

THE UNIVERSITY OF HULL

The experiences of South Asian men with diabetes mellitus and erectile  
dysfunction

being a Thesis submitted in partial fulfilment of the requirements for  
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## **Overview**

This portfolio thesis consists of three parts.

Part one is a systematic literature review investigating existing research on the illness perceptions of men with erectile dysfunction (ED). The following five online databases were searched; PsycINFO, MEDLINE via EBSCO, Scopus, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Web of Science Core Collection. With the application of relevant inclusion and exclusion criteria, 13 studies were found to be eligible for inclusion in the review. A narrative synthesis of the findings of the included studies was conducted. Findings were organised into five categories of men's perceptions about ED. These were as follows; severity and permanence of ED, communicating about ED, causes of ED, consequences of ED and treatment for ED. A discussion of the findings is presented, with consideration of the impact of illness perceptions on communication about and treatment-seeking for ED. The limitations and the clinical implications are proposed, as well as avenues for future research.

Part two is an empirical paper investigating the experiences of South Asian men with diabetes mellitus (DM) and ED, utilising exploration of their illness perceptions and the impact on quality of life. Qualitative methodology was employed. Semi-structured interviews based on the Self-Regulatory Model (Leventhal, Nerenz, & Steele, 1984) were conducted with six South Asian men with DM and ED. Interpretative phenomenological analysis (IPA) was employed. Four superordinate and ten subordinate themes were identified. The findings are discussed in consideration of clinical implications and limitations of the study. Avenues for future research are proposed.

Part three consists of the appendices for the systematic literature review and the empirical paper, including an epistemological statement and a reflective statement.

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## Part One:

### Systematic Literature Review



An exploration of the illness perceptions of men with erectile dysfunction:

A systematic literature review

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Please see Appendix A for the Guideline for Authors

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## Abstract

**Objectives:** To systematically review the literature on the illness perceptions of men with erectile dysfunction (ED).

**Method:** Five online databases were systematically searched. These included:

PsycINFO, MEDLINE via EBSCO, Scopus, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Web of Science Core Collection. Relevant inclusion and exclusion criteria were applied to the returned literature.

**Results:** A total of 13 studies were eligible for inclusion in the systematic review. The illness perceptions of men with ED were organised into five categories via a narrative synthesis: severity and permanence of ED, communicating about ED, causes of ED, consequences of ED and treatment for ED. Heterogeneous measures of illness perceptions were employed by the included studies.

**Conclusion:** Future research needs to further explore the illness perceptions of men with ED utilising reliable and valid measures of illness perceptions and needs to do so within different health populations of men.

*Short title: Illness perceptions of men with erectile dysfunction*

*Keywords: Erectile dysfunction, illness perceptions, men, systematic literature review*

## Introduction

When a male cannot satisfactorily engage in sexual intercourse, due to an inability to achieve and sustain an erection, he is experiencing erectile dysfunction (ED) (Aikey, 1992). There are multiple causes of ED, including both organic/physiological and psychogenic in nature. Stress, fatigue, depression (Aikey, 1992) and anxiety are examples of psychogenic factors that may result in the onset of ED (Urology Care Foundation, 2014). Physical origins of ED include inflammatory (e.g. Cystitis<sup>1</sup>), vascular (e.g. Hypertension<sup>2</sup>), mechanical (e.g. Peyronie's disease<sup>3</sup>), neurogenic (e.g. Spinal Cord injury<sup>4</sup>), traumatic (e.g. Radiation therapy<sup>5</sup>), chemical (e.g. alcohol and drugs), endurance (e.g. Anemias<sup>6</sup>), endocrine (e.g. Diabetes Mellitus<sup>7</sup> (DM)) and surgical causes (e.g. Radical Cystectomy<sup>8</sup>) (Aikey, 1992).

The physical antecedents contribute to the development of ED in a number of ways but generally a limited blood supply to the penis results in the inability of the penis to retain blood or to receive appropriate nerve signals from the central nervous system (Urology Care Foundation, 2014).

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<sup>1</sup> Bladder irritation due to an infection (NHS Choices, 2013<sub>a</sub>).

<sup>2</sup> High blood pressure (NHS Choices, 2014).

<sup>3</sup> The formation of a plaque in the penis shaft, results in a bend in the penis when it is erect (NHS Choices, 2013<sub>b</sub>).

<sup>4</sup> Damage to the spinal cord as a result of trauma (National Institute of Neurological Disorders and Stroke, 2014).

<sup>5</sup> Form of cancer treatment that utilises radiation to destroy cancerous cells (American Cancer Society, 2014).

<sup>6</sup> Blood disorder, resulting from too few red blood cells or dysfunctional red blood cells (American Society of Hematology, 2014).

<sup>7</sup> A chronic health condition characterised by excess blood glucose, due to an insufficiency of the hormone insulin (NHS Choices, 2012<sub>a</sub>).

<sup>8</sup> The entirety of the bladder is removed, as well as neighbouring lymph nodes (Cancer Research UK, 2013).

The National Institute for Health and Care Excellence (NICE; 2013) have proposed that an amalgamation of lifestyle changes, inclusive of losing weight, stopping smoking and a decrease in alcohol intake, and medical treatments, can be effective for treatment of ED. Phosphodiesterase-5 (PDE-5) inhibitors<sup>9</sup> have been endorsed as first-line treatments for ED. These include; sildenafil, tadalafil and vardenafil. However, recommendations for referral to specialist services such as urology or cardiology are recommended if there are contraindications to the use of PDE-5 inhibitors or if these drugs have been deemed ineffective (NICE, 2013). Other available treatments include vacuum pumps<sup>10</sup>, alprostadil<sup>11</sup>, hormone therapy<sup>12</sup> and penile implants<sup>13</sup> via surgery (NHS Choices, 2012<sub>b</sub>). If the suspected cause of ED is psychogenic in nature, a referral to mental health services may be considered (NICE, 2013). Despite the multitude of treatments available for ED, access to them on the NHS is limited. Exceptions to this restriction occur for those individuals who experience ED as a result of a comorbid health condition such as DM. These limitations are in place to minimise the costs of ED treatment to the NHS. However, even with such restrictions applied, cost of ED treatments to the NHS exceeded £80 million in 2012, of which approximately half of this amount was spent on Viagra (sildenafil citrate) (Department of Health, 2014).

ED has been found to be a prevalent health condition (Nehra & Kulaksizoglu, 2002).

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<sup>9</sup> ED medication that facilitates greater blood flow to the penis, on a temporary basis. They are the most efficacious and extensively used ED medication (NHS Choices, 2012<sub>b</sub>).

<sup>10</sup> The penis is inserted into a tube and a pump is utilised to expel the air in the tube. As a result, a vacuum is generated and the blood flow to the penis is increased, producing an erection (NHS Choices, 2012<sub>b</sub>)

<sup>11</sup> An alternative treatment for ED; a manufactured hormone that facilitates blood flow to the penis (NHS Choices, 2012<sub>b</sub>).

<sup>12</sup> If the cause of ED is due to a hormonal condition, manufactured hormones can be injected to facilitate hormonal balance (NHS Choices, 2012<sub>b</sub>).

<sup>13</sup> Surgically inserted implants into the penis to aid erection. Examples include; semi-rigid and inflatable (NHS Choices, 2012<sub>b</sub>).

Almost 50% of men aged 40 plus have been found to experience ED (Nehra & Kulaksizoglu, 2002). Approximately 80% of men who experience ED do so because of physical causes (UK Health Centre, 2014).

Research investigating the occurrence of ED in men across eight countries, aged between 20 and 75, found an overall prevalence rate of 16% (Rosen et al., 2004). The prevalence of men in the UK reporting ED was 13%. The number of men reporting ED was greater with an increase in age and where men had comorbid health conditions such as cardiovascular disease and depression. Men with ED were more likely to have comorbid health conditions. Despite 58% of men with ED reporting that they had asked for medical support, less than half of these men, (16%), were using PDE-5 inhibitors (Rosen et al., 2004).

Where the worldwide prevalence of ED is high (Nehra & Kulaksizoglu, 2002) and there is a substantial demand for ED treatments (Department of Health, 2014), it is important to also consider the impact the condition has on men's quality of life (QoL). ED has been found to impact negatively on QoL (Litwin, Nied, & Dhanani, 1998).

Specifically, ED was found to impinge more on men's emotional as opposed to physical functioning. Additionally, men with ED were found to have poorer psychosocial functioning in comparison to controls (Litwin, Nied, & Dhanani, 1998). Fatt (2012) proposed that it is difficult to establish the impact that ED has on QoL, as ED itself may originate from psychogenic causes. However, ED may contribute to a decline in QoL, where it causes difficulties for the individual with regard to their mood, self-confidence, self-esteem and relationships (Fatt, 2012).

De Berardis et al. (2002) looked to investigate the effect of ED on QoL in individuals with Type 2 DM (T2DM) and found a link between ED and distress (related to DM) and to poorer psychological adjustment. These outcomes were subsequently associated with poorer metabolic control of T2DM (De Berardis et al., 2002). ED was also found to be linked to a greater occurrence of severe depressive symptoms, as well as to a poorer sex life. Despite the reported impact of ED on QoL, 68% of participants had not been assessed for difficulties in sexual functioning by their physicians (De Berardis et al., 2002).

