bothered” by ED nevertheless reported a need for treatment.

Study 18 found that men with ED consistently rated quality of life as lower on all attributes compared to men without ED (particularly with regards to satisfaction with sex life and overall health [Sand et al., 2008]). Study 8 elucidated that 55% of men felt that ED was a source of much sadness (Perelman et al., 2005). With a mean age of 57 years (range 20-75 years), only 9% of men felt that they were too old for sex. Overall, 49.3% of men stated that they would do almost anything to cure their ED whilst 47.2% felt they must learn to accept it. Most men (71.8%) said that they didn’t necessarily want to have sex, but merely be capable of doing so. Finally, 21% of men felt that ED only occurred in relation to their current partner (Perelman et al., 2005).

Study 16 compared reactions of men with ED and diabetes to those without diabetes. It found that men with ED and diabetes perceived ED as more devastating than men without diabetes. Secondly, more men with ED and diabetes felt that they would give almost anything to cure
ED. Finally approximately equal numbers with and without diabetes, thought that compared to other life issues, ED was unimportant (Eardley et al., 2007).

4. Age

Surprisingly three studies reported finding no association between age and HSB in men with ED (Ansong et al., 1998, 2000; Mirone et al., 2002). whereas other studies reported that the need for help for ED was clearly related to age - highest in men aged 51-60 (93%) and lowest in 81-90 year olds (38% [de Boer et al., 2005]). Additionally it seems that older men are less likely to discuss ED with a health professional compared to younger men (Holden et al., 2006).

5. Relationships

Four studies reported the significance of relationships on HSB for ED (Ansong et al., 1998, 2000; Holden et al., 2006; Tan et al., 2007). One study reported that among men who had sought treatment, 47.5% cited ED as the cause of difficulties in their marriage or relationship, whereas similar difficulties were reported by only 27% of men who hadn’t sought treatment (Ansong et al., 1998). Study 12 identified that men who had never been married were significantly less likely to discuss ED with a health professional than married men. Studies 1 and 2 however found that marital status per se was not a predictor of help-seeking (Ansong et al., 2000; Holden et al., 2006). Study 14 reported a strong association between a man’s concern to satisfy the sexual needs of his partner and treatment seeking (Tan et al., 2007). Across Asia, most men identified their partner as having the most influence over their treatment seeking for ED (China 27%; Korea 62%; Malaysia 56%; Taiwan 53%; Japan 38% [Tan et al., 2007]).

6. Duration and severity of ED

Two studies reported no association between severity of ED and HSB (Haro et al., 2006; Shabsigh et al., 2004). Conversely, two studies reported a positive effect of duration of ED
and help-seeking (Matic & McCabe, 2008; Mirone et al., 2002). For example, Australian men who had experienced ED for at least 12 months were significantly more likely to have discussed ED with a doctor than men with ED of less than 12 months duration (Matic & McCabe, 2008). An isolated study in the UK found the reverse pattern however- 70% of men attending a London clinic having consulted a GP within 6 months, whilst 30% had waited at least 18 months (Sookdeb, 2007).

7. Professionals consulted

When men were asked from whom they would most likely seek help, study 13 found that they would most likely consult a urologist or GP equally (44.5%); solely a urologist (35.9%); or solely a GP (3.7% [May et al., 2007]). The remainder (15.9%) stated they would neither consult a urologist nor a GP (reasons unspecified).

Five studies provided data on men who reported to have already sought treatment for ED (Ansong et al., 1998; Berrada et al., 2003; Kitai et al., 2002; McCabe & Matic, 2007; Mirone et al., 2002). Two of these studies reported to whom men first went for help with ED. Study 17 found that Australian men tended to consult their GP rather than an urologist (73.7% vs. 19.2% respectively [McCabe & Matic, 2007]). Similarly, study 1 observed that most men first sought treatment from a primary care provider (44.7%) or urologist (40.7%), with other sources being a local pharmacist, sex therapist or health food store (Ansong et al., 1998).

Three studies found that urologists or andrologists (specialist in male reproductive health) were most frequently consulted for help (Berrada et al., 2003; Kitai et al., 2002; Mirone et al., 2002). In a study of Moroccan men, 37% of men with ED had seen an andrologist; 31.4% an urologist; 11% a family physician; 3.2% a general physician; 2% a psychiatrist; 1.4% a dermatologist or venereologist; and 1.1% a public health nurse (Berrada et al., 2003). In study 3, of Italian men with ED, 47.5% sought help from an andrologist/urologist; 28.2% from a GP; 25.9% from other physicians (including diabetologists and endocrinologists); and 1.3% from a sexologist (Mirone et al., 2002). Study 4 found that in Israel, a urologist was
again, more commonly seen for ED than a family doctor (28% and 17% respectively [Kitai et al., 2002]). The authors speculate that the relatively small proportion of men consulting their GP for ED may be due to a mistaken belief that these medics are unable to prescribe treatments for the disorder (Kitai et al., 2002).

8. Treatment Choices

Study 1 found that the number of men who knew of effective treatments for ED was low (26.7% [Ansong, 1998]). A significant number of men (31.9%) did not know of an effective treatment, with the majority of men (41.4%) uncertain. In contrast, study 13 found that 75.9% of men with ED thought it could be successfully treated (May et al., 2007).

Several studies reported treatment preferences, with the use of oral therapeutic agents always ranked first. Study 4 found that 83% of men preferred treatment with tablets whilst 8% indicated a preference for penile injections (Kitai et al., 2002). Study 13 however, found a much smaller proportion of men (3.3%) willing to use intercavernosal injections (May et al., 2007). Preferences were: oral drugs 66.9%; vacuum device 9.3%; medicated urethral system 4.8%; penile implants 1.0% (May et al., 2007) Interestingly, 38.4% of men with ED said they would refuse treatment altogether, and 91.4% would explicitly refuse treatment by intercavernosal injection (May et al., 2007)

Men’s awareness of pharmaceuticals known by name were: Viagra (95.7%); Cialis (12.6%); and Levitra (12.2%). As well as being the most commonly known oral treatment for ED, Viagra was the treatment most men would choose to use (May et al., 2007) Furthermore, of men experienced in using oral medication for ED, Viagra was most commonly taken (9.4% Viagra vs. 6.3% Cialis vs. 4.7% Levitra [May et al., 2007]).

9. Co morbidities

A study conducted in Italy found that more men with co morbid illness sought treatment for ED than men without (60.0 vs. 39.2% respectively). Highest rates of treatment seeking for ED were seen in men with diabetes (70.7%); men who had experienced pelvic trauma/surgery
(77.5%); men who had a benign prostatic condition (69.4%); and men with cardiovascular disease (60.9%). As well as being more likely to seek treatment for ED (72.0% vs. 55.0%), men with diabetes were also more likely to perceive ED as severe and permanent (Eardley et al., 2007).

10. Masculinity

Study 18 found that perceptions of masculinity in men with and without ED who had or had not sought help for ED differed markedly from widely held stereotypes of what it means to be a man. Attributes involving self-respect (such as being honourable, self-reliant and respected by friends) were overwhelmingly more often cited as the most important constructs of masculinity than attributes centred on sexual prowess (e.g. having an active sex life and being physically attractive [Sand et al., 2008]). The effect of having a partner was minor, although “being seen as a man of honour” was seen as most important for men in relationships, whilst “being in control of your own life” was ascribed as most important for single men. Of note however, is study 18’s finding that rankings of constructs of masculinity did not differ significantly between men with or without ED, and men with ED who did or did not seek treatment for erectile difficulties (Sand et al., 2008)

11. Barriers to help-seeking for ED

Six papers reported men’s reasons for not seeking help for ED. All reported discomfort or embarrassment as a major barrier to help seeking, with 14-45% of men endorsing these factors (Ansong et al., 1998; Kitai et al., 2002; Shabsigh et al., 2004; Fisher et al., 2005; Perelman et al., 2005. Study 6 found that being embarrassed to talk about ED presented more of a barrier for younger men and those with the severest dysfunction (Shabsigh et al., 2004). Study 8 reported that some men were reluctant to seek help thinking the doctor would be uncomfortable discussing ED (Perelman et al., 2005).

Four papers (studies 1, 4, 6 & 9) found that poor knowledge or little faith in treatments available was a key barrier for men considering help seeking (Ansong et al., 1998; Kitai et al.,
Worry about prescription medication and not wishing to take such drugs were cited as discouraging of help seeking in studies 6, 8 and 9 (Shabsigh et al., 2004; Perelman et al., 2005; McCabe & Matic, 2007). Study 1 reported that some men did not seek help because they believed treatment to be too expensive (Ansong et al., 1998).

Men in studies 4 and 6 stated that they did not seek help because they believed ED to be normative for their age (Kitai et al., 2002; Shabsigh et al., 2004). This was more often seen in older rather than younger men.

Studies 4 and 6 reported 25 to 28% of men not seeking treatment because they did not consider ED important enough (Kitai et al, 2002; Shabsigh et al., 2004). Men with concomitant disease endorsed this reason more often than others, with those experiencing more severe ED being least likely to perceive this as a barrier at all. Severity of ED was also negatively associated with infrequent or intermittent erection problems discouraging help seeking (Shabsigh et al., 2004).

Study 9 identified that 21% of men did not seek help because they did not believe ED was a medical problem. Similarly equal numbers avoided help seeking because they were worried about bothering a doctor when it was not an emergency (Fisher et al., 2005).

12. Drivers to help-seeking for ED

A number of studies have identified a range of factors that have encouraged or prompted men to seek help for ED.

In Asia, men describe their partner as having influenced their decision to seek help (Tan et al., 2007). In Australia, study 19 found that, of men who had consulted a doctor, 37.1% had been influenced by their spouse. The majority however had been influenced by no one (57.2%) and were thus self-motivated (McCabe & Matic, 2007).
In study 15, as well as reporting influence of others on help-seeking (43% of men had sought help due to partner pressure and 43% because of encouragement/support) the authors found that desire to regain potency (84%) was a key driver. The desire to start a family was also raised by a minority of men (8% [Sookdeb, 2007]).

Study 1 reported that the primary reasons for men seeking help was: to improve self-esteem (44.8%); awareness of new treatment (33.4%); partner insistence (11.3%); coverage by health insurance (10.4% [Ansong et al., 1998]).

Study 9 found that reasons for having consulted a physician regarding ED included: to regain a normal sex life (17%); awareness of a prescription drug that could help (17%); to determine the cause of ED (12%); worries about an underlying illness (11%); to regain sexual prowess (10%); not wanting one’s relationship to suffer (8%); not wanting to disappoint a sexual partner (8%); to regain self-esteem (6%); unhappiness (5%); being prompted by a partner (4%). Those who had not yet sought help for ED were asked what would motivate them to do so and they suggested: thinking their relationship was in danger (43%); thinking it a medical problem (40%); thinking the doctor could solve the problem (36%); their partner suggesting help seeking (34%); thinking it would restore previous functioning (31%); knowing their doctor would make them feel comfortable (28%); thinking their doctor was an expert on ED (26%); having another reason to go to the doctor when they could mention it (21%); going for an annual check-up when they could mention it (19%); being invited to a well-man check-up (19%); knowing their doctor was interested (11%); believing their doctor would take them seriously (10% [Fisher et al., 2005]).

Study 6 reported similarly diverse reasons behind help seeking for ED. The drivers/influencers identified were: self-motivation (57.8%); spouse or partner (39.8%); friend or relative (7.0%); something received in the mail (4.8%); sex counsellor or psychologist (3.4%); pharmacist (1.7%); and internet (1.22%). Study 6 also investigated predictors of HSB for ED and found that having severe ED, a desire to have sex but no
partner, and current untreated depression, were positively associated with self-motivated help seeking. Conversely, being married or living with a sex partner was positively associated with being prompted to seek help by a spouse or partner. Being single was positively correlated with HSB suggested by a friend or relative (Shabsigh et al., 2004).

One study specifically researched the effect of a mailed questionnaire on men’s readiness to seek help for ED, finding that the number of men reporting ED to their family physician to be small, but that by mailing out a brief questionnaire, awareness of ED was increased and the incidence of help seeking also. The researchers speculated that an anonymous questionnaire overcomes the tendency to avoid dealing with sensitive topics like ED without the need for personal contact with a doctor in the first instance (Kitai et al., 2002).

13. Response to help-seeking

Four studies reported men’s experiences of having sought help for ED. Study 9, asked men to indicate the most difficult aspects of their first conversation about ED with a physician. They recorded the following responses: admitting ED was not going away (33%); accepting they had a problem (29%); difficulty knowing how to talk about ED (24%); finding a way to start the conversation (23%); inability to talk about emotional topics; (10%); not knowing what language to use (21%); overcoming fears and inhibitions (21%); the doctors reaction (9% [Fisher et al., 2005]). These researchers also asked men to indicate what emotions they felt during their consultation for ED. The majority of men said they felt hopeful (52%); 30% said they felt nervous; 29% embarrassed; 28% relieved; 26% anxious; 14% frustrated; 11% depressed; and 4% angry. Men’s appraisals of their physicians’ responses to consultation for ED were overwhelmingly positive with the majority experiencing their physician as non-judgemental (83%), comfortable discussing ED (80%), respectful of their feelings and opinions (79%) and putting them ease (74%). Other evaluations of physicians included: the doctor demonstrating competency regarding ED (69%); the doctor explaining what was
necessary (68%); the doctor encouraging questions and answering them clearly (67%); the
doctor checking patients’ understanding of ED (58% [Fisher et al., 2005]).