Where research has highlighted the negative impact of ED on men's QoL, it is important to consider the perceptions that men experiencing ED have about their ED. Leventhal's Self-Regulatory Model (Leventhal, Nerenz, & Steele, 1984) proposes that individuals will attempt to comprehend and make sense of their illness by adopting a cognitive belief system. This system is used to regulate health behaviours and coping strategies. The beliefs held about illness are referred to as illness perceptions or representations. Illness representations encompass five domains; identity, causal beliefs, time-line, consequences and cure/control. The identity domain is concerned with thoughts about the symptoms and diagnosis; causal beliefs refer to thoughts about the origins of the illness; time-line is concerned with the beliefs about illness duration and course; the consequences domain consists of beliefs about illness severity and its impact on multiple aspects of functioning, inclusive of psychological, physical and social. Finally, the cure/control domain is representative of those beliefs held about the degree of control that can be had over the illness and the extent to which it can be cured (Leventhal, Nerenz, & Steele, 1984).

Two additional domains have subsequently been added to the original model; 'coherence' and 'emotion'. Coherence corresponds to the knowledge possessed about the illness and the degree to which the individual understands it. The emotion domain describes the elicited affective/emotional reaction (Moss-Morris et al., 2002).

Either an emotion-focused or problem-focused coping strategy will be employed, dependent upon the perceived level of illness threat (Leventhal, 1997).

Illness representations have been found to influence health outcomes for multiple health conditions (Hagger & Orbell, 2003). Hagger and Orbell (2003) conducted a meta-analytic review to investigate associations between illness representations, coping and health outcomes. An association was found between perceived control over the illness and the adoption of active coping strategies, as well as cognitive re-appraisal of the importance of the illness (Hagger & Orbell, 2003). An association was found between the identity domain of illness representations and avoidance and affective expression. It was suggested that this could be indicative of an appraisal of active coping as being inefficacious and thus the individual adopts more maladaptive coping strategies such as avoidance. A weaker illness identity and an appraisal of minor illness consequences were linked to adaptive health outcomes. These outcomes included; social, physical and role functioning, psychological well-being and vitality (Hagger & Orbell, 2003).

A systematic analytic review by Hudson, Bundy, Coventry and Dickens (2014) found a link between worse emotional health and greater perceptions of the severity, consequences and cyclical timeline of DM. There was a related rise in anxiety and depression with the perception that an individual had less control. This study showed that there is an association between illness representations and emotional outcomes, as well as self-care behaviours in DM (Hudson, Bundy, Coventry, & Dickens, 2014).

An exploration of the illness perceptions of men with ED may provide a greater understanding of their adopted coping strategies and health behaviours e.g. help-seeking. This information could be used to better inform service provision, to ensure that the physical and psychological needs of these men are met. This is particularly important in consideration of the predicted increase in prevalence of ED (Nehra & Kulaksizoglu, 2002), its impact on QoL (Litwin, Nied, & Dhanani, 1998), its cost to the NHS, (Department of Health, 2014) as well as its indication of serious underlying illness (Shin, Pregenzer, & Gardin, 2011; Sun et al., 2006).

To widen the scope of this exploratory systematic review, the term ‘perceptions’ has been adopted over ‘representations’, in order to encompass men’s perceptions of ED that may otherwise have not been captured by Leventhal’s Self-Regulatory Model (Leventhal, Nerenz, & Steele, 1984). The ‘coherence’ domain of the Self-Regulatory Model (Moss-Morris et al., 2002) has informed the definition of ‘perceptions’ as used in this review. This includes the understanding that men have about their ED and how they make sense of it.

Therefore the aim of this systematic literature review was to explore the illness perceptions of men with ED.



## **Method**

### **Data sources**

A systematic search of the literature was conducted electronically, utilising the following five online databases; PsycINFO, MEDLINE via EBSCO, Scopus, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Web of Science Core Collection. The choice of databases was informed by those adopted in previous systematic literature reviews, with a focus on ED or illness perceptions in another health domain (Orchard, 2008; Foxwell, Morley, & Frizelle, 2013). A range of databases were searched to maximise the scope of relevant literature obtained, as well as to include literature from a number of healthcare disciplines inclusive of; social and life sciences, mental health and medicine.

### **Search Strategy**

Electronic databases were searched in May 2014. Search terms employed were informed by those used in previously conducted systematic literature reviews. Search terms “erect\*” and “impot\*” were utilised by Orchard (2008, p.12) and search terms “health\* OR illness\* (AND) percep\* OR expect\* OR belie\* OR represent\* OR cognit\* OR attitud\*” were utilised by Foxwell, Morley and Frizelle (2013, p. 213). A combination of search terms adopted in previous systematic literature reviews was used in order to ensure that search terms were robust. Table 1. highlights the search terms employed.

Table 1.

*Search terms utilised for the current Systematic Literature Review.*

	<b>Search Field</b>	<b>Search Terms</b>
	Title	erect* OR impot*
(AND)	Abstract [Topic] <sup>14</sup>	health* OR illness*
(AND)	Abstract [Topic]	percep* OR expect* OR belie* OR represent* OR cognit* OR attitud*

The truncation symbol [\*] was used to encompass the potentially variable endings of search terms, thus optimising inclusion of relevant literature. The Boolean operator [AND] was employed to connect the search terms and [OR] to optimise the inclusion of variable search terms, as a means of maximising the return of relevant literature. Search terms were applied to the title and abstract fields only, in order to minimise the return of irrelevant literature and optimise the return of literature specifically concerned with the illness perceptions of men with ED. A search term encompassing more general sexual dysfunction was not included, as the researcher wanted to ensure that literature specific to ED were returned. References lists of the studies eligible for inclusion in the review were hand searched for any additional eligible studies. An author of one of the eligible studies for inclusion was contacted about additional research in the field<sup>15</sup>.

<sup>14</sup> The search field 'Topic' was used in Web of Science as there was no option for 'Abstract'.

<sup>15</sup> Dr Beth Grunfeld, School of Psychology, University of Birmingham.

## **Inclusion Criteria**

The inclusion criteria for papers in the systematic review were as follows:

- Participants were men with ED (including samples of men with former ED).
- Age of participants was 18+.
- Participants' perceptions were reported as outcomes in the abstract of the paper.
- At least two different aspects of participants' perceptions about ED (could include perceptions about its treatment) were reported in the abstract e.g. perceptions about cause and perceptions about consequences of ED.
- Published and peer-reviewed papers only for the enhancement of scientific rigor.
- Empirical papers.
- Papers written in the English-language.
- Both quantitative and/or qualitative papers were eligible for inclusion.

## **Exclusion criteria**

The exclusion criteria for papers in the systematic review were as follows:

- Participants did not have ED (and not specified to have had historical ED).
- Papers that reported on men's perceptions that were not ED-specific e.g. sexual performance.
- Papers that did not report participants' perceptions in the abstract.
- Papers that did not report a minimum of two different perceptions of ED in the abstract (see inclusion criteria).
- Participants with ED and a specific comorbidity e.g. DM.
- Papers that excluded participants with a determined origin of ED e.g. organic versus psychogenic.
- Papers that included the participation of women, partners and/or physicians.

- Studies which aimed to investigate the effectiveness of ED treatments, as this is not a focus on men's illness perceptions.
- Papers that were not empirical investigations e.g. meeting abstracts, conference abstracts and article reviews.
- Papers not published or peer-reviewed.
- Papers not written in the English-language.

### **Rationale for inclusion and exclusion criteria**

As the systematic review question was exploratory and thus broad, the scope of literature returned was wide. The literature was heterogeneous in aims, methodology and outcomes. Therefore, in order to focus the review on the research question being asked, as well as to enhance scientific rigor, the above inclusion and exclusion criteria were applied. Thus, only peer-reviewed empirical publications were included. To focus the review, whilst not restricting the perceptions explored, only men with ED were included, whose perceptions on more than one aspect of ED were reported (this included papers reporting both perceptions of men with and without ED, as long as perceptions of men with ED were separately identified and presented). The reason for the requirement that these be reported in the abstract of any included study was to demonstrate that these formed part of the main findings. The rationale for including papers that made reference to two aspects of perceptions of ED as a minimum in their abstract, was to facilitate a wider scope of men's perceptions about ED, in order that the review was less restrictive and more encompassing of a wider variety of perceptions conveyed. In order to enhance the generalisability of the review findings, papers that only recruited participants with ED and a specific health comorbidity were excluded, as well as those that excluded participants due to a specific cause of ED. Men 18+ were included, as the review was concerned with the perceptions of adult men with ED.

Papers that did not report on ED-specific perceptions were not included, as the current review was concerned with the perceptions of ED itself.

Both quantitative and qualitative papers were eligible for inclusion, as there were too few qualitative papers alone to conduct the review and some of the quantitative papers reported too little information about the perceptions of men with ED. Thus, in light of the heterogeneity of the literature and so as not to be restrictive in the consideration of men's perceptions of ED, both methodologies were eligible for inclusion.

Only papers written in the English-language were included, due to the limited resources to retrieve and interpret papers written in a language that was not the researcher's first language.