Quality of included articles

Criteria were rated on a dichotomous Y/N scale with a maximum score of 20. Mean quality
score was 12 with a range of 6-16 criteria met. Poorly scored items included:
representativeness of the sample; response rate and non responder details; definition of help-
seeking; study implications with reference to limitations; and identification of future work
needed. Areas scoring highly included; clear rationale and study aims; nationality of
participants or country of recruitment; clear specification of data collection; findings related
to study aims; and conclusions supported by data presented. Of particular note is that all 19
reviewed publications clearly related findings to original aims but only one adequately
specified a definition of help-seeking (Sand et al., 2008). Reporting definitions of ED was
also poor with little consistency in the definitions used across papers.

[See Table 3, Appendix 7 for itemised quality scores]

Discussion

This review identified 19 articles reporting data on HSB for ED. The quality of papers was
reviewed and the characteristics of men seeking and not seeking help for ED were identified.
Some key drivers and barriers were highlighted and the impact of masculinity assessed.
ED seems to have a negative impact on many aspects of a man’s life. Most men seem
bothered by the disorder and perceive a need for help with it, yet few accept having the
problem and few go onto receive treatment. Certain groups of men seem more inclined to
seek help e.g. diabetics, despite stating that compared to other problems in their lives, sexual
functioning is unimportant. Men welcome appointments with doctors concerning other
problems so that they can use the opportunity to discuss ED whilst there. Older men perceive
less of a need for help for ED despite only 9% of men feeling too old for sex. Help seeking
does not appear to be driven by a desire to have sex but more a need to know that one is capable.

The most salient drivers of help seeking identified in the review were: a desire to regain potency; treatment awareness; restoration of sex life; and preservation of relationships. Most men were found to be self-motivated but a significant number were influenced by their spouse, friends or relatives.

A similarly broad range of barriers to treatment seeking was also reported: discomfort with discussing ED; lack of knowledge about treatment; concerns over the consequences and efficacy of treatment; unwillingness to take drugs for ED; and cost of treatment. Men feared ED may be an indication of something more serious; hoped it would resolve itself; believed it was a normal part of aging, thought it not serious enough to trouble the doctor with; feared doctors’ reactions.

There was clear agreement across studies that men held a preference for seeking help from urologists and andrologists with a relative aversion to discussing ED with GP’s. Men favoured treatment by oral pharmacotherapy and unsurprisingly were unwilling to use penile injections (presumably, due to the perceived pain expected with such treatment modes).

Despite being fearful prior to seeking help, most men reported positive experiences afterwards.

The most surprising finding in the literature was Sand et al. (2008) reporting no effect of masculinity on help seeking, since its effects on attitudes towards help seeking have been reported elsewhere (e.g. Good, Dell, Mintz, 1989; Good & Wood, 1995; Robertson & Fitzgerald, 1992). Whilst Sand et al. (2008) assert that their results refute claims that ED strikes at a man’s masculine core and that help seeking is avoided because of men’s unwillingness to confront a threat to masculinity, their findings may not be entirely valid. Their results may be mere artefacts of the methodology they employed. Firstly, their study relied upon self-report of ED and no objective measures were taken to verify men’s responses.
Secondly, the sexual orientation, socioeconomic status and educational status of participants were neither recorded nor controlled for. It is known that homosexual and bisexual men, hold more traditional masculine beliefs about masculinity than do heterosexual males (Courtenay, 2000). Furthermore, socioeconomic and educational status have been shown to be greater predictors of HSB than gender alone (Cor, 2002; Emslie, Hunt & Macintyre, 1999; Galdas, Cheater & Marshall, 2005). Sand et al. (2008) was the only study found to examine the effects of masculinity on HSB for ED, it is suggested that there findings should therefore be interpreted with caution since the effects of self report, sexual orientation, socioeconomic and educational status cannot be ruled out.

Other findings of this review are hindered by further limitations of the review itself as well as in the papers reviewed. Firstly, the overall quality of papers assessed was somewhat disappointing with many studies failing to recruit samples deemed representative of the population of interest. In addition, a lack of papers clearly defining key concepts of interest, namely erectile dysfunction and help seeking made it difficult to be certain that precisely the same phenomena were being examined. For the sake of presenting a comprehensive overview of available literature, it was however assumed that the studies reviewed were adequately comparable although this is not necessarily the case. It is important that future studies take care to specify precisely what is meant by the terms they employ to reduce ambiguity for reviewers and participants.

A further limitation concerns the fact that all studies reviewed utilised quantitative methodologies. Such methods limit understanding of multi-factorial interactions potentially involved in HSB. Using closed questions and checklists limits participants to responding in a certain manner using predefined categories and since knowledge of ED is currently underdeveloped, it is unhelpful to limit discovery in this way. As is evident from this review, there are a range of drivers and barriers involved in HSB for ED but currently they exist as nothing more than a list of discrete items. Qualitative studies minimise the simplifications
imposed by quantification and enable more complex aspects of experience to be studied. Qualitative research is therefore useful for exploratory, discovery-orientated research. Future qualitative research into HSB for ED would thus be welcomed so that an understanding of how the key factors involved in HSB are negotiated by men can be gained.

A further criticism of the reviewed studies is the paucity of data from single and/or bisexual or homosexual men. A man’s partner can be a major influencer in HSB for ED and so the extent to which the current findings can be generalised to men who are single and/or have male partners is unclear. It may be that key influencers of HSB associated with such men’s lives may have been overlooked in studies to date. Future research in this area should aim to address this underrepresentation of certain subsections of the male population.

Finally, the launch of Viagra in 1998, arguably changed awareness of ED and its treatment. It is possible at this time that the manner in which services responded to men with ED also altered. Therefore in attempting to provide up-to-date data on HSB for ED, it is important to know whether participants were surveyed pre- or post-Viagra release. Unfortunately, only 12 of 20 papers in this review clearly specified a study period. Further publications concerning HSB for ED should specify the date over which data was collected to enable meaningful conclusions to be drawn.

With regards to limitations inherent in the review itself, three issues seem worthy of acknowledgement. Firstly, the review was conducted by a sole researcher. Due to the primary purpose of the review being partial fulfilment of a doctoral course, it was not possible to have every decision evaluated by a co-researcher. As far as possible however, attempts were made to minimise subjectivity and bias. A research supervisor experienced in research and review methodology was consulted throughout the entire process. Nevertheless an element of subjectivity might remain.

Secondly, the quality assessment tool used in this review was a bespoke tool that was/has not been vigorously tested for its psychometric properties. Attempts were made to assess its face
validity and re-test reliability and it was judged to be good on both accounts but further evaluation is warranted.

Finally, the eligibility criteria chosen for this review confined inclusion to papers written in English and published in peer-reviewed journals. Some researchers suggest that having done this, may have led to bias and loss of precision in the review since evidence suggests that under-inclusion of available research produces questionable results (Cook, Guyatt, Ryan et al., 1993; Moher, Pham, Jones et al., 1998). Due to resource constraints, it was not possible to include grey literature and non-English materials on this occasion. It is however suggested, that future systematic reviews do so.

Despite the aforementioned limitations, the findings of this review have clear implications for service and practice. Awareness of ED should be raised with educational materials reporting ED prevalence, treatment availability and efficacy; the importance of prompt treatment seeking; and the fact that ED is not an inevitable part of aging. A clear message should also be given that rather than ED being a sign of the presence of a more serious underlying illness, treating ED can be a useful means of preventing future chronic illness.

The structure of services should also change to take into account men’s preference for discussing ED with sexual health specialists and their aversion to GP’s treating ED. Direct access to urologists/andrologists should be made available so that GP’s who currently act as gatekeepers to secondary services do not represent a barrier to treatment seeking for men with ED. The establishment of “well-man clinics” or annual health checks overseen by specialist consultants could facilitate this. Such initiatives could allow for routine screening of all aspects of men’s physical and mental health thereby providing a forum for the disclosure of ED.

By making such service improvements, an increase in help seeking for ED might occur with a concurrent reduction in mortality and morbidity related to the disorder.
Conclusion

This review presents the first systematised synthesis of data concerning HSB for ED. A number of factors involved in men’s decision to seek help have been highlighted. Due to the limitations of methods used, understanding of HSB is currently relatively impoverished however. What is now needed is qualitative research that takes care to define the concepts studied, selects a sample representative of the population of interest, and includes men of various orientations and marital and educational statuses.

Contemporary knowledge nevertheless provides many and far reaching opportunities for change in service provision and practice, which if implemented appropriately, could increase the numbers of men seeking help for ED.
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PART TWO:

Understanding the help seeking behaviour of cardiac patients with erectile dysfunction: An exploratory study

This paper is written in the format for submission to the Journal of Clinical Psychology

Please see Appendix 2 for Guidelines for authors

Word Count: 9,027 including references (8,054 excluding)
Understanding the help seeking behaviour of cardiac patients with erectile dysfunction: An exploratory study

Abstract

Erectile dysfunction (ED) is a highly prevalent sexual disorder. The incidence of ED among cardiac populations is particularly high. Just 30% of men with ED seek help.

Very little is known about men’s help seeking for ED. Quantitative research has identified factors thought to influence men’s decisions to seek help for ED, but there is no understanding of any process through which men may progress.

This study explores cardiac patients’ experiences of help seeking for ED, examines the role of masculine beliefs in it and elucidates a process of help seeking for ED.

Using Interpretative Phenomenological Analysis and interviews of eight cardiac patients led to the emergence of two super-ordinate themes and the proposal of a preliminary model of HSB for ED.

Keywords: help seeking; treatment seeking; erectile dysfunction; impotence; masculinity
Introduction

The aim of the study was further understanding of issues underlying male cardiac patients decisions to seek help (or not) for erectile dysfunction (ED). Current knowledge in this area is poor with only a basic understanding of discrete factors considered by men when deciding to seek help for ED. Further research is required to move beyond this and potential interactions amongst factors involved in help seeking for ED.

Erectile Dysfunction

The World Health Organisation defines ED as “a continuous or repetitive inability to achieve or maintain an erection sufficient for satisfying sexual activity” (Jardin et al., 1999),

ED affects more than 30% of men between 40 and 70 years of age (Feldman, Goldstein, Hatzichristou, Krane & McKinlay, 1994; Laumann, Paik & Rowen, 1999; deBoer, Bots, Nijeholt, Moors & Verhij, 2005). Despite recent increased awareness of the problem, ED remains largely undertreated - just 30% of men seek medical help (Shabsigh, Perelman, Laumann and Lockhart, 2004). There has been considerable research into the prevalence, biology and treatment of ED, yet little is known about help-seeking behaviour for this problem.

Men are notoriously bad at seeking help for a range of problems (O’Brien, Hunt & Hart, 2005). As a group, men of varying ages, nationalities, ethnicity and racial background, seek professional help much less frequently than women (Addis & Mahalik, 2003). Chances of early detection, treatment and prevention of disease are thus attenuated (O’Brien et al., 2005). One reason proposed for men’s poor help-seeking rates is masculinity.

Masculinity & male help-seeking behaviour (HSB)

Literature suggests that men’s experiences of illness and help seeking are greatly influenced by how men and their communities define masculinity (Oliffe, 2005). Many of the tasks
associated with seeking help from professionals may conflict with messages men receive about what it is to be a man i.e. the importance of self-reliance, physical toughness, and emotional control (Brannon & David, 1976; Pollack, 1998). Addis and Mahalik (2003) propose a model of male help seeking in relation to masculine ideologies. They suggest the extent to which a male is likely to seek help depends upon his perceptions of the: 1) normality of the problem; 2) ego centrality of the problem; 3) characteristics of potential helpers; 4) characteristics of his social group; and 5) loss of control.

Erectile Dysfunction & Cardiovascular disease

The incidence of sexual dysfunction post-myocardial infarction (MI) is estimated at 50-70% (Drory, Kravetz, Florian & Weingarten, 1998; Schover & Jensen, 1988). Post-cardiac event, there is much confusion among patients about whether (and how) they should resume sexual activity (Akdolun & Terakye, 2001) - many fear that strenuous activity might induce further heart attacks. For most men however, ED is treatable and the resumption of sexual activity poses little risk (Schwarz & Rodriguez, 2005).

Some researchers propose that ED may function as a marker for occult cardiovascular disease (Johannes et al., 2000; Feldman et al., 1994). Consequently, it is suggested that men presenting with ED should immediately undergo investigations for other cardiac risk factors so that preventative/corrective measures can be promptly initiated. This, in conjunction with services increasing numbers of men seeking help for ED, could lead to significant reductions in morbidity and mortality associated with heart conditions and ED.

Help seeking for Erectile Dysfunction

A review by Orchard (in submission) highlighted the paucity of data on men’s help seeking for ED. Published data identifies a range of factors that men report as influencing their HSB for ED. It could however be argued, that current knowledge of factors involved, comprises little more than a list of ingredients, without a recipe: There is no literature suggesting how
identified factors may interact in HSB. In addition, whilst there is consensus on some factors, there is disagreement over others (see Orchard, in submission) for review of existing literature).

Most studies into HSB for ED have employed quantitative methodology (e.g. deBoer, Bots, Nijeholt, Moors & Verheij, 2005; Moreira et. al., 2004; Schover et al., 2004). Whilst such methods allow objective scoring, they may limit understanding of multi-factorial interactions likely involved in HSB. Using questionnaires and checklists restricts participants’ responses. Qualitative methodologies avoid simplifications imposed by quantification and enable more complex aspects of experience to be studied.