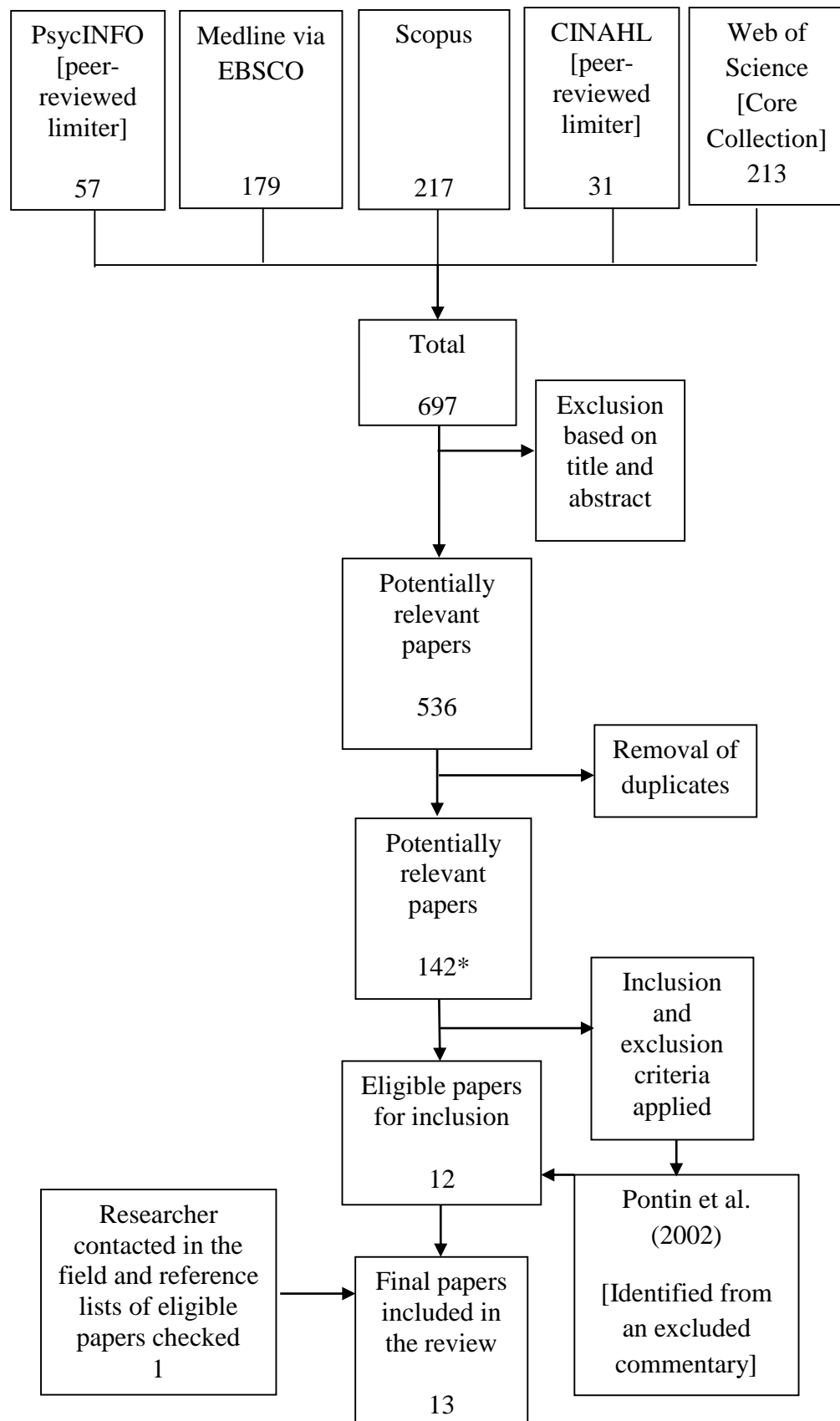


Figure 1. Process of paper selection for inclusion in the systematic review.

\*The main exclusion criteria that studies were not meeting here were that they were either not written in the English language, they were not empirical research papers, they employed samples of men with ED from a specific health population e.g. DM and either the perceptions of men with ED were not reported in the abstract of the paper at all or a minimum of two perceptions were not reported. As such, it appeared that there were few papers that sufficiently reported on the perceptions of men with ED in their abstracts, to indicate that they were a main outcome of the studies investigation.

### **Quality Assessment**

Two quality assessment tools were utilised; one to assess the quality of quantitative papers and one to assess the quality of qualitative papers. The quantitative quality assessment tool [see Appendix B] was adapted from that used by Orchard (2008) (Prins, Blanker, Bohnen, Thomas, & Bosch, 2002; Criteria for methodological quality assessment of prevalence studies). Elements of the Down's and Black (1998) quality assessment checklist were also incorporated into the modified tool. The researcher included these modifications to ensure that the quality checklist questions were most relevant to papers included in the current review. The above tool was deemed appropriate and relevant for use, as it has been previously used within a systematic literature review investigating ED (Orchard, 2008). The NICE qualitative research quality assessment tool (2009) [see Appendix C] was utilised to assess qualitative papers. The researcher independently assessed the quality of all 13 studies. All three qualitative studies included in the review plus a random sample of four of the quantitative studies were independently quality assessed by an additional rater. This allowed the inter-rater reliability of the quality assessment to be determined.

## **Data synthesis**

A narrative synthesis of the data was conducted, due to the heterogeneous nature of the studies included in the review. This involved textually describing and interpreting the findings of the studies (Pope, Mays, & Popay, 2007). For quantitative studies, textually presented findings of the perceptions of men with ED about their ED were extracted. This process was also carried out for qualitative papers, however, as there was more descriptive information in the findings of qualitative papers e.g. the perceptions of individual participants, themes from the data were extracted on the whole rather than individual accounts. Once the textually presented findings were extracted from the studies, they were grouped into commonly occurring themes of the perceptions of men with ED about ED. As such, the textually presented findings from both qualitative and quantitative studies were organised into five themes of men's perceptions, as the most commonly occurring themes evident in the findings of the papers. The findings were organised in this way in order to create a coherent narrative of the perceptions of men with ED about ED.



## Results

Table 2.

*Data extracted from included studies.*

Author(s), Date and Origin of Study	Aims of the study	Participant demographics	Design and Methodology	Main findings	Quality Rating (issued by first rater)
Tomlinson and Wright (2004)  United Kingdom (UK)	To investigate the impacts of ED and ED treatment with Sildenafil (Viagra).	<i>N</i> = 40 men with ED using Sildenafil. Age range = 22-72 years (Median = 51.8 years)  Success with Sildenafil <i>N</i> = 20  No success with Sildenafil <i>N</i> = 20	Qualitative: semi-structured interviews.	Participants were severely distressed by ED. ED was found to impact on their self-esteem as well as on their relationships. When Sildenafil was effective, it resulted in better wellbeing. The emphasis that the media placed on Sildenafil expectations impacted negatively on the morale of men for whom Sildenafil was ineffective. Serious distress was experienced by those for whom treatment was ineffective, reinforcing their sense of worthlessness.	28

Pontin, Porter and McDonagh (2002)  UK	To establish and investigate the concerns of men with ED. More specifically, with reference to their relationships with female partners and their interaction with the world.	<i>N</i> = 9 men with ED Age range = 28-72 years (Median = 52 years)	Qualitative: semi-structured interviews.	Two over-arching themes: <ul style="list-style-type: none"> <li>• “loss” (Pontin et al., 2002, p. 264)</li> <li>• “being alone with it” (Pontin et al., 2002, p. 264)</li> </ul> Meta-categories: <ul style="list-style-type: none"> <li>• “making sense of it”(Pontin et al., 2002, p. 264)</li> <li>• “telling other people”(Pontin et al., 2002, p. 264)</li> <li>• “place of sex” (Pontin et al., 2002, p. 264)</li> </ul> The last meta-category links the two themes.	26
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Perelman, Shabsigh, Seftel, Althof and Lockhart (2005).  Cross-National: United States (US), Germany, UK, France, Italy and Spain.	To gain a greater understanding of the following components of ED; psychological and behavioural. Additionally, to consider ED attitudes across countries.	<p><math>N = 2829</math>. Age range = 20-75 years. (Median = 57 years).</p> <p>Employment: Minimal Part-time = 47% Retired = 43% Unemployed/students: remaining participants.</p> <p>Marital Status: Married/living with partner = 77% Single/Never married = 9%</p> <p>Education: Primary only = 34% Secondary and postsecondary = remaining participants.</p>	The Cross-National Survey on Male Health Issues: Men across six countries completed a questionnaire about: 1) Attitudes 2) Behaviour 3) Doctor-related issues 4) Comorbidities.  91.5% were able to be evaluated.	There were similarities in the attitudes held by men across the different countries. Men across the six countries concurred that ED resulted in much sadness for them, as well as for men's partners. Most men in all countries did not agree that they were too old to have sex. Participants across all countries wanted to know that they were able to sexually perform. Fifty percent of participants claimed willingness to do almost anything in order for their ED to be cured. All men across the six countries concurred that their doctor was the most favourable provider of information about sexual concerns. Participants in the US and UK were not as accepting of ED, had more drive to seek a cure and had a lesser likelihood of perceiving ED to be psychological in origin.	14
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Stamogiannou, Grunfeld, Denison and Muir (2005).  UK	<p>To investigate the beliefs about ED that men with ED hold. This was based on the illness representations model. Additionally, to determine the link between such beliefs and QoL.</p>	<p><math>N = 41</math> Age range = 27-77 years. (Median = 57 years).  Participants were diagnosed with ED at least 4 months before the study began. Range of time since diagnosis = 4 months to 11 years.  Ethnicity: White = 51% Black Caribbean and Black African = 37% Asian = 12%  Marital status: Married/with partner = over two-thirds Single = 12% Divorced/widowed/separated = 22%.  Comorbid conditions: Prostate cancer = 24% Cardiac disease and diabetes = 34% No disease/psychological = 10% Other (back pain/HIV/Peyronie's disease) = 32%  ED management: Sildenafil citrate (Viagra) = 37% No treatment = 32% Alprostadil (Viridal) = 7% Apomorphine hydrochloride (Uprima) = 5% Vacuum constriction device = 5%.</p>	<p>Questionnaires employed measuring:</p> <ul style="list-style-type: none"> <li>• QoL</li> <li>• Sexual functioning</li> <li>• Illness representations</li> <li>• Perceptions of masculinity.</li> </ul> <p>Measures employed to investigate illness perceptions, sexual functioning, masculinity perceptions and QoL respectively:</p> <ul style="list-style-type: none"> <li>• Adapted version of the revised Illness Perception Questionnaire (Moss-Morris et al., 2002).</li> <li>• ED scale of the Prostate Cancer Index of Sexual Function scale (Litwin, Nied &amp; Dhanani, 1998)</li> <li>• Brief questionnaire was generated to measure masculinity, based on Feldman, Goldstein, Hatzichristou, Krane and McKinlay (1994).</li> <li>• ED Effect on Quality of Life questionnaire (ED-EQOL) (MacDonagh, Ewings &amp; Porter, 2002).</li> </ul> <p>73% response rate.</p>	<p>There was a significant correlation between QoL and each of the following:</p> <ul style="list-style-type: none"> <li>• Masculinity</li> <li>• Sexual function</li> <li>• Emotions</li> <li>• Beliefs concerned with consequences.</li> </ul> <p>Greater QoL was best predicted by greater sexual functioning. Second to this, it was predicted by greater positive beliefs about the impact of ED on masculinity.</p>	15
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Low, NG, Choo and Tan (2006).  Malaysia	To investigate the perceptions that men with ED have about their ED and the origin of these perceptions.	<p><math>N = 17</math>. Age range = 40-75 years. (Mean = 56 years).</p> <p>16 participants were married, one was not.</p> <p>Men included who self-reported ED for a duration of 6 months and who had a score of &lt; 21 on the IIEF-5 (International Index of Erectile Function; Rosen, Cappelleri, Smith, Lipsky &amp; Peña, 1999)</p>	Qualitative: semi-structured interviews.	<p>Participants were mistaken in their beliefs about the definition of ED. The majority believed impotence to be greater in severity compared with ED. The majority of men had an awareness of medical causes of ED, yet culturally-bound causes were also reported including; using the penis too much and black magic. Men viewed ED as severe, resulting in an absent manhood, as well as significantly affecting their partner relationships. A few men accepted ED as associated with aging and fate. The majority of men were aware of traditional therapies and PDE-5 inhibitors for ED only. Although men viewed PDE-5 inhibitors as being efficacious, they expressed worries about the cost of them and their side effects.</p>	26
Fisher, Rosen, Eardley, Niederberger, Nadel, Kaufman and Sand (2004).  US, UK Germany, France, Italy, Spain, Mexico and Brazil.	To investigate the treatment-seeking of men with ED, for PDE5 inhibitors.	<p>Phase II: <math>N = 2912</math>.</p> <p>Age range = 20-75 years.</p>	<p>Self-report questionnaires about:</p> <ul style="list-style-type: none"> <li>• ED characteristics.</li> <li>• PDE5-inhibitor treatment-seeking.</li> <li>• Factors and attitudes that may impact on treatment-seeking.</li> </ul>	<p>A strong link was found between the perceived severity of men's ED and their use of PDE- inhibitors. Additionally, their use of PDE5-inhibitors was strongly linked to perceptions that ED medication is dangerous, as well as beliefs about the support of others in their treatment-seeking. This included; physicians and additional professionals and spouses/family members. There was a greater likelihood of men using PDE5-inhibitors where they perceived their ED as greater in severity, did not perceive ED medication to be dangerous and who believed others to be supportive of their treatment-seeking.</p>	16

Matic and McCabe (2008)  Australia	To investigate the impact of ED duration on treatment-seeking and subsequent satisfaction with PDE5-inhibitors.	<p><math>N = 409</math>. Age range = 45-75 years (Mean age = 55.7 years; SD = 14.6).</p> <p>In a sexual relationship = 85.8%. In relationship for &gt; 2 years = 84.6%. ED for &gt; 3 years = 61%.</p>	<p>Men's health questionnaire:</p> <ul style="list-style-type: none"> <li>• Duration and severity of ED.</li> <li>• Information and help-seeking behaviours (ED)</li> <li>• Treatment utilisation</li> <li>• PDE5 inhibitor satisfaction.</li> </ul>	<p>Men having experienced ED for longer had a greater likelihood of talking about their ED to their physician or partner. They were also more likely to have sought out treatment and information regarding ED. Controlling for age, there were no differences in ED medication satisfaction or intention to use medication in the future, across men with different ED durations.</p>	13
Gülpinar, Haliloglu, Abdulmajed, Boga and Yaman (2012).  Turkey	To investigate the beliefs, attitudes and additional aspects impacting on the delay in help-seeking of Turkish men with ED.	<p><math>N = 191</math> (no treatment-seeking). Age range = 20-80 years (Mean age = 50.1 years)</p> <p>Employed = 51.8% Primary school education only = 32.5%</p> <p>Relationships status: Married/ongoing relationship = 92.7% Single = 5.7% Divorced = 1.6%</p> <p>Mean relationship duration = 25 years (Range = 9 months to 51 years).</p>	<p>A standardised questionnaire was employed, from which participants were interviewed (see Supplemental Data, available online at <a href="http://www.andrologyjournal.org">http://www.andrologyjournal.org</a>)</p> <p>The questionnaire investigated:</p> <ul style="list-style-type: none"> <li>• Demographic details</li> <li>• Relationships</li> <li>• Help-seeking intervals</li> <li>• Attitudes and beliefs</li> </ul>	<p>Had sexual intercourse one year prior to the interview = 93.7%</p> <p>Mean help-seeking interval = 24.5 months Mean approximate time since last satisfactory sexual intercourse = 10.5 months.</p> <p>Participants with low household income and education levels had greater help-seeking delays.</p> <p>Delayed consultation due to embarrassment = 33%</p> <p>Delayed consultation due to the belief that ED is a natural part of aging = 26.7%.</p>	14

Wong, Tan, Low and Ng (2008).  Asia: China, Japan, Korea, Malaysia and Taiwan.	To report the practice, perceptions and experiences of Asian men utilising traditional and complementary medicine (T/CM) for ED.	<p>Phase I of the Asian Men's Attitudes to Life Events and Sexuality (MALES): <i>N</i> = 10,934 men residing in China, Japan, Korea, Malaysia or Taiwan.</p> <p>Phase II of the MALES study: <i>N</i> = 1, 286 men with ED residing in China, Japan, Korea, Malaysia or Taiwan.</p> <p>Age range = 20-75 years (Mean age = 51.7 ± 0.35 years).</p>	<p>Multi-regional survey (MALES Study) consisting of two Phases and participants from China, Malaysia, Japan, Korea and Taiwan.</p> <p>Phase I survey (not specific to ED):</p> <ul style="list-style-type: none"> <li>• Men's health issues</li> <li>• Treatment-seeking behaviour</li> <li>• QoL</li> </ul> <p>Phase II survey (men with ED):</p> <ul style="list-style-type: none"> <li>• ED</li> <li>• Related health conditions</li> <li>• Treatment-seeking behaviour and needs.</li> </ul>	<p>There was found to be some satisfaction with T/CM for ED. T/CM exceeded conventional medicine as it was believed to have lesser side effects (56.1%).</p> <p>The majority of participants who utilised T/CM viewed their ED to be moderate in severity.</p>	13
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Shabsigh, Perelman, Laumann and Lockhart (2004)	To establish the factors that predict treatment-seeking. This included both drivers and barriers.	<p><math>N = 32,644</math> men: responded to the screening questionnaire (to screen for current/former ED)</p> <p><math>N = 4622</math> of the above</p> <p><math>N = 4622</math> sent follow-up questionnaire. Response rate = 33%.</p> <p>Phase two of follow-up questionnaires: completion in doctors' offices.</p> <p>Final dataset: <math>N = 1938</math> men.</p> <p>46% sought treatment. 54% did not seek treatment.</p> <p>Age range: 20-75 years</p>	<p>Cross-National Survey on Male Health Issues.</p> <p>Screening questionnaire completed by 32 644 men:</p> <ul style="list-style-type: none"> <li>• Overall health</li> <li>• Urinary problems</li> <li>• Prostate problems</li> <li>• Erectile difficulties</li> </ul> <p>Men with ED were given a follow-up questionnaire.</p>	<p>Majority of men experiencing ED did not seek treatment. Men who sought treatment for ED expressed that they were self-motivated to do so or encouraged by a partner. Men aged 20-39 were less likely to pursue treatment. For men not pursuing treatment, those who were younger in age perceived that their condition would solve itself. Older men, however, chose not to pursue treatment as they perceived ED to be inevitable with increasing age.</p>	15
Lyngdorf and Hemmingsen (2004)	The aim of this study was to assess the prevalence of ED in the Danish population, as well as comorbid health conditions, marital status, use of drugs, education level, medication and unwillingness to seek treatment.	<p><math>N = 4310</math> Danish men provided with validated questionnaire.</p> <p>Age range = 40-80 years</p> <p><math>N = 2210</math> men responded: 51.3% response rate.</p> <p>Men with ED = 52%. Median age of men with ED: 65 years</p>	<p>Validated questionnaire:</p> <ul style="list-style-type: none"> <li>• Age</li> <li>• Marital status</li> <li>• Education level</li> <li>• International Index of Erectile Function</li> <li>• Length of time sexual difficulties have been experienced</li> <li>• Comorbid health conditions</li> <li>• Medication</li> <li>• Effects and risks of previous treatment</li> <li>• Inclination to find treatment for sexual difficulties</li> </ul>	<p>Greater ED prevalence with age was found. Men undergoing medical treatment were three times more likely than those not, to have ED. ED risk factors encompassed smoking tobacco, as well as poor level of education. Nine percent of those with ED had obtained treatment for their condition and 75% of these men were content with treatment utilised. Erectile function and age were associated with the inclination of men to talk about sexual issues. Elderly individuals most often held taboos.</p>	11