One study that incorporated qualitative aspects to investigate male HSB, employed focus groups (O’Brien et al., 2005). These focus groups aimed to examine the influence of men’s ideas of masculinity on HSB for ED. As the authors state however, their findings must be interpreted with caution given the inherent flaws of focus groups:

“Men’s descriptions in the groups are perhaps best viewed as …a presentation of masculinity, for the consumption of other men, and may not necessarily reflect their “actual” practice. Rather, these accounts are likely to be renditions of men’s expectations and experiences of acceptable masculine practice.”

Willig (2001) asserts that if participants are expected to talk about intimate aspects of experience, disclosure may be inhibited by the presence of other participants. Given the sensitive nature of sexual topics, when discussing ED and help seeking it is likely that men may not provide accurate representations of their actual experience and instead may respond in ways they believe to be socially acceptable.

An alternative qualitative methodology, that minimises the pressure to behave or respond in “socially acceptable” ways, is the 1:1 semi-structured interview. In the privacy of an individual discussion between a single participant and researcher, it is more likely that a truer account of behaviours and opinions may be gained.
No studies to date have utilised this methodology to examine male HSB for ED. Therefore, this study aimed to address this gap in the literature by investigating HSB for ED utilising a qualitative, exploratory methodology employing one-to-one semi-structured interviews.

Interpretative Phenomenological Analysis (IPA) was chosen as the method of analyses since the researcher was primarily concerned with understanding men’s lived experience of having ED and deciding whether or not to seek help for it, rather than: a) how they speak about ED; b) generating theory or; c) how men’s accounts effect other people (these three latter foci being the aims of alternative qualitative methods such as discourse analysis, grounded theory, and content analysis respectively). IPA researchers accept that people can experience the same phenomena in vastly different ways and this method would thus seems to fit with HSB for ED whereby some men seek help and others do not (Barker, Pistrang & Elliott, 2002).

Cardiac patients were selected as a convenience sample for the study since ED is highly prevalent among such populations and the researcher was able to access such men through local contacts with a cardiac rehabilitation service. As such it was felt that chances of successful recruitment would be maximised.

In using the methodology employed it was expected that participants would willing to share thoughts, feelings and behaviours regarding help-seeking for ED and in eliciting such information an insight into drivers and barriers influencing help-seeking for ED would be gained. The effect of masculine beliefs on HSB was of particular interest.

[See Appendix 8 for an explanation of the terms “drivers” and “barriers”]

**Research questions**

1. What factors are common in cardiac patients’ experiences of HSB for ED?

2. How do beliefs about masculinity impact on the HSB of men with ED?
3. What are the drivers and barriers of cardiac patients HSB for ED?

**Method**

*Design*

An individual semi-structured interview design was selected to address the research questions. This design has been used extensively with IPA and is an appropriate method of conducting exploratory research where it would be unwise to make prior assumptions about participants’ experiences of a phenomenon (Willig, 2001). [See Appendixes 9 & 10 for full rationale for study design and details of IPA]

*Participants*

Participants were recruited via a cardiac rehabilitation service in the north east of England between January and June 2008. Participants were patients who responded to recruitment materials inviting men with former or current ED to take part in an exploratory study aimed at understanding men’s HSB for ED. ED was identified via self-report with men responding positively to one or both of the following questions: *Have you ever suffered from erectile dysfunction?*; *Do you currently suffer from erectile dysfunction?* (ED having defined to participants prior to being asked these questions). Non-English speakers were excluded from participation due to resource constraints prohibiting the use of a translator.

*Materials*

Demographic details were collected from participants using a brief questionnaire [see Appendix 11]. Men’s Hospital anxiety and depression scores (HADS; Zigmond and Snaith, 1983) were obtained from routine data collected by the cardiac rehabilitation service. These scores were collected in order to adequately describe the participant pool and state whether as a group they were depressed and/or anxious (such states/traits could potentially affect a participants behaviour). A semi-structured interview schedule was created by the researcher
to guide questioning during interviews. This schedule comprised eight questions with accompanying prompts. [See Appendix 12]

Procedure

This study was approved by the South Humber Local Research Ethics Committee and the relevant NHS research and development department. [See Appendixes 13 and 14]

Recruitment packs comprising a leaflet [Appendix 15]; consent for contact form [Appendix 16]; stamped addressed envelope; and covering letter [Appendix 17] were distributed to patients by nurses during routine appointments. Recruitment packs and posters were also displayed in the cardiac wards of two hospitals within the research locality [Appendix 18]. Volunteers for the study completed and returned the consent for contact form in the envelope provided, upon receipt of which, the researcher contacted them to arrange an interview appointment. A more detailed information sheet was also mailed to them at this time [Appendix 19]. Interviews took place in participants’ homes or in a private room within the host institution. At interview, participants were given the opportunity to ask questions before completing a standardised consent form [Appendix 20]. Once consent was given, participants completed the study questionnaire and a recorded interview commenced. Interviews lasted approximately one hour and were conducted in accordance with published guidance (see Smith, 1995). After the interview, participants were given a standardised debriefing sheet [Appendix 21]. All transcripts were fully transcribed and analysed using IPA (Smith & Osborn, 2003).

Credibility Checks

Credibility checks in this study involved multiple analyses of transcripts, member validation and the use of a reflective diary.
Multiple analyses occurred through participation in an IPA group at the host institution. This involved discussion of transcripts with four other independent analysts with knowledge or experience of using IPA. Ideas of themes from the analyses were discussed and members took care to ensure that concepts discussed were grounded in the data by specifying quotes and their locations within the text.

Two participants provided member validation of the study results and were invited to comment on emergent themes from the analysis. Specifically, they were instructed to consider the material in relation to their experience of ED and to comment on any areas of controversy or concordance with their experiences of HSB for the disorder.

A reflective diary was kept by the researcher to ensure transparency in the development of themes and their inclusion in the final results. The diary allowed decisions made to be tracked, and facilitated understanding of the context within which the research was conducted.

All three credibility checks enabled the researcher to reflect upon the potential impact of his own knowledge, ensuring that reported findings were based on the participants’ experiences not preconceived ideas.

Results

Sample description

Eight men participated in the study with one man failing to complete demographic and HADS data (his data is thus omitted from the descriptive statistics). Participants' marital status varied (married n=3, single n=3, widowed n=1), as did employment (full-time employment n=2, retired n=4, temporary sick leave n=1). An indication of socio-economic status was obtained via social deprivation scores generated from participants’ postcodes using 2001 Census data where 1 = most deprived and 5 = least deprived. Mean deprivation score was 4 (Range = 2-5, SD = 1.00). Men had experienced a range of cardiac events: myocardial
infarction (n=6); bypass surgery (n=1); cardiac arrest (n=1); pacemaker (n=1); angioplasty (n=5); angina (n=1); heart failure (n=2); implanted cardiac defibrillator (n=2). All men had current ED the mean duration of which was 5.61 months (range = 3 months-20 years, $SD = 7.31$). Three men had sought help for ED; four had not. HADS scores provided mean anxiety and depression scores of 4.86 (range = 1-8; $SD = 2.41$) and 3.29 (range = 0-12, $SD = 4.31$) respectively.

Themes drawn from the analysis

Two super-ordinate themes and five sub-ordinate themes emerged from analysis of the data. All themes are presented in Table 1 and described below. Names used are pseudonyms and are accompanied by the man’s age in parentheses.

Table 1. Super-ordinate themes with corresponding sub-ordinates

<table>
<thead>
<tr>
<th>Super-ordinate theme</th>
<th>Sub-ordinate theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is it a problem?</td>
<td>Theme 1: I don’t know much about it</td>
</tr>
<tr>
<td></td>
<td>Theme 2: Is it not normal considering..?</td>
</tr>
<tr>
<td>Do I need/want to ask for help?</td>
<td>Theme 1: Is it important?</td>
</tr>
<tr>
<td></td>
<td>Theme 2: The threatened male</td>
</tr>
<tr>
<td></td>
<td>Theme 3: Who’s available to provide help?</td>
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</table>

SUPER-ORDINATE THEME ONE: IS IT A PROBLEM?

The first super-ordinate theme represents the challenge that men face in recognising ED as an abnormality rather than inevitability. Characterised by poor access to reliable information and
a battle to legitimise dissatisfaction with ED, these issues seem like necessary first steps in
determining whether a man will seek help for ED.

**Theme 1: I don’t know much about it**

Most men suggested they had seen little information about ED and consequently conveyed
little knowledge of the disorder. Because of this there seemed to be a struggle in some men’s
minds as to whether the changes in their erections were “problematic” or merely normal
changes in their bodies requiring no action.

Some only seemed inclined to consider ED a problem after seeing literature pertaining to the
current study. When it was suggested that it might be a “true disorder,” men were initially
quick to reject the notion following which defences dropped and the information was re-
appraised. In some cases, there remained some reluctance to acknowledge its significance
however:

“Well looking at it at first [study leaflet] I thought “oh what a load of rubbish!” ... and then you start to
think it over and “yeah maybe I’ve got a slight problem”, I wouldn’t say I’ve got a major problem but yeah
... (Neil; 61 years)

Some men’s declaration of poor knowledge seemed less than genuine, with clear sign’s of
independent research having taken place. This was demonstrated through men’s apparent
understanding of causal mechanisms of erections and ED. For instance, Paul (86 years) states

“...I somewhere read ... possible treatments for ED but never studied it or anything ... I was just aware that’s
all...”

Later on he comments:

“glancing through my medical book ... it pointed out that vascular is the underlying cause (usually
insufficient blood flow) ... it also pointed out that in many cases there can be psychological effects”
Where there was prior knowledge of ED, it generally centred on treatment. This knowledge was largely confined to Viagra however, with very poor awareness of the full range of alternative treatments available:

“I don’t know if there is anything we can do about it [ED] ... can I take Viagra or I don’t know if there’s anything else I can take? I’ve no idea – I don’t know” (Ashley, 67 years)

Most men presented as preoccupied with negative (mis)conceptions of ED treatment which left them with a sense of helplessness. Thinking Viagra was unavailable to heart patients, they believed treatment options were restricted (e.g. to painful injections or by prohibitive cost). Many such schemas appeared to have evolved from information obtained through informal, social contacts:

“he said ‘you don’t want to bother with that Viagra’ he says ‘its bloody forty quid’! Then you hear things that people with heart conditions can’t have Viagra ... you know there maybe loads of things available ... but 90% of them are not applicable because of your condition” (Ashley, 67 years)

**Theme 2: Is it not normal considering..?**

It seemed important to participants that the cause of their ED be identified with considerable searching having taken place. For some it seemed an easy task identifying what they perceived as the definite precipitant, but for others it was more difficult:

“what’s wrong with me? Am I getting too old, is it because of the heart attack? Is it because, you know, this lady doesn’t turn me on? Or is it maybe the age thing?” (Ben, 61 years)

Participants often considered a number of possibilities but all seemed to believe that ED was inevitable in their situation and/or something for which they were not responsible:

“I was diagnosed with prostate cancer ... had treatment by radiation therapy and hormone therapy, both of which can do considerable damage to your penis and general functioning in that area ... they did considerable damage to my rectum – it is likely they did considerable damage to my penis area ...” (Paul, 86 years).
“well my girlfriend you know, certain girlfriends do certain things and so on, you know. Maybe it’s, you know ... I think she’s great – we get on but you know” (Ben, 61 years)

Many men implied that their age was a key factor in their ED, believing that with increasing age, loss of erectile function was to be expected:

“I’m getting on, I’m nearer 70 than I am 60 so my little man tells me ‘you’re getting old you know’”

(Ashley, 67 years)

Due to beliefs about the supposed inevitability of ED, some men seemed uncomfortable expressing unhappiness with it. They seemed to believe that sex was something in which only young men should be interested. Consequently men who wished to deviate from this perceived social norm attempted to legitimise such desires with certain statements:

“I’ve got a young outlook on life ... old fuddy duddy’s ... I don’t go out with people my age ... I’m 61 but I’ve still got dreams and goals you know, we’re only here once ... enjoy it ...” (Ben, 61 years)

Despite being ‘bothered’ by ED, men appeared to have difficulty in believing ED was a genuine problem and that they were not responding abnormally to a “normal” problem by wishing to address their ED.

SUPER-ORDINATE THEME TWO: DO I NEED/WANT TO ASK FOR HELP?

The second super-ordinate theme comprises three sub-themes relating to the difficulties men have in deciding how significant a problem ED is, how other people will react to their disclosure of ED, and how able they are to identify a potential helper.

Theme 1: Is it important?

Men seemed to expend considerable energy in deciding whether ED was something that they had a right to be concerned about given other aspects of their lives. Men often contemplated their disorder in the context of their relationship with their partner and the life-threatening
illnesses they had survived and/or were recovering from. They seemed quite clear that during the acute phase of cardiac illness, ED had been much less of a priority:

“when you come up against real life threatening problems you get down to the level of survival, you’re not thinking about self acts ... it changes you priorities immensely... thoughts of sex and intercourse didn’t really surface because we were down to survival level” (Paul, 86 years)

Short term, men seemed tolerant of their ED but hoped for eventual improvement. In considering the possibility of their erections never improving, men were unhappy but seemed to feel obliged to accept it ‘all things considered’:

“its just one of those things ... I mean it would have been more ... in consequence it isn’t as bad as a having a stroke; to lose you virility is it?  (Nathan, 70 years)

For some men this public opinion extended beyond the critical phase of their cardiac problems but with indications that lately ED had increased in significance for them e.g. note the use of “didn’t” by Neil (61 years):

“I didn’t place no great importance on any [sexual] dysfunction ... you get on with life and count your blessings that you’ve come through all these things [heart attacks, spinal injuries]”

Indeed men’s comments suggested a certain amount of shame in their wanting more from life than mere survival. Rather than being satisfied at having survived (as they felt they should be) they felt that without ED, life would be more enjoyable. They seemed fearful in expressing these thoughts however, for fear of being seen as ungrateful for their “second chance at life”. They appeared to feel that they were being greedy in hoping for such a “luxury” as erectile functioning:

“Well you’ve gotta accept it, you’re alive and that’s it... you’ve just gotta accept it aint you? Life still goes on ... but it puts the icing on the cake doesn’t it?” (Nathan, 70 years)

In some men, these perceptions and apparent need to conform, bred frustration and anger:
‘you think of sod it, got a reasonable life ... the only bit that’s missing ... you see – I’m doing it again! Only bit that’s missing is the sexual act but it is important to a man – to me! (Chris, 67 years)

Despite its importance to many of the participants, there was concern at seeking treatment for ED because they were not sure if they should expect medical attention for the disorder seemingly believing that their problem was unimportant compared to others’ ailments:

‘the surgery is busy; the last thing I want to do is waste his [the doctor’s] time” (Ashley, 67 years)

Ideas about doctors not seeing ED as important seemed to have arisen from men’s interpretation of medics’ past behaviour:

‘it is possible going back twenty years when I had a triple bypass my GP might have said to me ‘one of the consequences of this maybe ED’. But nobody said ‘well if you do [experiences ED] come back and we’ll do something about it’ (Paul, 86 years).

This left some men believing ED was a common and “to be expected” side effect of their circumstances and therefore something with which they had to live and supposedly be unconcerned about. Despite some men’s ideas that doctors might not be interested in ED, they seemed steadfast in planning to seek help in the future:

“Maybe somebody’s prepared to take you seriously and treat you, I don’t know. I believe if I’d have broached it early [ED] it may have been dismissed. I shall broach it but whether I get any proper response is a different matter” (Neil, 61 years)

Some seemed to evaluate how important ED might be in terms of how much they believed their partners were bothered by it. Although not all men had discussed ED with their partners [see Sub-theme: Perceived Threat] those that had seemed led to believe that ED was not a significant problem for their wives:

“she says, don’t worry about it – if it happens, it happens; if it doesn’t, it doesn’t – I can survive without it” (Ashley, 67 years)
Where women had seemingly been supportive of their partner’s help seeking and dismissive of the significance of ED to their relationship, participants stated that their partner would make frequent comparisons to the past, perhaps indicating greater concern than originally disclosed:

“when we go to bed ... she’ll say “you’ve changed a lot you know ... it didn’t used to be like this did it?”(Ashley, 67 years)

Consequently some men appeared suspicious of how genuine their partners support for their predicament was and made statements apparently serving to reassure themselves.

Where women had stated being unconcerned about their partner’s ED, men displayed greater ambivalence towards seeking help. If men believed their partners were bothered by ED however, many indicated that this would prompt them to immediately seek treatment:

“yeah, oh yeah ... I would be banging down the bloody doctor’s door ... yeah no question of that ... (Chris, 67 years).

**Theme 2: The threatened male**

Many men relayed the idea that ED is not something spoken about and did so in the context of fearing the potential consequences of raising such a topic with another person. This fear spanned both interactions with partners and discussions amongst friends.

Whilst men described that they often spoke about other problems with friends, they believed ED to be a taboo:

“We talk about each others medical problems, not that [ED] cos it ... I don’t know if he’s got that and its never come up ... he makes remarks sometimes about never gets nothing nowadays cos his wife gone off it ... then we talk about something else ... we don’t talk about those kind of things (Ashley, 67 years)”
Consequently, men were unwilling to initiate discussions about ED themselves, yet conveyed an openness if somebody else was to first declare having similar difficulties (any perceived threat seemingly lessened by another party’s prior declaration of having ED):

“I never discuss it … I’ve never had call to … if somebody, if one of my friends had it and they wanted to talk, I would talk to them quite openly (Ashley, 67 years)

Many men drew attention to the fact that ED is often joked about and it is perhaps for this reason that men were unwilling to initiate discussions with others. Some men seemingly took the jokes in their stride, whereas others seemed angrily discouraged from discussing their problem with anyone, fearing that they might personally become a target of ridicule:

“even comedians that you see … you know ‘so and so is taking Viagra for this...’ and you think ‘I’m not having that – I’m not having them laughing at me!’” (Mike, 56 years)

Men were particularly concerned with how their partner might react to their man’s revelation of having ED and some envisaged quite catastrophic outcomes in which they would feel quite helpless or discouraged from seeking help:

“if wife said you’re no good to me I’ll find another fella … I don’t know how I’d handle that” (Ashley, 67 years)

“I’d be quite happy to ask for help if it only involved me…I would not want to explore that help if it meant X [wife’s name] coming, because she wouldn’t bloody come, she wouldn’t get involved!” (Chris, 67 years)

The perceived taboo of ED seemed to lead men to feel a sense of isolation, seemingly wondering if they were alone with their problems, as they could only speculate about other men having similar difficulties:

“as far as I am aware … I am a completely isolated and only case because I know of no others at all” (Darren, 49 years)

Participants believed that masculinity was responsible for men’s reluctance to talk about ED:
“with men there is a lot of manhood status involved, feeling if you’re man you don’t have these kind of problems and you certainly don’t discuss them ...” (Paul, 86 years)

Participants defined masculinity in terms of being able to protect their family; getting erections; having no problems; doing certain chores (e.g. Do-it-Yourself) and not needing help.

Men apparently evaluated themselves negatively against perceived gender roles and failing to live up to their ideologies of a man capable of erections, appeared distressing in itself, but was also considered a further source of shame if others found out about it:

“It’s all tied up with the male of the species and if that side has stopped or seized up, you do feel less of a man. I feel less of a man but there aren’t many people that know that ... I keep it well hidden ... I don’t walk around with a white flag or something all evening, you know, ‘I’m a useless man!’” (Chris, 67 ages)

Inadequate erections appeared to leave participants feeling powerless and useless. Discussing ED with a woman seemed particularly problematic with men believing it might be interpreted as man having no purpose or value, in stark contrast to powerful, professional females within society:

“man in relation to woman wants to appear sexually active and sexually powerful ... going to a woman ... a doctor even ... is like saying ‘I’m a useless male’” (Paul, 86 years)

**Theme 3: Who’s available to provide help?**

Some men had experienced considerable difficulty in knowing where to turn for help with ED. Having decided it was something for which they would like help, they appeared desperate and frustrated in their aid-seeking efforts. There was considerable concern to avoid behaving in a way that they felt might be judged inappropriate by others:

“I want to get it sorted ... where can I go and get it sorted? Tell me where and who and I’ll go and get it sorted! ... you wouldn’t go along at the end of [physiotherapy] session ‘can I have a quick word?’ Because it might appear ... inappropriate person to talk to ... wrong time ... or wrong place ...” (Darren, 49 years).
Whilst some seemed to have less difficulty identify the professional group that might be able to help, they subsequently seemed faced with the task of identifying a particular person with whom they would feel comfortable discussing ED. Thus, it seemed that professional qualifications, per se, were insufficient to convey a person’s suitability for providing help for ED. Instead, professionals’ personal attributes seemed equally important.

Most men commented on the fact that they rarely saw the same doctor regularly, implying that this lack of continuity of care was a hindrance to help-seeking for ED. Men seemed to feel that familiarity in a doctor-patient relationship was of key importance. They suggested that having such a relationship facilitates trust, understanding and open communication, all of which seemingly lead to a “comfort” with discussing personal issues.

Some men seemed unconcerned by the gender of a potential helper whilst others were reluctant to seek treatment from a female, suggesting that a woman might be unable to understand what ED is like for a man. Whilst the helper’s age seemed inconsequential to treatment-seeking, participants implied that a person close to their own age was preferable. Apparently associated with a potential consultant’s age, was concern regarding their knowledge and experience. One man stated:

“a doctor who’s newly qualified is not probably the best because ... he hasn’t got any experience and if he’s been in practice 30 years it’s unlikely he’ll be up-to-date ... so ... someone in the middle” (Paul, 86 years)

A doctor who listened and was perceived as non-judgemental and respectful was highly desired for ED-related treatment-seeking. A doctor deemed thorough, who spends time with a patient, and probes into whether there is anything that they would like to talk about also seemed important. One participant offered an exemplary experience:
“he went through every detail as to what was necessary to put me right ... he knew exactly ... he went through it all in detail ... and then said ‘is there anything you want; any questions ...’ he’s a fabulous man” (Nathan, 70 ages).

Any difficulties in assessing the suitability or likely response of a potential helper to one’s ED were overcome by men using opportunities arising out of contact with doctors for other ailments. One described how he’d used the opportunity of a medication review in such a manner and subsequently decided to ask for help with ED:

“Well I didn’t really go through for that ... I had a heart attack, on all these pills er...saw the doctor...went to him to let him know and I said ‘just this one other thing doc’ you know ‘I’ve got this problem you know about erection right? I don’t seem to be getting one anymore?’” (Ben, 61 years)

Deciding to seek help and having identified a potential source did not always lead to immediate treatment-seeking. Some participants with the intention of seeking help, were overcome with negative thoughts and feelings about how the doctor would respond to them [see Threatened male]. The fact that emotions got the better of them seemed to be particularly problematic and led to a further source of shame and frustration:

“I remember going to the doctors, I think it was a medication review and remember getting up, going out and making another appointment to go back the next day ... because I was embarrassed ...it mean it was just embarrassment ... it’s a hard thing to say you know. I was saying ‘go on, go – say it!’ ... then afterwards ... ‘what did you do that for?’ (Mike, 56 ages)

Some men had not needed to consciously identify a source of help for ED and instead considered themselves fortunate having had their doctor raise ED with them first.

Participants had clear ideas of what needed to change and what would make help-seeking easier. They highlighted the need for increasing awareness of places to go to seek help and providing choice and a safe (secure, one-to-one) environment in which to raise the issue. They felt health professionals could easily do more to help them:
“what would make me volunteer the info more is ... [doctors asking] ‘is there anything else which ... is causing you concern?’ They keep saying all the obvious ones ... ‘have you got any chest pains? ... are you out of breath?’ They didn’t actually ask anything further ... they didn’t ask an open ended question ... ‘Is there anything else?’” (Darren, 49 ages)

Men drew attention to a perceived inequality between the sexes in awareness, resources and treatment of gender-specific health problems. Although aware of women having frequent screening and clear advertising for conditions such as breast cancer and cervical cancer, men perceived a lack of availability or awareness of similar initiatives for men. They felt that such schemes were key in providing a forum for discussing ED with doctors and facilitating help seeking:

“I believe any man, any age would warrant some sort of health screening on a regular basis ... I know of well-women clinics ... but I’ve got to 61 and never been offered anything like that” (Neil, 61 years)

Put simply, most men implied that help-seeking for ED would be greater if doctors took the initiative and considered sexual matters more routinely rather than expecting patients to raise the topic first:

“somebody there asking the question rather than you having to volunteer things [ED]!” (Darren, 49 years)

Discussion

There were many commonalities in men’s accounts of HSB for ED yet there were also some clear differences. Masculinity played some part in men’s decisions to seek help but there was a clear interplay between this and other variables.

Previous research identified some common drivers and barriers to men’s help-seeking for ED and some of these are supported here (see Orchard, in submission, for a review of drivers and barriers).
In employing qualitative methodology this study extends previous data by elucidating a process of HSB for ED. In this process a complex network of factors interact, and are considered together rather than as a list of discrete, unrelated items. Factors serving as barriers for some men do not do so for others and equally the same applies for factors serving as drivers. Furthermore, drivers at one time, can operate as barriers at others and vice versa.

What follows is a description of a preliminary model of HSB for ED, before a discussion of the relevance of existing theories of health behaviour. Thereafter the implications and limitations of the study findings are presented, with recommended future work proposed.

**Preliminary model of HSB for ED**

*Identifying a problem*

Help seeking for ED begins with recognising that “something’s not right” regarding the ability to achieve/maintain an erection. Access to reliable information on the disorder may affect this recognition process. Many men in the current study knew little about ED, were unaware of the range of treatments available, and/or simply believed that ED was normal, given their circumstances. Consequently many had never considered seeking help.

Consistent with previous research, the study findings suggest that HSB for ED is affected by awareness of ED, consideration of it as a medical problem; its presumed cause; and perceptions of normal aging (Kitai, Vinker, Kijner & Lustman, 2002; Shabsigh et al., 2004; Eardley et al., 2007; Fisher, Meryn & Sand, 2005).

*Deciding to seek help or not?*

How a man responds to ED also affects his HSB: If sexual functioning is important to a man, help seeking is more likely. Men in the current study assessed the importance of ED relative to other illness they had experienced/were experiencing and the presumed reactions of other
people. Men were especially concerned about negative reactions from partners and healthcare professionals, consistent with data presented elsewhere (e.g. Ansong, Lewis, Jenkins & Bell, 1998; Fisher et al., 2005; Shabsigh et al., 2004; Perelman et al., 2005).

Although other researchers report a positive effect of co-morbid illness on HSB for ED (Eardley et al., 2007), for men in the current study co-morbid illness was not always associated with increased HSB. Instead, at certain times in these men’s lives, concerns about survival far outweighed concerns regarding sexual functioning. At such time, thoughts of HSB for ED were set aside.