Zhang, Yu, He and Jin (2014)  China	The aim of this study was to investigate help-seeking in men with ED amongst the Chinese population.	<p><math>N = 2693</math></p> <p>Age range = 25-70 years old</p> <p>73% = &lt; 50</p> <p>IIEF-5 Score = <math>\leq 21</math>.</p> <p>International Index of Erectile Function (IIEF-5) (Rosen et al., 1999)</p> <p>Marital Status: Married = 89 men Not married = 8 men Divorced/Widower= 3 men</p>	<p>IIEF-5 Questionnaire was completed to determine ED diagnosis.</p> <p>Questionnaire survey:</p> <ul style="list-style-type: none"> <li>• Demographics</li> <li>• Marital Status</li> <li>• Household income</li> <li>• Level of education</li> <li>• Understanding of medical treatments</li> <li>• Help-seeking behaviour</li> </ul>	<p>Of 2148 men:</p> <p>4.3 <math>\pm</math> 2.1 months was the men duration from men observing their ED and first using treatment.</p> <p>2577 men reported where they sought advice/information about ED:</p> <p>54% sought advice from physician and 52% from the internet. These were the sources utilised most often for this purpose. Older men were more inclined to see the physician, with younger men more inclined to utilise the internet in order to seek help. The most commonly utilised treatments were Western and Chinese medicine, at 19% and 16% respectively. The biggest worry for men was regarding treatment side effects and this was particularly the case for older men.</p>	14
Giuliano et al. (2002). France	To investigate ED prevalence, impact on QoL and views about ED treatment.	<p>1004 men: 40 + years</p> <p>Mean age = 57.3 years</p> <p>31.6% with ED to mild or moderate degree.</p>	<p>Survey: Telephone interviews.</p>	<p>Most men with ED conveyed that they were not satisfied with their relationship with their spouse. Many reported that they were amenable to communicating with a doctor about their ED.</p>	14

## **Overview of study characteristics**

The age range of participants across the 13 included studies was 20-80 years old. One study reported the mean age but not the age range (Giuliano et al., 2002). The range of comorbid health conditions of participants in addition to ED included; psychological (e.g. depression), coronary heart disease, angina, hypertension, DM, high cholesterol, urinary problems, heart trouble (including angina), intermittent prostate problems, prostate cancer, cardiac disease, back pain, HIV, Peyronie's disease and arthritis/joint pain. Information about the comorbid health conditions of participants was not available in all studies (Low et al., 2006; Zhang et al., 2014; Tomlinson & Wright, 2004; Lyngdorf & Hemmingsen, 2004; Matic & McCabe, 2008; Gülpinar et al., 2012; Perelman et al., 2005; Pontin et al., 2002; Fisher et al., 2004; Giuliano et al., 2002).

The countries of origin of participants across all studies included; Denmark, US, UK, Germany, France, Italy, Spain, Mexico, Brazil, China, Korea, Japan, Malaysia, Taiwan, Turkey and Australia. Both men who were treatment seeking (or who had historically sought treatment) and those who were not were included for participation across the 13 studies.

The 13 studies included in the review varied in their use of methodology including both quantitative and qualitative methods.

## **Quality assessment**

The quality assessment scores for each study are presented in Appendix D for quantitative studies and Appendix E for qualitative studies.

For studies which were reviewed by both independent raters, the scores issued by the second independent rater are presented in parentheses. Quantitative studies could obtain a maximum quality assessment score of 19 and qualitative studies a total quality assessment score of 34.

For the purpose of this systematic review, studies which achieved total quality assessment scores above the total mean of quality assessment scores across all studies, were considered to be good quality. Total mean quality scores were calculated individually for qualitative and quantitative studies. The total mean quality assessment score for quantitative studies was 13.9. Seven of the ten quantitative studies achieved total quality assessment scores above the total mean, suggesting that 70% of the quantitative studies were deemed high quality. These studies obtained above 70% of the total achievable score.

The total mean quality assessment score for qualitative studies was 26.67. Only one of the qualitative studies achieved a total quality assessment score above the total mean, obtaining a score above 80% of the total achievable score. This suggests that only a third of qualitative papers were deemed high quality. However, consideration must be given to the fewer number of qualitative papers from which a mean was calculated, compared with the number of quantitative papers. Furthermore, both qualitative papers that achieved total quality assessment scores below the mean total score, obtained above 75% of the total achievable score.

This may therefore highlight the limitations to using the mean total quality assessment score as a cut-off for determining high quality studies, particularly where there are a smaller number of scores from which to generate the mean.

Cohen's Kappa (Cohen, 1960) was calculated to determine the inter-rater reliability of the quality assessment conducted for the seven studies (4 quantitative and 3 qualitative) that were reviewed by both independent raters. A Kappa value of 0.68 was obtained for the 4 quantitative studies, which has been reported by Landis and Koch (1977) as a 'substantial agreement' between raters. A Kappa value of 0.36 was obtained for the 3 qualitative studies, reported as a 'fair agreement' by Landis and Koch (1977).

### **Severity and permanence of ED**

Men have been found to have mixed views about the timeline of their ED, ranging from temporary to permanent (Pontin et al., 2002). Matic and McCabe (2008) found that men conveyed a greater severity of ED where they had had it for a minimum of 12 months before participation in the study. Additionally, there was a greater likelihood that men would perceive their ED as permanent, the longer they had experienced it for (Matic & McCabe, 2008). To concur, Fisher et al. (2004) found that more men with severe ED, as opposed to mild and moderate, viewed their condition as permanent and as having been experienced for longer. There was a smaller likelihood that men with severe ED indicated that they had erections but that they were not long-lasting. Men with moderate/severe ED were twice as likely as men with mild ED to express that they struggled to achieve an erection. More men with severe ED, compared with those with mild or moderate forms, indicated an inability to attain any erection (Fisher et al., 2004).

Stamogiannou et al. (2005) reported variations in perceived timeline of ED between men with different health comorbidities, such that men with prostate cancer demonstrated a greater likelihood of viewing ED as being long-lasting, as opposed to those with DM or cardiac illness (Stamogiannou et al., 2005). Giuliano et al. (2002) found 68% of men experiencing ED expressed unhappiness at the prospect that their condition was permanent.

Consideration should be given to the cross-sectional research designs employed by the above studies, which prevent causal assumptions being made about the factors under investigation. Additionally, although Stamogiannou et al. (2005) utilised a validated measure of sexual function, Fisher et al. (2004) and Matic and McCabe (2008) relied on self-report measures of ED. However, Fisher et al. (2004) recruited men with ED from across six countries, which may suggest that the findings of this study are more generalisable.

Men have been shown to vary in their perceptions of the severity of their ED (Zhang et al., 2014; Shabsigh et al., 2004; Fisher et al., 2004; Tomlinson & Wright, 2004). Zhang et al. (2014) found that 48% of men indicated that they had no intention to seek help for their ED due to the perceptions that it is not a severe condition. Shabsigh et al. (2004) reported a positive association between existent comorbid health conditions and men choosing not to treatment-seek due to the perception that ED is not sufficiently important. To concur with this, Fisher et al. (2004) found that it was not probable that men would obtain PDE-5 inhibitor treatment if they perceived that their erectile difficulties were not severe.

However, men in the study by Tomlinson and Wright (2004) viewed ED to be a permanent condition that resulted in men being unable to have sex ever again. Consideration should be given to the samples used across the above studies and thus the generalisability of the above findings.

Although Fisher et al. (2004) and Shabsigh et al. (2004) recruited men from across six countries, Tomlinson and Wright (2004) only recruited men in the UK, with no reference to the ethnicities of participants. Furthermore, Tomlinson and Wright (2004) only included men who had been prescribed sildenafil, questioning the generalisability of the findings to populations of men with ED, who have not sought treatment.

### **Communicating about ED**

A number of studies reported the perceptions that men had about discussing their ED (Zhang et al., 2014; Gülpinar et al., 2012; Perelman et al., 2005; Shabsigh et al., 2004; Tomlinson & Wright, 2004; Pontin et al., 2002; Fisher et al., 2004; Lyngdorf & Hemmingsen, 2004).

Some studies identified men that felt embarrassed about talking to their doctor/healthcare professional about their ED and this was found to hinder or result in delayed help-seeking (Zhang et al., 2014; Gülpinar et al., 2012; Perelman et al., 2005; Shabsigh et al., 2004; Fisher et al., 2004). Gülpinar et al. (2012) found embarrassment to be the most likely factor influential in delayed help-seeking, reported by 33% of the Turkish respondents. Shabsigh et al. (2004) found a positive link between embarrassment to discuss and severity of participants' ED. In this study, embarrassment to discuss ED was evident in participants from all countries including; USA, France, Germany, Italy, Spain and UK (Shabsigh et al., 2004).

The findings of Perelman et al. (2005) were similar to those of Gülpinar et al. (2012), with a third of all participants suggesting that they would be embarrassed to discuss their ED with someone else. Although this was found across all countries of the sample population, it was most evident in France (47%) and least so in the USA (23%), with regard to a face-to-face interaction with another person. In 30% of participants, embarrassment was the obstacle to treatment-seeking (Perelman et al., 2005). Zhang et al. (2014) found 35% of men did not intend to consult a physician about their ED. Of these men, 17% reported that their reason for not doing so was that they did not want to allow others to be aware of their ED, which they believed may occur if they were to come into contact with someone they knew in the hospital that they were attending (Zhang et al., 2014). Fisher et al. (2004) found that those participants who perceived it to be inconceivable to talk about their ED with someone else, were significantly less likely to obtain treatment (Fisher et al., 2004). Giuliano et al. (2002) found that 44% of men experiencing ED did not intend to communicate with a doctor about their condition. Yet 29% of those men who had previously done so, were not averse to doing so again but only 3% were amenable to doing so within the oncoming six months (Giuliano et al., 2002).

Additionally, men reported difficulties in feeling able to discuss ED with their partners or spouses (Tomlinson & Wright, 2004; Pontin et al., 2002). Tomlinson and Wright (2004) found that 15 of the 40 participants could not talk to their partners about their ED, due to avoidance and a sense of belittlement that ED evoked.