The biggest concern of most men about discussing ED with anyone was how declaring ED might affect their masculine identity. This finding is in stark contrast to Sand, Fisher, Rosen, Heiman and Eardley (2008) who found nothing to suggest an effect of masculinity on HSB.

In the current study, participants listed several attributes that they felt important to a man’s masculine role – one being achieving and maintaining erections. Whilst other attributes were listed, e.g. performing certain tasks such gardening and DIY, for a large proportion of men in the current study, masculinity could not be demonstrated via these routes due to the disability imposed by cardiac illness. One might thus expect that on discovering ED, men in such predicaments would be prompted to seek help for ED (in order to restore this aspect of masculine identity). This was not always the case however and three reasons for this anomaly are proposed. Firstly, HSB may conflict with men’s ideas of masculinity (Addis & Mahalik, 2003; Courtenay 2000). Secondly, men’s expectations of how a helper may respond may be negative (Fisher et al., 2005). Thirdly, a man may not believe that suitable treatment is available (Ansong et al., 1998; Kitai et al., 1998).

Men’s concerns about discussing ED with others, presented a significant barrier not just to seeking help from professionals, but also from informal contacts. Many men felt that ED was too taboo to be discussed with friends. This may have effected men’s access to collective
knowledge on the disorder and how able they were to recognise ED as a “problem” (see Identifying a problem).

**Identifying a suitable helper**

Another influential factor in HSB for ED concerns the identification of a suitable helper. Previous research has highlighted men’s preferences for certain professional groups e.g. urologists over general practitioners (May et al., 2007). However the current study has gone further by elucidating specific characteristics (e.g. being respectful, familiar, trustworthy) deemed necessary in a potential helper to increase the likelihood of help seeking.

Before character evaluations of potential consultants can take place though, one must know who is available to help. A novel finding in the current study is that, for some men, this was a significant problem and potentially a huge barrier to help seeking.

Where uncertain of the suitability of an identified helper, men used the guise of other illness/treatment-needs to attend a consultation in order to assess this. Some reported being fortunate that doctors spontaneously enquired about sexual functioning on such occasions, whilst others needed to initiate discussion of ED themselves.

At this point help seeking was not inevitable since men still had to overcome a barrier of negative affect (e.g. shyness and embarrassment [Ansong et al., 1998; Perelman et al., 2005]) to indicate the presence of ED.

For those men who successfully overcome their emotions, help is sought. A process of appraisal then begins in which men assess how successful help seeking was, and their level of satisfaction. If both seem negative, the process of help seeking continues with possible re-appraisal of prior decisions initiated.
Related pre-existing theories

Although a preliminary model of help seeking for ED has been proposed, two existing theories seem relevant to this area: 1) the self-regulatory model (Leventhal, Diefenbach and Leventhal, 1992); and 2) Stages of Change theory (Prochaska and DiClemente, 1982).

[For an outline of these theories, see Appendixes 22 & 23]

Self-regulatory model

A major component of this model is the concept of illness representations and how they effect health behaviour. There appear to be elements of this model in the current study. When considering HSB for ED, men clearly form illness representations using information available to them about “Identity” (illness or normal aging); “Cause” (heart attack, medication; aging); “Consequences” (others [especially partner’s] reactions, masculinity); and perceived “Controllability” (suitability and availability of treatment).

In the current study, there are also the coping strategy choices made by men, as described by Leventhal et al. (1992) in there model. For instance men choose to live with ED until more serious health problems have settled perhaps hoping for spontaneous recovery (avoidance coping), or seek help immediately (approach coping).

What is not obvious from the current study is to what extent Leventhal et al.’s elements of “Appraisal” and “Timeline” are involved in HSB for ED.

Stages of change

The behaviour and decisions of men in the current study seem to influenced by the stage of change they are at when considering any of the factors involved in HSB for ED. At any one point in the process of HSB for ED, individuals may be at any ‘stage’ of change. This may have a significant bearing on how likely help seeking is to occur at any time. For
example, it is possible that a man who attempts to identify a potential helper may not immediately ask for help once such a person has been identified, as he may still be unsure how other people would react if they found out he had ED (e.g. his partner or peers). Consequently, he may avoid discussion of ED with the helper demonstrating his position at Prochaska and DiClemente’s (1982) Contemplation stage of change. Alternatively, a man may notice a change in his erections, be unaware of ED as disorder and treatments available, think it’s just normal for his age and thus not consider help seeking. As such, he could be classed as at the Precontemplation stage of change.

While Leventhal et al. (1992) and Prochaska and DiClemente (1982) adequately account for an individual’s health-related cognitions and actions, their models fail to account for wider systemic factors influencing such behaviour – something which the current study has found to be highly influential in HSB for ED (e.g. awareness of and access to treatment).

It is therefore proposed that although useful to some degree in their own right, the Stages of change, Self-regulatory model and preliminary model of HSB for ED should be used in parallel in trying to understand (and perhaps facilitate) men’s help-seeking for ED.

**Implications**

Findings from this study clearly imply that clinical practice and service development need to be organised to respond to men at differing stages of change within the ED help-seeking model and who have varying illness representations of the disorder.

A first priority is to raise awareness and increase knowledge of ED, in both men and their partners. Information concerning the prevalence, aetiology, services, and treatment of ED should be easily available.

Doctors of all specialism’s, likely to encounter sufferers, need to radically change their approach so that they are more proactive in addressing sexual dysfunction. A recent paper
by Hatzichristou et al. (2004) provided practice recommendations for the diagnosis and treatment of ED by health professionals. These researchers advocate a patient-centred approach that may empower more men to seek help for ED. They also proposed a simple algorithm “ALLOW” (Ask; Legitimize; Limitations & refer; Open up further discussion; Work together) to guide practitioners in their coverage of sexual health.

Consideration should be given to the provision of screening services or “well-man” clinics. Places where men are enabled to reflect upon and consider help seeking for ED alongside a whole raft of other disorders should be available. Given the evidence, suggesting ED has much co-morbidity, screening for other problems could occur alongside ED in such settings. In so doing, help seeking for ED may increase and male morbidity and mortality reduce.

**Limitations**

Several limitations of this study exist. Firstly, the study focussed on a specific group of men with ED – cardiac patients involved in rehabilitation services and residing in the North East of England. This may limit the extent to which findings and the emergent HSB model can be generalised to other men with ED. Participants all had histories of significant illness and many had been threatened with death at one stage in the lives. They made judgements on the significance of their ED and help-seeking for the disorder, based upon their current and previous health status. The extent to which other groups of men are willing or able to draw on such experiences is unclear.

The study however was exploratory in nature and aimed at enhancing understanding of the complexity of the help-seeking process for ED with as few constraints as possible placed upon men’s reflection of that process. For this reason, it was considered prudent to study a homogenous group of men, to provide a base from which theory could be developed, not confounded by too many extraneous variables.
A second limitation is the sexual orientation of the men in this study, which was neither recorded nor controlled for. All participants however discussed ED in the context of a male-female relationship in which they were involved/looked forward to, and it could thus be assumed they were heterosexual. The effect that sexual orientation has on help seeking for ED has not been studied and so whether this study’s results apply to non-heterosexual males is unknown.

A final limitation of the current study is the age and gender of the interviewer. The interviewer was visibly younger (31 years old) than the men being interviewed. The extent to which this may have affected results is unclear. The involvement of a male interviewer could be subject to the same caution asserted by O’Brien et al. (2005) when interpreting the findings of focus groups involving men - that is men’s accounts may have been descriptions deemed socially appropriate for the consumption of a fellow male and not necessarily reflective of their actual behaviour. Other studies have demonstrated however, that use of same-sex interviewers is preferable to opposite sex-interviewers in researching sensitive issues such as ED (Catania, Binson, Canchola, Pollack & Hauck, 2008).

**Conclusion**

The current study investigated HSB of cardiac patients with ED using a qualitative methodology and employing Interpretative Phenomenological Analysis. Rich data was collected and analysed and found to provide some support for previous findings. There were some commonalities in experiences of the participants but no two experiences were the same. As such, factors involved in the HSB of men with ED cannot be usefully categorized as “drivers” or “barriers” as factors may have different effects in different circumstances. Nevertheless, a combination of multiple factors seems to interact in a complex process through which men decide whether or not to seek help for ED.
Emergent themes in this study led to the development of a preliminary model of help seeking for ED that could usefully be investigated further in order to assess its validity. When used in parallel with other health behaviour models it may eventually prove helpful in increasing the number of men seeking treatment for ED.
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*British Journal of Urology International, 100*(5), 1110-1115.


PART THREE:

Appendixes
Appendix 1: Reflective Statement

Throughout the process of this study, a reflective research diary was kept to document decisions made, reflections on the research process and discussions with my research supervisor and other key personnel.

I begin here with a brief explanation as to why I chose the *Journal of Clinical Psychology* to submit my research papers to. Next I will move onto discuss some of the challenges of tackling such a sensitive topic as ED and describe my experiences of attempting to recruit men into this study. I will then move on to discuss my concerns as an inexperienced qualitative researcher and trainee clinical psychologist using IPA. This reflective statement will then conclude with a reflection on parallel processes (Searles, 1955) and transference (Jacob, 2004) seemingly evident in interactions between the researcher and others, particularly close to thesis submission date.

In deciding which journal(s) to target for submission of my research papers a number of factors required careful consideration. The *Journal of Clinical Psychology* was judged to be most suitable for both papers since it best addressed the key factors are required for my study. Firstly, it reaches a relevant audience (i.e. clinical psychologists as well as other health professionals) that are well placed to help men disclose erectile difficulties; move them onto the action stages of change to seek treatment; further research on HSB of ED; and effect service change and improvement. Secondly, it advertises an adequate impact factor (1.222) that means my work would achieve a fair level of exposure within appropriate professional sphres. Thirdly, it publishes qualitative research and systematic literature reviews and so would consider both my papers. Fourthly, it is not overly restrictive on word count/page
specification and thus I can do justice to the topic matter and present a comprehensive but reasonably concise account of my work for submission.

From the word go, I always expected a research project with such a sensitive topic at its core to present a number of problems recruiting people into the study. There is so much of a taboo around the subject of sex and in particular anything involving erections it seems. I am ashamed to admit that I myself was nervous of the topic I had chosen to investigate initially. Nevertheless having submitted a preliminary literature review on the topic I was enthused by what appeared to be an extremely important but under-researched area. With it too, came a deep desire to understand why so few men seek help for any kind of disorder and I chose ED as I thought this might be the area most avoided by men for seeking help.

As time passed, I became very comfortable with discussing ED and presenting to peers on my research. What was striking however was that discomfort remained in my audience and at times I felt shunned for being open about men’s dilemma’s and societies treatment of men and ED. This aside, I never expected to find health professionals such as doctors and nurses to be uncomfortable in considering men’s sexual health issues. One of the most eye-opening experiences I had, was attending a medical research conference for which I provided a poster presentation of my study. Despite being situated in a key spot within the conference room and having a high level of passing traffic, very few people stopped to fully digest my poster. Once the term ‘erectile dysfunction’ was noted in the title, delegates seemed to quickly flee in any direction away from my poster. It could be that this was not due to taboo and alternatively could be due to the topic not being of interest or importance to many medics. This in itself I found alarming however in light of ED’s key role in highlighting risk of future cardiac ill-health and its impact on quality of life for so many men.
I consequently remained steadfast in my drive to progress my research and attempted to use every opportunity available to “model” a comfortable, respectful and appropriate approach to researching the subject matter. At times I received mixed opinions about how best to do this with some suggesting humour was the most helpful way of recruiting men into the study and yet others suggesting a low key, discrete approach. To a large degree both approaches failed and consequently recruitment into the study was slow and numbers poor initially. A substantial period then had to be spent investigating alternative routes of recruitment since the discrete manila envelopes distributed covertly to patients in the community were not generating enough participants. Psychosexual therapists, a local urologist and a GP specialising in ED were all approached as potential new recruitment channels, and considerable time and effort went into beginning the process of creating new materials and preparing to submit a notice of substantial amendment to the Local Research Ethics committee for approval of the changes.

Fortunately for a number of months I attended a cardiac physiotherapy group every week to spend time talking with men about experiences of having a heart attack and its treatment process. Naturally during these conversations men were keen to know the reasons for my interest and therefore I would tell them. Quite by accident it seems, it soon became apparent that being very matter of fact about my research topic and highlighting the importance of the topic, led to men feeling comfortable enough to openly share their experiences of ED. Consequently, this new disposition was adopted and with no exaggeration, the pace of the research increased exponentially with men in the physiotherapy group starting to volunteer themselves having perused the recruitment materials available in the physiotherapy ward. It seems that once men were given permission to talk openly about ED they took the opportunity to engage in a conversation about it fairly quickly. I would suggest that this is something for future researchers investigating topics such as ED bear in mind.
Having overcome the challenges of recruitment the next significant challenge for me was balancing my dual roles of researcher and clinician. At times, I found it extremely difficult not to prematurely interpret and delve into areas of clinical interest during the one-to-one interviews. This was particularly so when participants became upset or demonstrated what Beck (1979) might consider ‘cognitive distortions’. I was however careful to avoid succumbing to temptation by reminding myself of the researchers role, the extent of my ethical clearance for the study and the rationale behind remaining as researcher merely reflecting, listening and recording participants experiences of the topic under investigation. I was however, careful to check-in with the participants after the recording had ceased, to ensure that they were ok to leave the interview being in a suitable frame of mind to do so.

The role conflict also arose during analysis of the transcripts. As a clinician, I am encouraged not to pre-suppose how a client thinks or feels about something, and to make tentative interpretations for my clients to validate or falsify in their dialogue or behaviour towards me. As an IPA analyst however, I was expected to be fairly bold in drawing out themes and making interpretations with just participants’ written accounts in front of me and their not being present to inform this until a preliminary list of themes was constructed. There was an in-built reluctance to engage in making interpretations and extracting themes in the absence of my participants since I wanted to check in with the participant themselves each time I drew out something I felt was meaningful. Obviously, member validation allows you to do this to some degree but largely post-hoc after ideas are more likely to have become fixed in the researchers mind and so it was difficult to turn off my clinical head that desired more direct contact with clients during the process of abstraction itself. With this in mind, I was careful to ensure that adequate credibility checks were in place to ensure that the emergent themes were grounded in the text. I remained both reflective and reflexive to my supervisors, peers
and participants opinions on the themes arising in the texts. It appears that my interpretations were well supported by other IPA analysts as well as by the participants who provided member validation, their comments about suggested themes being “excellent” and “super” was somewhat reassuring after ensuring that they did not feel the need to remain positive and/or uncritical. Needless to say I cannot overemphasise the importance of researchers using IPA, engaging in member validation and other credibility checking exercises prior to final reporting of themes.

Another area I would like to comment on regarding the conduction of this research, is the reactions that I and other people had to the study topic and its participants. As has been touched on already, there are professionals who seem to feel that sexual health is of little importance or significance particularly in light of men who have had or continue to have life-threatening illnesses. Having ED also appears to lead to men doubting themselves and their worth which is evident in the lay terms used to describe ED i.e. not being able to “perform” and “useless male”, as if there is some standard that they cannot reach that others perhaps can which therefore devalues their lives. In clinical practice, psychologists are very aware of and careful to take notice of parallel (Searles, 1955) and transference processes (Jacobs, 2004). At times during my research endeavours there were times where I seemed to feel caught up in such processes. I often felt inadequate and feared not being able to produce work of the required standard for doctoral research. I felt that I might not measure up in the viva and consequently I should stop trying in many ways mirroring participants passivity to help-seeking or initiating any form of sexual contact despite desires to do so. In addition, towards the submission date my supervisor and I had cause to reflect on the manner with which at times she had been uncharacteristically slow or poor at responding to my requests for assistance. Instead she seemed to prioritise her other duties (often involving threat-to-life sort of issues e.g. cardiac topics) ahead of this research. Fortunately, my supervisor was very
approachable and accepting of such reflections. When she and I discussed such matters there was an acknowledgement from her of the fact we might well have fallen into an unconscious, parallel process that meant I got to experience being “a pain” and “a burden” and that my research was not important – feelings that some of the participants expressed with regards to help-seeking for ED.

Having been through the aforementioned experiences during my research activities, it has highlighted to me the utility of my clinical skills and competence to empirical research. Whilst carrying out the interviews and interpreting the data had led to me feeling torn between my clinical and research roles, my clinical skills nevertheless did allow me to identify why I was perhaps having trouble with feeling the way I was and how the men in my study might have felt the same at points in their lives. I feel that such experiences can only be positive and in hindsight have helped me to gain a richer understanding of the lives of my participants and my roles as researcher and clinician. I just hope that my written ability and the time pressure on me in submitting this research does not distract from the importance of the findings of the research and that I clearly convey men’s messages about what its like to seek help for ED.

It is now for me to sit back in nervous anticipation of my viva voca and subsequent submission of both research papers to the journals identified. Regardless of either of the outcomes, I feel I have grown as a researcher, a clinician and a layperson through my involvement in this research and interaction with the participants. I have already begun to raise awareness of the need for research on men’s HSB for ED by having achieved two publications to-date (See Appendix 24 for an example).

I hope too that in some way the men I interviewed have truly benefited from being provided the opportunity to discuss their experiences having told me that they had never been afforded
the time to do so by any other professionals. At the very least, I hope I have made it easier in
some way to discuss ED with others if they feel they would like to do so.
Appendix 2: Guidelines for authors for the Journal of Clinical Psychology

Aims and Scope

Journal of Clinical Psychology

Founded in 1945, the *Journal of Clinical Psychology* is a peer-reviewed forum devoted to research, assessment, and practice. Published eight times a year, the *Journal* includes research studies; articles on contemporary professional issues, single case research; review papers; brief reports (including dissertations in brief); notes from the field; and news and notes. In addition to papers on psychopathology, psychodiagnostics, and the psychotherapeutic process, the journal welcomes articles focusing on psychotherapy effectiveness research, psychological assessment and treatment matching, clinical outcomes, clinical health psychology, and behavioral medicine. From time to time, the *Journal* publishes Special Sections, featuring a selection of articles related to a single particularly timely or important theme; individuals interested in Guest Editing a Special Section are encouraged to contact the Editors.

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The Journal of Clinical Psychology
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P.O. Box 870348
Tuscaloosa, AL 35487-0348
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Appendix 3: Definition of help seeking

No published definition of help seeking could be found after extensive searching. So for the purpose of this study, help seeking is defined as any behaviour that involves seeking advice, support or intervention from any health or allied health professional. This differs from social support in that help seeking involves trained personnel providing input in an expert capacity, as opposed to informal contacts between friends, acquaintances or family members in which unqualified information might be shared.

In this study, the terms help seeking and treatment seeking are used interchangeably to mean the same thing.
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Appendix 5: Quality Assessment tool

Papers should be scored yes/no on each of the following criteria. Each “Yes” is scored one and each “No” zero, with a maximum score of 20.

1. Is a clear rationale for the study presented and a focussed question or aim stated?

External Validity

Source Population

2. Does the method to select and invite participants result in a study population that is representative or random sample of the total population of interest?

Description of eligibility

3. Is the age range specified?
4. Are the inclusion and exclusion criteria specified?

Participants and non-responders

5. Is the response rate specified, >70, or is information on non-responders sufficient to make inference on the representativeness of the sample?
6. Is missing data explained and considered prior to analysis?

Description of study period?

7. Is the study period specified?

Description of study population?

8. Are important population characteristics specified?
9. Is the country/continent from which the study population recruited or the nationality of the participants described?

Internal Validity

Data collection

10. Is the method of data collection clearly specified?
11. Is the measurement instrument described and its psychometric properties reported?

Definitions

12. Is a definition of erectile dysfunction stated?
13. Is a definition of help-seeking stated?

Data analysis and reporting

14. Is the method of data analysis described and appropriate/justified?
15. Are totals as well as more detailed statistics provided?
16. Do the statistics add clarity/increase confidence in the data?

Informativity

17. Are findings described in relation to the original aims of the study?
18. Are conclusions clearly supported by the data reported or with reference to previous research?
19. Are implications of the current findings discussed and any limitations considered?
20. Has further research needed been identified?
Two or more of: (i) age distribution; (ii) relevant comorbidity; (iii) lifestyle characteristics (e.g. alcohol consumption and smoking); (iv) socioeconomic data (e.g. income, educational level); (vii) marital status

Questionnaire, interview, focus groups

Total prevalence and prevalence by severity or duration for example.

Adapted from the Criteria for methodological quality assessment of prevalence studies by Prins et al. (2002).
Appendix 6: Studies excluded from review

Papers excluded from the review due to not being freely available were:


Papers rejected from the review after application of the inclusion and exclusion criteria, based on 1) data on ED not reported separately from other disorders; 2) participants under 18 years old; 3) no information provided on help seeking; 4) not published in English were:


### Table 3. Quality assessment scores by author(s).

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Note: *Missing data not apparent or specified: positive score given by default. **Specific question asked of participants detailed in paper however: "Using the following categories, how would you define your sexual performance?": a) Always able to have any keep an erection during intercourse; signifying no ED; b) Generally able to have and keep one erection during sexual intercourse; signifying mild ED; c) Sometimes able to have and keep one erection during sexual intercourse; signifying moderate ED; d) Never able to get or maintain an erection sufficiently hard for sexual intercourse; signifying severe ED." †"Discussed ED with physician or partner." ‡"Mention of ED" in case notes. ¥"Have you ever consulted a doctor before about the difficulty getting or keeping an erection?" $"Have you ever spoken to a professional about treatments for ED?"
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Appendix 8: Explanation of the terms “drivers” and “barriers”

In this research, the terms barriers and drivers are used in line with descriptive terms used by Shabsigh et al. 2004. Whilst these researchers did not provide a definition of these terms, for the purpose of this paper “barriers” refers to factors that might dissuade help seeking and “drivers” factors that encourage help seeking.

A formulation of these factors was considered inappropriate for this study because formulation arguably implies hypotheses and predictions both which do not fit within the framework of IPA which is an exploratory, philosophical approach.
Appendix 9: Rationale for study design

Given that the nature of this research is exploratory, a qualitative methodology in which 1:1 semi-structured interviews were analysed using Interpretative Phenomenological Analysis (IPA) were employed.

Qualitative research aims to understand people’s experiences. It looks at a subject matter in detail. Whilst its findings cannot always be directly generalised (due to relatively small samples usually employed) qualitative research can help in the eventual development of far reaching theories or frameworks. Consequently, qualitative approaches are seen as effective methods for examining topics that, to-date, have been under-researched.

Semi-structured interviewing is the most widely used method of data collection in qualitative research in psychology (Willig, 2001). Semi structured interviews provide the opportunity for a participant to tell a researcher, in detail, about particular experiences (Willig, 2001). Often described as non-directive, this style of interviewing is less confining on participants’ responses than structured interviews or quantitative methods. In semi-structured interviews, researchers ask open-ended questions that guide and encourage participants to talk about a particular subject of interest whilst placing few limits on the precise detail or aspects of the subject spoken about. For exploratory research like the proposed study, semi-structured interviewing was thus well suited since to confine subjects to specific discussion areas might have led to loss of valuable insights into a relatively poorly understood subject.

IPA was chosen for this study since the approach is concerned with trying to understand lived experience and how people make sense of their world. IPA shares the aims of phenomenology by trying to capture the texture and quality of individuals’ experiences. Concerned with a person’s subjective world i.e. how they see things, it offers no judgement
on the objective reality of participants’ reported experience i.e. whether their accounts are “realistic”. IPA researchers believe that individuals can experience the same phenomena, but in vastly different ways (Willig, 2001). In this way, the positivist view that external reality dictates one’s perception of the world is rejected. Instead, IPA theorists state that a person’s experiences are mediated by their idiosyncratic thoughts, beliefs and expectations. In trying to understand a person’s subjective reality, IPA researchers accept that it is impossible to gain direct access to a person’s unique experience of a phenomena; they realise that in arriving at an understanding they are influenced by their own beliefs, values or ideas (Willig, 2001). Instead of trying to ignore these personal cognitions the researcher utilises them. In other words, a researcher’s understanding of a participant’s experience requires interpretation (Smith, Jarman & Osborn, 1999). This has been described as a double hermeneutic which put simply is:

“participants … trying to make sense of their world; the researcher … trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2003, pg. 51).

IPA is actively concerned with cognition, and aims to identify what respondents think or believe about a topic (Smith, 1996). Due to the approach supporting connections between verbal report, cognition and physical state, it is compatible with a social cognition paradigm (Willig, 2001). Prior research into men’s help-seeking has asserted that men’s views on what it means to be a man (heavily influenced by society’s hegemonic views) play a significant role in men’s decisions to seek help for a problem. IPA thus seemed to have a natural fit with the proposed topic of study and is of course compatible with semi-structured interview methodology.
Appendix 10: IPA analysis

In order for the participants accounts to be analysed. The audio-recordings of each interview were transcribed verbatim. The transcripts were then transcribed using Interpretative Phenomenological Analysis as described by Smith et al. (1999; 2003) described below. IPA assumes that “the analyst is interested in learning something about the respondent’s world” (Smith et al., 2003, p.64). Meaning is central to this and in trying to understand the content and complexity of these meanings, the researcher must sustain engagement with the text whilst interpreting participant’s accounts (Smith et al., 2003). Smith et al. (1999), describes IPA as an “idiographic approach” and one that necessitates that each participant be considered in their own right, before moving onto compare themes of other participants’ transcripts.

Initially, the researcher read and re-read each transcript separately. Whilst doing this, initial thoughts about what the participant was saying were annotated in the left hand margin. There were no rules about what to comment on, but Smith et al. (2003) suggest these should be summaries or paraphrases of what was said as well associations and connections between them. Some preliminary interpretations were also allowed. My aim here was to capture the thoughts and feelings conveyed in the material, using the participants own language as much as possible. Quotes were thus extracted to support the notes I made.

Next, each paper was taken in turn and emergent themes were noted in the right hand margin using key words to capture the essence of the experience described. A high level of abstraction was allowed at this stage but it was important that concepts remained firmly rooted in the text and used words that most closely summarized what the participant was saying (Smith et al., 2003). Following this, themes were listed separately to allow the researcher to make sense of them and attempt to make connections or form clusters amongst them. With this list, the researcher referred back to the original text to check that the themes fit the context from which they arose. As suggested by Smith et al. (1999) the researcher was
careful to ensure that previous theoretical knowledge did not bias or distort the emergent themes and that they were clearly supported in the source material.