Pontin et al. (2002) generated a theme of ““Being alone with it”” (Pontin et al., 2002, p. 269) in relation to the difficulties that men faced with regard to discussing their ED with others. The majority of participants were unable to talk to their partners in any depth about their ED, due to either both or one of them feeling embarrassed or shy to do so. Additionally, this resulted from a reduction in communication between both parties. None of the participants had chosen to talk to friends of either gender about their ED, to prevent ridicule. Moreover, men felt obliged to maintain the status quo, in so much as not disclosing sexual deficiency but only those sexual encounters which were somewhat indicative of their accomplishments or strengths (Pontin et al., 2002). One must consider that Tomlinson and Wright (2004) and Pontin et al. (2002) only recruited men from the UK and so it is difficult to generalise these findings to men with ED in other cultures.

Despite the reported reluctance or inability of men to discuss their ED with either healthcare professionals or their partners, some men had also conveyed an explicit willingness to discuss their ED with others (Zhang et al., 2014; Perelman et al. 2005; Pontin et al., 2002). Perelman et al. (2005) found that there were participants across all countries who were inclined to discuss ED with their doctor, such that less than 43% of participants were uncomfortable to do so. Additionally, 9-35% of men perceived that their doctor would not feel comfortable discussing ED, with participants from Spain perceiving this to be most likely the case (35%) more than men from other countries. However, Zhang et al. (2014) found that of 57% of Chinese participants who had not consulted a physician in the last 3 months, as few as 13% intended to do so in the following 6 months. This arguably highlights a discrepancy in the willingness of men to discuss their ED, as shown from the perspective of men from different cultures. Pontin et al. (2002) found that the majority of participants were content with talking about ED with healthcare professionals, regardless of their gender.



These participants highlighted the importance of professionalism and confidentiality as part of such discussion (Pontin et al., 2002). Consideration should be given to the heterogeneous methodologies employed in the above studies, thus arguably making it difficult to draw consistent conclusions. Despite a willingness to discuss ED with others, some men have been found to have a preference for who they do this with (Fisher et al., 2004; Pontin et al., 2002).

Pontin et al. (2002) found that some of the older participants conveyed struggling to discuss ED with a male healthcare professional and thus reported that they would be unable to with a female, even if she were a professional. However, Gülpinar et al. (2012) found that only 3.1% of Turkish participants perceived the GP as being of the opposite sex as a reason for delayed help-seeking. Fisher et al. (2004) found that those men who preferred to talk to a GP/doctor about their ED had a greater likelihood of obtaining treatment. Gülpinar et al. (2012) and Pontin et al. (2002) collectively highlighted the cross-cultural differences in gender preferences for the healthcare professional that ED is discussed with. However, both studies employed different methodologies and as such, Pontin et al. (2002) had a smaller sample, which may question the appropriateness of between study comparisons.

Gülpinar et al. (2012) and Lyngdorf and Hemmingsen (2004) found that men preferred healthcare professionals to commence the discussion about ED. In Lyngdorf and Hemmingsen's study, men were found more likely to desire their GP to initiate a discussion about ED, if men had ED, as opposed to those men who did not. This was more so the case for men above the age of 65. Gülpinar et al. (2012) found that 76.9% of participants believed that the discussion of sexual difficulties/performance should be a part of routine healthcare practice.

Yet only 10% of participants had been previously asked about such difficulties by their GPs, during routine appointments (Gülpinar et al., 2012). For some participants in Pontin et al. (2002), who struggled to initiate a conversation about their ED, their problem became evident to the GP when the GP directly asked about ED, as part of a consultation about an additional health problem (Pontin et al. 2002).

Some studies have highlighted the perceptions of men regarding being informed about ED (Fisher et al., 2004; Zhang et al., 2014). To further highlight the usefulness of providing men with information about ED, Fisher et al. (2004) found that for those men who were uncertain about where to enquire about a solution for ED, it was improbable that they would obtain PDE-5 inhibitor treatment. Zhang et al. (2014) found differences between older and younger men in their preferences of the source used to obtain information about ED. For older men, this was the physician and for those who were younger, it was the internet (Zhang et al., 2014).

It was difficult to ascertain the representativeness of the samples employed in the above studies, with variation in the reported participant characteristics in each study. Zhang et al. (2014) and Fisher et al. (2004) did not report on the comorbid health conditions of participants, so it was difficult to generalise the above findings to men with ED from different comorbid health populations.

## **Causes of ED**

### **Age**

A number of studies reported the varying perceptions of men with ED, about the causes of their condition (Gülpinar et al. 2012; Perelman et al., 2005; Fisher et al., 2004; Low et al., 2006; Pontin et al., 2002; Shabsigh et al., 2004; Stamogiannou et al., 2005).

Low et al. (2006) found that participants perceived age to be one of many causes of ED. Some studies found that men perceived their ED to be a natural part of the ageing process and it was this belief that resulted in a reduced likelihood or a delay in help-seeking (Gülpinar et al., 2012; Fisher et al., 2004). This was the most common perception which hindered help-seeking in participants from across six countries in Shabsigh et al. (2004), particularly for older men aged between 60 and 75 (Shabsigh et al. 2004). Gülpinar et al. (2012) found that 26.7% of participants perceived ED to result from natural ageing. However, Fisher et al. (2004) found that men who attributed their ED to ageing had a greater likelihood of obtaining treatment. In contrast to the views that increasing age naturally resulted in the onset of ED, Perelman et al. (2005) and Low et al. (2006) found that men did not generally perceive themselves to be too old to be having sex. Only 9% of participants in Perelman et al. (2005) believed themselves to be too old to have sex (from 5% in Spain to 15% in France). On average, participants in Low et al. (2006) perceived sex to be important despite increasing age, thus ED was not necessarily accepted as an inevitable part of the ageing process.

Participants in Pontin et al. (2002) were uncertain about the impact of age on ED, conveying ambivalence about what is considered normal for their age.

Generally, there appear to be differences and discrepancies in the perceptions of men with ED about whether age contributed to the onset of their condition. However, this may result from the variety of cultural influences on participants' perceptions.

### **Additional psychological and physical causes**

Stamogiannou et al. (2005), Perelman et al. (2005), Fisher et al. (2004), Low et al. (2006) and Pontin et al. (2002) presented a range of perceptions about the psychological and physical causes of men's ED.

Perelman et al. (2005) found that men from different countries had varying perceptions of the causes of ED. Those in Spain, France and Italy showed a greater likelihood of agreeing that the origin of ED was psychological more than it was physical in nature, in comparison to men in the US and the UK (Perelman et al., 2005). Low et al. (2006) found that the majority of participants perceived ED to be caused by both physical and psychological factors inclusive of; DM, smoking, medication side effects, hypertension, limited circulation, injuries, stresses in life and relationship difficulties. Sexually transmitted infections, aging and food were additionally viewed as causes. As well as these causal factors, participants, as being part of a multicultural society such as Malaysia, possessed culturally influenced perceptions about their ED. These included; black magic and excessive use of the penis (Low et al., 2006). Stamogiannou et al. (2005) found psychological causes to be strongly supported by participants including anxiety and stress. Second to these was the influence of prescription drugs, with additional physical causes considered least; hormonal treatments, alcohol and smoking (Stamogiannou et al., 2005).

Pontin et al. (2002) found that participants were uncertain about the causes of their ED, but suggested possibly perceived causes including both those of a physical and psychological nature; “malfunctions” (Pontin et al., 2002, p. 266) and guilt and pressure from work/business respectively. Due to this uncertainty, participants sought clarification of their perceptions of the causes of their ED (Pontin et al., 2002).

This included clarification that pre-existing health conditions may be the cause, as opposed to feelings for their partners or sexuality. Men appeared to be in search of confirmation that ED results from something within themselves as opposed to their relationship. Only one man placed blame with his wife for his difficulties (Pontin et al., 2002).

Fisher et al. (2004) found a reduced likelihood that men would receive PDE5-inhibitor treatment if they held perceptions that; their ED was caused by stress, caused by an unhealthy lifestyle or were uncertain about the cause of ED.

## **Consequences of ED**

### **Psychological impact**

Perelman et al. (2005) showed that just fewer than 55% of participants were in agreement with; ““The erection problem is a source of great sadness for me”” (Perelman et al., 2005, p. 401). Participants in the UK endorsed this statement more than those in Germany, who conveyed a neutral perception about ED resulting in sadness. Additionally, the amount of men who ruminated about ED day-to-day varied across countries, however those from Germany were the least likely to do so (Perelman et al., 2005). Giuliano et al. (2002) found 69% of men with ED ruminated about their condition in moments of engaging in sexual activities and 28% did so throughout the daytime.

Other studies found that ED resulted in a loss of perceived manhood or masculine identity, with the inability to perform sexually (Low et al., 2006; Tomlinson & Wright, 2004; Pontin et al., 2002). Additionally, Pontin et al. (2002) found that the emotional responses elicited by men, as a result of the difficulties associated with ED, were variable.

These included; denial, embarrassment, depression and acceptance (Pontin et al., 2002). Giuliano et al. (2002) found that men with ED were more resigned to their ED, with greater concerns about ED in men who did not experience it. Stamogiannou et al. (2005) found that those men who reported a greater QoL held greater positive beliefs regarding the impacts of ED, as well as fewer negative beliefs regarding the impact of ED on masculinity.

Greater sexual functioning and positive beliefs about the impact of ED on masculinity most strongly predicted QoL (Stamogiannou et al., 2005). Fisher et al. (2004) found that those men who perceived ED to be devastating and to have impacted negatively on their confidence were more likely to obtain PDE-5 inhibitor treatment.

### **Interpersonal impact**

A number of studies have reported on men's perceptions of the impact of ED on their relationships with others (Tomlinson & Wright, 2004; Low et al., 2006; Perelman et al., 2005; Fisher et al., 2004; Pontin et al., 2002). In particular, men have reported a negative impact of ED on their relationships with their partners (Giuliano et al., 2002), generally resulting in depression (Tomlinson & Wright, 2004). Some men have felt insecure about maintaining such relationships in light of ED (Low et al., 2006) and have experienced less confidence as a result. This reduced confidence has further impacted on additional relationships and other aspects of life; work, social lives, family (Low et al., 2006) and relationships with friends and work colleagues (Tomlinson & Wright, 2004). Low et al. (2006) only recruited men with ED aged 40-75, thus restricting the generalisability of the findings. Although Tomlinson and Wright (2004) encompassed men in their sample from a larger age range, findings represented the views of those men prescribed sildenafil treatment for ED.

Perelman et al. (2005) highlighted that 52.8% of men perceived their partners to have been affected by their ED, such that the condition was a ““source of great sadness”” (Perelman et al., 2005, p. 402) for them. There was a discrepancy between participants in different countries as to whether their partners were perceived to be the reason for the onset of ED. The majority of men did not agree that their ED would disappear if they were to have a different sexual partner (Perelman et al., 2005). However, men in both Italy and Spain had a greater likelihood of attributing blame to their partner for their ED, with 32% and 30% respectively agreeing that their ED would cease to be an issue with another partner. Additionally, 41.7% of men across all countries had an awareness of other ways to seek sexual gratification without an erection, with half perceiving to have the ability to work around ED (Perelman et al., 2005).

However, Pontin et al. (2002) reported men younger than 60 to perceive their partners as accepting of the ED and supportive, withholding blame. However, men conveyed that their partners may be holding their feelings back, to spare those of the men. With this, men may have thoughts or concerns about the possibilities that their partners may venture to find sexual fulfilment somewhere else. The majority of men in this study conveyed concerns that they would be unable to fulfil their partner’s sexual needs and so looked to solve the ED (Pontin et al., 2002). Fisher et al. (2004) found that men who were worried about losing their partner as a result of ED were more likely to obtain PDE-5 inhibitor treatment. However, those who believed that their partners were not interested in sex were significantly less likely to obtain treatment (Fisher et al., 2004).

Some studies reported men’s perceptions of their partner’s perceptions about ED (Low et al., 2006; Fisher et al., 2004; Pontin et al., 2002).

Low et al. (2006) showed that some men were unwilling to talk about PDE-5 inhibitor utilisation with partners, for fear that they would oppose use of this treatment and that partners may anticipate that the man is having relations outside of the marriage. In addition, Fisher et al. (2004) found a link between men perceiving their partner to be eager to discover a means of solving the ED difficulty and men obtaining PDE-5 inhibitors.

The majority of men in Pontin et al. (2002) perceived that women were more inclined towards sexual penetration, despite participation in other sexual activities that resulted in orgasm for both man and partner. Both Low et al. (2006) and Pontin et al. (2002) employed qualitative methodologies. However, whilst Low et al. (2006) specifies that multiple researchers each reviewed transcripts to establish consistent analysis, Pontin et al. (2002) did not, thus questioning the reliability of the themes generated in this study.

### **Treatment for ED**

Variations in men's coherence of available ED treatments was conveyed; Low et al. (2006) found men to be aware of both traditional and PDE-5 inhibitor treatments for ED, whilst not as mindful of other forms of treatment such as injections and vacuum mechanisms. Additionally, Pontin et al. (2002) reported that men assumed physical over psychological treatments for ED, where psychological treatments may act to complement those of a physical nature. They viewed treatment as aimed at the man himself, not the relationship. Men appeared to lack coherence of treatment options, including the utility and rationale for them (Pontin et al., 2002).



A number of studies highlighted men's perceptions about the extent to which there exists any control over their ED and thus a solution to this condition (Matic & McCabe, 2008; Shabsigh et al., 2004; Gülpinar et al., 2012). Some participants expressed a belief that their ED would resolve without external influence and this perception was found in some to result in a lesser likelihood of seeking treatment or trying medication (Matic & McCabe, 2008; Shabsigh et al., 2004). This was particularly the case in men who had ED for a shorter time (Matic & McCabe, 2008) and in younger men (Shabsigh et al., 2004). Gülpinar et al. (2012) found men to perceive their ED as a self-limited problem, thus choosing not to seek help. However, in this same study, one of the least favourable reasons for not help-seeking was the belief that the doctor would be unable to provide help (Gülpinar et al., 2012). Yet Shabsigh et al. (2004) showed that some men, particularly those with more severe ED, posited that there was no solution to their ED, thus creating a barrier to treatment-seeking (Shabsigh et al., 2004). However, one must consider that causal associations cannot be assumed in the above studies, due to the nature of the research designs employed (Matic & McCabe, 2008; Shabsigh et al., 2004; Gülpinar et al., 2012).

To concur with the above studies, others reported on the acceptance of ED by some men (e.g. Low et al., 2006), whilst others were less likely to, in desire or hope of treatment (e.g. Perelman et al., 2005). Low et al. (2006) found some men to have established an external locus of control, suggesting that it is the will of God and thus must be accepted. However, Perelman et al. (2005) found a similar percentage of men who believed that they should accept their ED and those emphasising the importance of obtaining a cure for their condition. Those men in the US and UK were not as likely to accept their condition (Perelman et al., 2005). In support of these conflicting views, some men have been found to express ambivalence; hopeful of a solution to their ED, but accepting of the chance that there may not be one (Pontin et al., 2002).

Two studies reported men's perceptions about possessing the ability to have sex if they desired versus wanting the frequency of sex to increase (Fisher et al., 2004; Perelman et al., 2005). Fisher et al. (2004) found that men were more likely to obtain PDE-5 inhibitor treatment if they expressed that they would like to have the ability to have sex as opposed to an increase in the frequency of having sex. To concur, Perelman et al. (2005) found that 71.8% of men participating did not particularly desire an increase in the frequency that they had sex, but rather they wished to have the ability to have sex if they desired to. This perception was endorsed by men in Spain most frequently (Perelman et al., 2005). Both studies recruited men across six countries, thus these findings can arguably be generalised beyond one cultural population. However, the association between the above perceptions and treatment seeking in Fisher et al. (2004) cannot be used to infer causal relationships due to the research design employed (Fisher et al., 2004).

Two studies highlighted the impact of men's expectations of treatment on their perception of treatment effectiveness and thus their satisfaction with it (Tomlinson et al., 2004; Low et al., 2006). One participant in Low et al. (2006) expressed that he wanted treatment (PDE-5 inhibitors) to result in an erection that would last for the duration that he wanted it to. Tomlinson et al. (2004) found that the majority of participants had been informed about sildenafil via the media and as such had great expectations of it. These included the onset of instant erections for imminent intercourse, complete erections as well as a success rate of one hundred percent. The majority of men who found sildenafil to be effective experienced increased confidence and well-being, as well as a regained sense of manhood. This confidence was concerned with the ability to sexually perform and satisfy their partners. However, those men who did not find treatment to be successful experienced a loss of hope and devastation, particularly as they expected one pill to effectively treat ED (Tomlinson et al., 2004).

These men had extremely high expectations for sildenafil and perceived its subsequent ineffectiveness to be due to the reduced spontaneity of sex and the dependence of the sex life on treatment (Tomlinson et al., 2004).

Despite expectation, men were found to have varying views on the effectiveness and thus their satisfaction of ED treatments (e.g. Wong et al., 2008). Some participants in the study by Low et al. (2006) experienced increased confidence and improvements in their partner relationships with PDE-5 inhibitors.

Matic and McCabe (2008) found participants to be mostly neutral about PDE-5 inhibitor satisfaction. Whilst Lyndorf and Hemmingsen (2004) found 75% of those participants utilising sildenafil to perceive the outcome as satisfactory or excellent, 15% expressed reduced effectiveness with time. Wong et al. (2008) highlighted men's satisfaction with traditional/complementary treatments. The prominent view was that men were somewhat satisfied with these treatments, although differences in satisfaction were evident across countries (Wong et al., 2008). Consideration should be given to the focus by Wong et al. (2008) on Asian men's perceptions of culturally specific traditional/complementary treatment, even as compared to Western treatment for ED. Therefore, these findings are arguably specific to Asian men with ED and therefore not generalisable to men with ED in other cultures.

A number of papers have reported that men are concerned with the side effects of ED treatment (e.g. Zhang et al., 2014). Zhang et al. (2014) found that about half of participants across the age range (25-70 years) who had indicated a reason for not taking ED medication were most worried about its side effects. Of these men, most were concerned about the side effects of Western medicine in the treatment of ED. (Zhang et al., 2014).

This was particularly the case for older participants, who reported worries about Western medicine greatly expending energy, as well as being detrimental to health as it is not deemed natural (Zhang et al., 2014).

Low et al. (2006) found that despite many of the men expressing PDE-5 inhibitors to be the better of the ED treatments, they did have concerns about side effects. They viewed this treatment to be strong, causing unnatural erections and possessing the potential to result in harm or death (Low et al., 2006).

Fisher et al. (2004) found that those men who perceived medication for ED as dangerous were not likely to use PDE-5 inhibitors. Pontin et al. (2002) highlighted the mixed views of men about side effects of ED treatments. Some perceived them as acceptable, demonstrating a willingness to use treatments at their convenience, whilst others expressed concerns about the pain of injections and the sense that treatments such as penile injections and vacuum devices are not right (Pontin et al., 2002).