The above process was repeated for each transcript. Smith and Osborn (2003) caution that after examining the first paper and whilst looking at subsequent transcripts one must be disciplined enough to discern any repeating patterns but also recognise new issues arising from the texts. They say one should aim to respect convergences and divergences in the data, noting similarities and differences between transcripts. As any new themes arose, the researcher carefully checked them against earlier transcripts. This third step of the process resulted in eight separate theme lists.

In the fourth phase of analysis, the eight themes lists were analysed together to identify relationships amongst them. Themes were sorted into clusters or groups of concepts, which the researcher felt reflected similar meanings and experiences. Supporting quotes were carefully selected and noted to provide evidence of their existence in the raw material. Clusters where then arranged in a hierarchy where related themes were placed together. These clusters were then labelled based on the concepts that defined the essence of the theme content. Lastly, a final hierarchy was drawn up that consisted of two super-ordinate themes and five lower order themes. All themes were summarized in a table for inclusion in the results of the final empirical paper once member validation had taken place (see methods section for details of member validation).
PARTICIPANT QUESTIONNAIRE

Title of Study: Understanding the help-seeking behaviour of cardiac patients with erectile dysfunction: an exploratory study

Name of researcher: Mr Adam D Orchard

Thank you for showing an interest in this study.

In order for the researchers to accurately report this study, it is necessary that they collect some background information about the people who take part. Therefore, please could you answer the following questions honestly and completely as possible.

All information you provide will remain STRICTLY CONFIDENTIAL.

1. Your name:______________________________________________

2. Your date of birth:__________________________________________

3. What is your full postcode? e.g. HU6 7RX____________________

4. How many children do you have?______________________________

5. How many heart attacks (myocardial infarctions) have you had? _____

6. How long has it been since your last heart attack? _yrs _months _weeks

7. Have you ever suffered from erectile dysfunction? Yes-No □ □
8. Do you currently suffer from erectile dysfunction?  
   Yes ☐  No ☐

9. For approximately how long have you/did you suffer from erectile dysfunction?  
   (weeks/months/years).______________________________

10. Have you ever sought help for your erectile dysfunction? If yes, from WHO and WHEN?___________________________________________
    __________________________________________________________
    __________________________________________________________

11. Have you received any treatment for your erectile dysfunction? If so, WHAT and WHEN?__________________________________________
    __________________________________________________________
    __________________________________________________________

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

PLEASE RETURN THIS TO THE RESEARCHER BEFORE THE END OF YOUR INTERVIEW
Appendix 12: Semi-Structured interview schedule

Research questions
4. What factors are common in cardiac patients’ experiences of help-seeking behaviour for ED?
5. How do beliefs about masculinity impact on the help-seeking behaviour of men with ED?
6. What are the drivers and barriers of cardiac patients help-seeking for ED?

As you know from the information you have received, I am interested in hearing about your experiences of having erectile dysfunction (ED) and how you came to decide whether or not to seek help for it. There may be many different reasons why people seek (or not) for ED but I am interested in your story.

I am going to ask you as few questions as I can – I really just want you to tell me as fully as possible your story on how you came to decide to seek help for ED/not seek help for ED?

(Hopefully participant will start to say something about his experiences)

1. Perhaps you might start by telling me about yourself and your situation regarding ED and when you found you had a problem?

   Prompts:
   - When did you first realise you had a problem?
   - How did you feel/think/behave at this time?
   - Did/does anyone else know about you having ED? If yes, how did this affect their thoughts, feelings, behaviour towards you?

2. Have you ever sought help for your ED?

   Prompts:
   - What/why/how/when/from who?
   - What was that like?
   - How did it make you feel/think/behave?
   - Was there a delay in deciding to seek help and acting on that decision? For what reason? How long was it between making the decision and actually seeking the help?
   - Have you ever been given any information about ED? Tell me about this and how it affected you?

3. How has having erectile dysfunction made you feel as a person?

   Prompts:
   - How important is a healthy sex life to you? What does it mean to you, that you have/have had ED?
   - Has how you see yourself as a man changed because of the ED? In what way?
What does being a man mean to you? e.g. should men be self-reliant, physically tough, emotionally controlled? Have you always felt like that? How do you think your beliefs compare to those of other men (with and without ED)?

**How have your beliefs on being a man affected your help-seeking for ED do you think?**

How do you feel you compare to other men generally? Has your opinion changed in this area?

4. Can you tell me about any factors/issues that made you feel you didn't want to seek help for ED?

**Prompts:**

- Was embarrassment a factor? How?
- Did others people’s opinions or behaviour discourage you (friends, family, TV, celebrities)? Whose? What were these opinions/behaviours and how did they make you feel/or act?
- Were you bothered about having ED? Did you have any ideas about how treatable or normal ED was that may have stopped you seeking help? How do you think your age affected your help-seeking for ED?
- How did the idea of relinquishing control effect your decision making?

**Do you think your beliefs on being a man affected your help-seeking for ED? How?**

5. Conversely, what things helped you decide to go ahead and seek help for ED?

**Prompts:**

- As above……
- Did you have any opinions about your doctor/doctors in general that encouraged you?
- Did your health influence you? How?

6. Under what circumstances would you be most/more likely to seek help for ED?

**Prompts:**

- What would have made it easy for you to decide to seek help for ED? Doctors characteristics, friends/relatives opinions, expectations about treatability, being routinely asked about your sex life by a medical professional?

7. How do you think your help-seeking for ED compares to that of other men (with or without cardiac problems)?

**Prompts:**
How similar/different do you think your experiences of factors that encouraged/discouraged you from seeking help are, compared to those of other men?
What aspects of your help-seeking for ED are similar to those of other men’s?
What aspects of your help-seeking for ED are unique to you?
Thoughts, feelings, behaviours about life, health, sex, help-seeking, masculinity..

Thank you very much for your time

8. Is there anything you feel is important about your experiences of ED and help-seeking that we haven’t covered or do you feel we’ve captured you story quite well?

Thanks again. If you would like to hear about the outcome of this interview, I can contact you in the future to arrange a further appointment with you to discuss it, or I could mail a brief written report to you. Would you like feedback – which option is most suitable for you?
Appendix 13: Ethical approval documentation

Removed for hard-binding
Appendix 14: R&D approval documentation

*Removed for hard-binding*
WHAT ABOUT CONFIDENTIALITY?

We understand that with a subject so personal and private, confidentiality may be extremely important for people who take part in this research.

All information provided by you will remain strictly confidential and anonymous. Your audio tape, typed up interview and any details such as your age, ethnic group, marital status etc. will be kept securely and will not have any information that identifies you personally written on it; i.e. your name, address, date of birth.

The audio tape of your interview will be destroyed as soon as it has been typed up.

The only time confidentiality would be broken is if you were to tell the researcher anything that would lead us to believe that the safety of you, or anyone else, was in danger. In such circumstances, any action that would need to be taken would be discussed with you.

WILL YOUR CURRENT TREATMENT BE AFFECTED BY WHETHER YOU TAKE PART OR NOT?

No! You do not have to take part in this study. Even if you do initially agree to take part in the study, you can still withdraw from it at any time without giving a reason. A decision not to take part (made at any point) will not affect the standard of care you receive.

FURTHER INFORMATION

This leaflet aims to provide you with a brief overview of the study and how you could help.

You may have further questions and concerns.

If you feel you might like to take part in the study and agree to being contacted by the researcher, you will be provided with a more detailed information sheet and a consent form. You will have the opportunity to ask the researcher any questions you may have before deciding whether you do want to take part or not.

Please feel free to contact the researcher at any time if you are interested in this research. The researcher is more than happy to talk to you further about the study and address any concerns you may have. If you have already decided you would like to take part, you should also contact him. His contact details are provided below.

Why don’t men seek help for Erectile Dysfunction?

A Research Study

Information leaflet

Adam Orchard
Department of Clinical Psychology
Postgraduate Medical Institute
University of Hull
Hull
HU6 7RX

E-mail: a.orchard@nhs.net
Tel: 01482 318338

East Riding Healthcare NHS
Appendix 15: Participant information leaflet

**WHAT IS ERECTILE DYSFUNCTION?**

Erectile dysfunction (sometimes referred to as "impotence") is a continuous or repetitive inability to achieve or maintain an erection sufficient for satisfying sexual activity. It is one of the most commonly recognized sexual disorders and affects many men (in some groups as many as 50%).

Erectile Dysfunction is particularly common in men who have, or have had, heart problems.

Many men do not seek help for erectile dysfunction (ED). This is despite a wide range of treatments being available.

**HOW CAN YOU HELP?**

This study requires men who have had a heart attack(s) and who have or have had experience of erectile dysfunction. This problem may have arisen before or after a heart attack(s). The ED may be a problem now or it might be something that occurred in the past only. If you are someone who fits this profile — we'd really like to talk to you.

We understand that for many people this is an extremely personal and potentially embarrassing subject to talk about. The researcher will do his best to make you feel as comfortable as possible about discussing your experiences.

We would really value hearing your story. Each person is unique and an expert on their own life. You have your own experiences and feelings about ED and seeking help. Being able to understand these things is extremely valuable to us, as it will help us to understand how men address their problems with ED.

**WHAT IS THIS STUDY?**

This study is interested in men who have had a heart attack and who currently suffer from, or who have previously suffered from, erectile dysfunction. It is interested in trying to understand why some men decide to seek help for their ED whilst other men do not.

Having ED can be deeply distressing for anyone. It can affect a person's self-esteem, social life, sexual relationship and general quality of life.

If we can form a greater understanding of the help seeking process surrounding ED, it is hoped that we can increase the number of men who seek treatment and consequently improve the quality of many men's lives.

**WHAT WOULD YOU HAVE TO DO?**

In order for us to hear your story, you would be asked to have a private one-to-one interview with the researcher.

This interview would be held at a time and location convenient to you.

During the interview, you will be asked a few questions, but mostly it will be an open discussion where you will have an opportunity to talk about as much or as little as you want. The interviewer will ask you about different factors and the role they may have played in your decision to seek help, or not, for ED. Some factors may be important to you and you may talk at depth about these, others factors may not be, and you may choose to skip over them. What is important however, is that the researcher gains a clear understanding of your personal story.

The whole interview will last about an hour and will be audio taped. The content will then be typed up by the researcher, who will look at what you have said, and try to gain a clear understanding of your experiences. You will be offered written or verbal feedback, to provide you with the chance to see what the study findings were. This feedback is optional.

You are the expert in how ED has affected your life and how you decided whether or not to seek help. By spending one hour talking about this, you will help us understand how complex and difficult a decision that may have been for you. Your story matters because it is unique.

**WILL OTHER PEOPLE KNOW IF YOU ARE TAKING PART IN THIS STUDY?**

Other than you and the researcher — NO! Unless you choose to tell anyone else.

No family, friends or medical professional need know that you are taking part in this research.

The study is aiming to hear the story of men with ED, of which there are many, and so you will not be alone if you take part in this study. Please do not assume that your story is not important because it is, and we would value the opportunity to hear it from you.
CONSENT FORM FOR INITIAL CONTACT

Title of Study: Understanding the help-seeking behaviour of cardiac patients with erectile dysfunction: an exploratory study

Name of researcher: Mr Adam D Orchard

In order for the researcher to be allowed to contact you to make arrangements for your participation in this study, it is a legal requirement that prior written consent is obtained from you. Therefore, if you are interested in taking part in this research please complete the following and return it with your completed questionnaire in the enclosed stamped addressed envelope.

By completing this form, you are not consenting to take part in the study at this time: You are only consenting to being contacted by the researcher.

Your Name:________________________________________________________________

Your telephone number (including dialling code):___________________________________

Are there any days and/or times that you prefer we contact you?______________________

Please note: If someone other than you answers the telephone when the researcher calls, he will merely state his name and that he is "from the NHS and was hoping to speak to (name person above) regarding some research being conducted". He will leave his contact number and try to call you again another time.

I confirm that I have read the information leaflet for the above study. I understand that by signing this document, I am consenting to being contacted by the researcher in order for arrangements for my participation to be made and/or for further information to be provided to me.

Signature:_____________________________________________________

Date:_________________________________________________________

PLEASE RETURN THIS FORM IN THE STAMPED ADDRESSED ENVELOPE PROVIDED
Appendix 17: Recruitment letter

Cardiac Rehabilitation Service
NHS
Department of Clinical Psychology
Postgraduate Medical Institute
University of Hull
Cottingham Road,
Hull
HU6 7RX

CAN YOU HELP PLEASE?

Dear Sir,

Enclosed is some information about some important and exciting research being conducted with male heart patients.

Please take the time to read this information and consider if you would be willing to take part in the study. Your help would be really appreciated.

If you would like to take part, please could you:

1. Sign the consent form (to allow the researcher to contact you)
2. Return the consent form to the researcher in the stamped addressed envelope provided.

If you have any questions or concerns that you would like to speak to the researcher about, please feel free to get in touch using the details provided in the information leaflet and on the consent form.

Thank you for reading this.

Yours Faithfully

Adam Orchard
Appendix 18: Recruitment poster

Had a heart attack?
(myocardial infarction)

Problems with.....

SEX?

Many men suffer from erectile dysfunction (sometimes called impotence) but very few seek help for it. This is despite there being a wide range of treatments available. This is most concerning because for some men it is a deeply distressing experience.

Some research is being carried out in this area in order to find out why so few men seek help for erectile dysfunction.

If we can understand how men decide whether or not to seek help for erectile dysfunction, then we may be able to do something to encourage more to come forward for treatment in the future.

If you have had a heart attack and suffer from erectile dysfunction (or have done in the past) the researcher would be really interested in talking to you about your experiences.

Interested?

Please telephone the researcher on 01482 464087
Or e-mail on: a.d.orchard@psy.hull.ac.uk

PLEASE HELP YOURSELF TO A LEAFLET

Cardiac Rehabilitation Service

Version No: 07/06/2007(1)  REC Ref: 07/H1305/59
Appendix 19: Participant Information Sheet

Cardiac Rehabilitation Service

Participant Information Sheet

UNDERSTANDING THE HELP-SEEKING BEHAVIOUR OF CARDIAC PATIENTS WITH ERECTILE DYSFUNCTION: AN EXPLORATORY STUDY

You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear, or if you would like more information. Please take time to decide whether or not to take part.

What is the purpose of the study?

Many men suffer from erectile dysfunction (ED). Cardiac patients experience the problem in particularly high numbers. As with other difficulties, many men are reluctant to seek help for their ED. Past research involving men with ED has tended to look at the causes and treatment of the problem.

This study wishes to look at how men decide whether to seek help or not. It is interested in gaining an understanding of each participant's own individual story. If you take part in this study it will help to give a clearer picture of why and how men decide to seek help, or not, for their ED, because the reasons will be provided by men like yourself who really know.

Why have I been chosen?

Men who have suffered a heart attack (myocardial infarction) report experiencing ED in higher numbers than do men in the general population (i.e. those who do not have any heart conditions). You have been approached because you have suffered at least one myocardial infarction and have indicated to me, via completion of my screening questionnaire that you currently or have previously experienced ED. As I am trying to understand how men like you decide whether to seek help for ED, it would be extremely helpful to be able to speak to you about your experiences and to hear your story first hand. I am approaching many other men like you to take part and hope to be able to hear around 12 men’s experiences.

Do I have to take part?

In short – NO! It is up to you to decide whether or not to take part in this study. If you decide to take part you will be given this information sheet to keep, and asked to sign a consent form. If you decide to take part, you are still free to change your mind (withdraw) at any time without giving a reason. A decision to not take part (made at any time) will not affect the standard of care you receive.

What will happen to me if I take part?

Your involvement in this research need only last for around one hour and will comprise of a one-to-one interview with the researcher. All participants will be offered written or verbal feedback about the outcome of this meeting but the feedback is optional and will not occur until sometime in early-2008. The study itself is planned to run from June 2007 to July 2008. Your participation in this study does not replace any care you would normally receive and will not interfere with any assistance you are currently receiving.

The interview will last approximately one hour. The content of this hour will largely be dictated by you. The interview will be audio-taped so that it can be transcribed in full at a later date. The tape will be kept in a secure location and will not have your name on it. Information collected about you via a short questionnaire and from clinical records (e.g. your age, ethnicity etcetera) will also be recorded and kept securely for use in the study. Your tape, screening questionnaire and any other information on you will be stored separately so that your data will not be identifiable to anyone other than the researcher however.

What will I have to do?
All you will have to do is talk for around an hour with the researcher who will ask you to tell him about your experiencing of having ED and seeking help (or not) for it. The interview will look at things like what effected your decision to seek help, who might have been involved in that and how it has affected you. You will also be asked to complete a short questionnaire and provide consent for the researcher to access your clinical records. This information is required so that the group of participants involved in this study can be described in future written reports. The way this information is used however will prevent anyone from being able to identify any participant personally.

What will be the benefits of me taking part?

There are unlikely to be any direct benefits to for you if you do take part in this study, however by doing so, I hope that the study will benefit many other men in the future by giving us a better understanding of the help-seeking process for ED.

What if something goes wrong?

Due to the nature of this study, which essentially involves talking, it is unlikely that anything will go wrong. I am however required to let you know the following.

In the event of something going wrong and you being harmed during this research due to someone’s negligence you may have grounds for legal action but you may have to pay for your legal costs. Regardless of this, if you wish to complain or have any concerns about any aspect of the way you have been approached or treated during this study, the normal National Service Guidelines will still be available to you.

Should you become distressed during or after the session about anything you have discussed, you will be directed to your GP for advice regarding counselling or other suitable support.

Will my taking part in this study be kept confidential?

All information collected about you during the course of this research will be kept strictly confidential, and any information kept will have you name other personal details removed from it so that it cannot be recognised as yours. Your interview tape and questionnaire data will be kept separately and will be absent of any information that would make them identifiable as yours. For example, your name and address will not be present on these and instead the tape and questionnaire will be labelled with a unique research number. The tape of your interview will be destroyed as soon as it has been fully transcribed (typed up). The transcript will be handled in the same way as the tape and questionnaire data – your name and address will not be on it.

The only time where confidentiality would need to be broken, were if you were to say or do anything that would lead me to believe that you or anyone else where in danger. In such a situation, I would inform you of the action I would need to take.

The researcher will not inform your general practitioner (GP) of your participation in this study unless you indicate that you would like him to do so.

What will happen to the results of this research?

The results of this research will become part of a research portfolio. From this it is hoped that two separate journal articles will be published in reputable journal within the fields of psychology and/or health. From anything that is written or published, it will not be possible for anyone to identify you personally.

The research portfolio and journal articles will be completed by autumn 2008. Further information can be obtained from the researcher using the details at the foot of this information sheet.
Who is organising and funding this research?

I, the researcher, am a Trainee Clinical Psychologist who is undertaking this research as part of my training at the University of Hull. Although not paid for this research directly, I receive a salary from the National Health Service whilst I am training.

Who has reviewed this study and is it ethical?

All research in the National Health Service is looked at by an independent group of people called a Research Ethics Committee. Their job is to protect your safety, rights, well-being and dignity. This study has been approved by the South Humber Local Research Ethics Committee.

Further information and contact details

Should you require any further information about this study at any time, please feel free to contact the researcher using the details below:

Adam Orchard  
The Department of Clinical Psychology  
The University of Hull  
Hull  
HU6 7RX  
E-mail: A.D.Orchard@psy.hull.ac.uk  
Tel:  01482 804835

If you decide to take part in this study asked to sign a consent form of which you will be given a copy. Please keep it safe for your future reference along with this information sheet.

Thank you for taking the time to read this information.
Appendix 20: Consent form

Cardiac Rehabilitation Service
Department of Clinical Psychology
Postgraduate Medical Institute
University of Hull
Hull
HU6 7RX

REC Ref: 07/H1305/59
Patient Identification Number for this trial:

CONSENT FORM

Title of Study: Understanding the help-seeking behaviour of cardiac patients with erectile dysfunction: an exploratory study

Name of researcher: Adam Orchard

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.

3. I understand that I will attend an interview for this study and that this interview will be audio-recorded and the content typed up. I have been promised that the audio recording will be destroyed after transcription.

4. I consent to the researcher accessing my clinical records so that the study sample can be described in research reports and/or journal articles.

5. I understand that the researcher will retain demographic details about me e.g. age, ethnicity, marital status etc, but that this will be stored separately from my audio material.

6. I understand that all data whether audio or written will kept absent of any information that may identify me e.g. name and address.

7. I understand that any research reports and/or journal articles leading from this study may contain direct quotations of comments I have made during my interview (where it will not identify me personally). I consent to my interview material being used in this way.

8. I agree to take part in the above study.

Would you like your GP informed of your participation in this study?

YES*  

*Please provide GP details below

NO**  

**Please skip the next section

GP name: ___________________________________________________

Practice Name: ________________________________________________

Practice Address: ______________________________________________

Your NHS no: _________________________________________________
(if known)

Please sign below to confirm your consent to take part in this study

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When completed: 1 for patient; 1 for researcher
Appendix 21: Standardised debriefing sheet

Cardiac Rehabilitation Service
Department of Clinical Psychology
Postgraduate Medical Institute
University of Hull
HU6 7RX

REC Ref: 07/H1305/59
Patient Identification Number for this trial:

STANDARDISED DEBRIEFING FORM

Title of Study: Understanding the help-seeking behaviour of cardiac patients with erectile dysfunction: an exploratory study

Name of researcher: Adam Orchard

Thank you very much for taking part in this study. Should you have any questions or should you decide to retrospectively withdraw from this study at any time in the future (prior to submission/publication) please feel free to contact the researcher using the following details:

Adam Orchard
Department of Clinical Psychology
Postgraduate Medical Institute
University of Hull
HU6 7RX

Tel: 01482 464087
E-mail: a.d.orchard@psy.hull.ac.uk

Feedback regarding the results of this study are available should you like it. This can happen by meeting again with the researcher or by receiving a written summary through the post or e-mail. You have indicated that you:

1. Do not want feedback □
2. Would like face-to-face feedback □
3. Would like written feedback □

Feedback will be available in mid-2008. The researcher will contact you to arrange to meet for the face-to-face feedback where requested. Written feedback will be sent as soon as it is available.

Thanks again for your valued participation.
Leventhal et al.’s (1992) self-regulatory model suggests that the experience of illness is based upon general problem-solving procedures and proposes that individuals attempt to establish an equilibrium in three stages: interpretation of a problem; utilising coping strategies and appraisal of outcome (Hale, Treharne & Kitas, 2007).

A major component of the model is illness representation comprising five factors: 1) Identity – labels ascribed to the illness and symptoms attributed to it; 2) Cause – perceived cause of the disease; 3) Consequences – the expected impact and outcome of the problem; 4) Time line – expectations about duration of illness; 5) Controllability – how responsive the disease is to intervention (Leventhal & Nerenz, 1985).

The model highlights the importance that subjective meaning and perceived importance has on decisions regarding health behaviour. It suggests that behavioural coping strategies are chosen based upon appraisal in the earlier stages and that one’s response can be either ‘approach coping’ (seeking help) or ‘avoidance coping’ (hoping it will resolve itself [Hale et al., 2007]).
Appendix 23: Outline of stages of change model

Prochaska & DiClemente’s (1982) ‘Stages of Change’ model was originally developed to describe the phases through which patients progress in smoking cessation but has widely applied to other health behaviours.

The five stages that person is deemed to progress through in behavioural change are: 1) Pre-contemplation (unaware of one’s problems); 2) Contemplation (recognising illness); 3) Preparation (planning to change); 4) Action (behaviour modifying); 5) Maintenance (consolidating gains and preventing relapse [Gossop, 1994]).
Why do so few men seek help for erectile dysfunction?

Erectile dysfunction (ED) is defined as a continuous or repetitive inability to achieve or maintain an erection sufficient for satisfying sexual activity (World Health Organization, 1998). It is the most commonly recognised sexual disorder affecting more than 30 per cent of men aged 40 to 70 years (Laumann, 1999). Its prevalence is expected to double by 2025 (Pryor et al., 1998). The incidence of ED is particularly high in men post-myocardial infarction (MI); Estimates range from 50 to 70 per cent with much of the sexual dysfunction predating the coronary event (Dorsey et al., 1998; Schorer & Jensen, 1988).

Sexual function is an important determinant of a person’s quality of life and left untreated, sexual dysfunction can adversely affect mood, well-being and interpersonal functioning (Dealbus et al., 2000). Furthermore, some researchers have proposed that ED may function as a marker for occult cardiovascular disease (Johannes et al., 2000; Feldman et al., 1994).

Consequently, it is important that men with ED seek medical help for such difficulties. Not least to improve their wellbeing but also to enable prompt investigations for other cardiac risk factors to take place. In order that preventative medicines can be instigated.

Unfortunately, men are notoriously bad at seeking help for a wide array of problems and seek help much less often than women (Cohen, Hunt & Hart, 2003; Addis & Mahalik, 2003). In relation to ED, less than 30 per cent of men with this problem seek any sort of professional input (Shamloul et al., 2004). Because of this, many chances of early detection, treatment and prevention of disease are attenuated (Cohen et al., 2005). Clearly, this has major implications for the male population in terms of mortality and morbidity related to ED and cardiovascular disease. It also however provides an opportunity to reduce such statistics if ways of encouraging more men to seek help can be identified.

To do this we need to understand the process through which men go in deciding whether or not to seek help for ED.

There has been considerable research into the prevalence, aetiology and treatment of ED, but very little has looked at the help-seeking behaviour related to this disorder. Even less has looked at this phenomenon in cardiac populations specifically. Whilst we may be able to speculate that embarrassment, masculine ideologies and older age may be important factors in men’s decisions to seek help or not for ED, there is a need for rigorous research to confirm or disprove such ideas.

A qualitative study untold: Understanding the help-seeking behaviour of Cardiac Patients: An exploratory study ‘is about to be undertaken in Yorkshire. Up to 15 men at least 12 weeks post-MI will be recruited via the East Riding and Hull Cardiac Rehabilitation Service. Men recruited into the study will complete a short questionnaire and will take part in a one-to-one semi-structured interview with a male researcher. The interview aims to allow the men to talk freely and openly about their experiences of ED with few restrictions on what topics they cover specifically. Of particular interest to the researcher however will be the factors which men consider important in helping them decide whether to seek help for ED or not. The interviews will be audio taped to allow full transcription and all transcripts will then be analysed according to the principles of Interpretative Phenomenological Analysis. The results of the study will be written up for publication and peer review from early 2008.

For further information on this study please contact Aidan.orchard@psy.hull.ac.uk We are keen to hear from anyone with suggestions or comments on the study.

Mr Adam D Orchard, Trainee Clinical Psychologist, University of Hull, and orchard@psy.hull.ac.uk

Dr Dorothy J Prout, Clinical Psychologist, University of Hull

Cardiac Rehabilitation Service Manager