As well as the perceived side effects, men were found to have concerns about the costs of ED treatment. Lyngdorf and Hemmingsen (2004) found that 60% of men utilising sildenafil were troubled by the cost. Men have expressed that the cost of ED medication has impacted on their choice of whether to use it (Low et al., 2006; Matic & McCabe, 2008). Matic and McCabe (2008) found this to be most likely the case for those men who had been experiencing ED for twelve months plus. However, Shabsigh et al. (2004) reported that cost was less commonly endorsed as a reason for men not presenting for treatment. Additionally, Gülpinar et al. (2012) found only 16.8% of men to express cost as a factor that impacted on help-seeking. Wong et al. (2008) reported that approximately one third of men (33.4%) perceived conventional medicine to be more expensive than traditional/complementary medicines for erection difficulties.

Disparity amongst men's expressed willingness to use ED medication has been reported; Gülpinar et al. (2012) found that 20.4% of men would contemplate ED medication usage and Matic and McCabe (2008) found that in general, men reported being likely to re-use PDE-5 inhibitors.

It was also found to be as likely that men not having used ED medication before would use it in the future (Matic & McCabe, 2008). However, Shabsigh et al. (2004) found a positive link between men living in all countries (France, Germany, Italy, Spain and the UK), with the exception of the USA, and not wishing to use ED drugs. Additionally, Perelman et al. (2005) reported that 26.3% of men not engaged in treatment-seeking posited that one of the factors influencing this decision was that they did not wish to use ED drugs.

Both Low et al. (2006) and Wong et al. (2008) considered men's perceptions of traditional treatments. Low et al. (2006) found that men viewed one such treatment named tongkat ali (a type of Malay herb) as safe but ineffective. To concur with this, more than half of the men with ED in the Wong et al. (2008) study perceived traditional/complementary medicine to possess fewer side effects than that which was deemed conventional. Additionally, traditional/complementary medicine was perceived by 39.5% of men to enhance circulation, by 39.4% to increase well-being and by 39% to cure erection difficulties (Wong et al., 2008). However, Low et al. (2006) also found men to perceive additional traditional treatments as less safe. Wong et al. (2008) found differences between cultural groups in their appraisals of traditional/complementary medicine, with men from Japan and Korea possessing a more negative view than those from Taiwan, Malaysia and China (Wong et al., 2008).

However, one must consider that these treatments are culturally-specific and therefore men from other cultures would not necessarily have knowledge about or use of such treatments, thus rendering the findings inapplicable to other cultural populations of men with ED.

## **Discussion**

This systematic literature review aimed to explore the illness perceptions of men with ED. Thirteen studies were eligible for inclusion and the quality of these studies were assessed. The illness perceptions of men with ED were identified via narrative synthesis and organised into five categories; severity and permanence of ED, communicating about ED, causes of ED, consequences of ED and treatment for ED.

### **Severity and permanence of ED**

Men were found to vary in their perceptions of the severity and permanence of their ED and this was evident both within and between men from different cultures. There was a reported association between perceived severity and duration of ED, with some men more likely to view ED as permanent if they had experienced it for longer. Perceived timeline of ED was found to vary between men with different comorbid health conditions. Additionally, there was evidence that men who viewed their ED not to be severe or important were less likely to seek or obtain treatment. Research has investigated the impact of illness perceptions on health outcomes across a number of different health populations (Hagger & Orbell, 2003). Hudson et al. (2014) investigated the association between illness perceptions, emotional health and DM self-care outcomes. They found that worse emotional health was linked to greater perceptions of the seriousness of DM, as well as the view that the timeline of DM is repetitive (Hudson et al., 2014). Additionally, Rance et al. (2003) found that men with DM and ED emphasise ED as a complication of DM that should be considered as important to treat as other DM complications. Thus, it is pertinent that men's perceptions of the severity, permanence and importance of their ED are considered, as they may impact on health outcomes or may shed light on perceived importance of treatment seeking.

## **Communicating about ED**

The willingness of men to discuss their ED varied and these perceptual differences were evident across cultures. Some men expressed embarrassment, rendering talking about ED to either a healthcare professional or their partner difficult. As such, embarrassment was proposed to be a factor inhibiting treatment-seeking for ED. There were men who were willing to consult with others about ED, although some perceived that the doctors may be uncomfortable discussing the condition. Additionally, whilst some men expressed no gender preference, instead emphasising the importance of professionalism and confidentiality, others conveyed that it would be difficult to discuss ED with a woman. Men expressed a preference for healthcare professionals to initiate discussions about ED and they emphasised that this does not routinely occur. The significance of men receiving adequate information about ED was highlighted, with men found to be less likely to obtain treatment when lacking knowledge about where they could go for help. Difference in preference for the information source about ED was evident in older and younger men.

To concur with the findings of this systematic review, a study by Fisher et al. (2005) found that men with ED, as well as their partners, firmly endorsed communicating about ED, as well as seeking help for this condition. However, embarrassment was found to be one reason why men with ED and their partners refrained from communicating about ED. Additionally, physicians involved in the treatment of ED, although comfortable in discussion of this condition, did not often initiate a conversation about it (Fisher et al., 2005).



Men across different health populations have been found to wish to discuss sexual difficulties (Rubin, 2005; Bahouq, Allali, Rkain, & Hajjaj-Hassouni, 2013) and yet healthcare professionals have been found to rarely initiate conversations about them (Dyer & das Nair, 2013). Although healthcare professionals have endorsed the importance of discussing sexual difficulties, they have expressed limited knowledge, training and confidence to enable them to do so (Byrne, Doherty, McGee, & Murphy, 2010). Thus, where men with ED may be embarrassed to discuss their condition, it is important that healthcare professionals are offered appropriate knowledge and training such that they feel confident and competent to initiate such conversations. In turn, men with ED can gain more knowledge of their condition, including available treatment options.

### **Causes of ED**

Men were found to have varying perceptions about the cause/s of ED. These factors encompassed both psychological and physical factors. Some men were found to perceive ED as an inevitable condition that occurs due to increasing age. Whilst for some of these men this resulted in delayed or a reduced likelihood of treatment-seeking, for others they were more likely to seek treatment. However, other men perceived that they were not too old to be engaging in sex. Some men reported a perception that they would not have experienced ED with a different partner. Men were found less likely to obtain treatment if they perceived ED to have been caused by any of the following: stress, unhealthy lifestyle or an uncertainty about the cause. Consistencies and variations in the perceptions about the cause/s of ED, both within and across cultures, were evident. At times, culturally-specific beliefs about cause/s of ED were expressed.

The above findings highlight the variations in perceptions of men about the cause/s of ED and that these perceptions can be associated with health behaviours e.g. treatment-seeking. Leventhal's Self-Regulatory Model (Leventhal, Nerenz, & Steele, 1984) posits that an individual's perceptions about their illness, including those about cause/s of said illness, can impact on subsequent health behaviours. Additionally, Engel (1977) proposed the Biopsychosocial model, which endorses the combined impact that biological, psychological and social factors have on aspects of disease, including cause. Therefore, with men's multi-factorial perceptions of the cause/s of ED evident, it is important to consider how these may then go on to impact their health behaviours e.g. whether they choose to seek treatment. This is particularly pertinent where men may lack coherence of ED and therefore may need more information about the condition in order to make informed choices about seeking support or treatment.

### **Consequences of ED**

Men perceived ED to have a negative impact on various aspects of their QoL. Men expressed a negative psychological impact, including devastation, sadness, reduced confidence and for some a loss of perceived manhood or masculinity. An association was found between better QoL and less negative perceptions about the impact of ED on masculinity. Research has shown that men experiencing ED as well as those using medication for this condition, are more likely to endorse an association between masculinity and sexual performance (Thompson & Barnes, 2013). However, Sand, Fisher, Rosen, Heiman and Eardley (2008) found that men with ED and those without did not significantly differ in their perceptions of the factors that contribute to masculinity. Factors associated with sexuality were less so endorsed as qualities of masculinity than those regarding social respect (Sand et al., 2008).

The findings of the current review highlighted that men perceived ED to have negative consequences for their interpersonal relationships and their partners. Whilst some men expressed that their partners were accepting and supportive, there were some concerns that partners may seek sexual fulfilment from another. Men expressed views about the perceptions that they believed their partners to have regarding their ED. Some men expressed that women want penetration and men expressed a wish to fulfil the sexual needs of their partners. Those that perceived their partners not to be interested in having sex were less likely to seek treatment, whereas those who were concerned they may lose their partner, were more inclined to obtain treatment. Sand et al. (2008) showed that men experiencing ED reported poorer well-being on all aspects of QoL than those men without the condition.

Men perceived ED to have negative psychological and interpersonal consequences and these were evident across cultures. It is possible that where men have expressed a loss of masculinity or manhood due to ED, that there is a conflict between the self that they perceive and the self that they would ideally be, which could impede the process of 'self-actualisation', which is to reach one's full potential (Rogers, 1959). This may explain the psychological and interpersonal impacts of ED, such that men perceive not to be fulfilling their potential, within the context of their relationship.

### **Treatment for ED**

This review highlighted men's lack of coherence of treatment options for ED and this was evident cross-culturally. Men were found to perceive having limited control over their ED.

They were found less likely to seek or obtain treatment for their condition with the perception that it would resolve on its own and/or that there was no solution to it. There were cross-cultural variations in the willingness to accept ED and whilst some men chose to accept it, there was expressed hope for treatments. However, other men reported not necessarily wanting to have more sex, but desiring the control to do so if they wished to.

Men were shown to have expectations of certain ED treatments e.g. sildenafil, which when not met could result in a loss of hope. Men were found to have varying perceptions about the effectiveness of or their satisfaction with different ED treatments and these were evident across cultures. There were also evident concerns from men about side effects of various ED treatments, including factors such as cost and the use of drugs (medication).

Men's knowledge about or expectations of ED treatments need to be considered, as they may act to influence whether men choose to communicate about ED and thus seek help. For those men who do seek help, healthcare professionals need to explore their expectations of treatment outcomes and effectiveness, to prevent disappointment or loss of hope if these are not met. Again, this highlights the importance of men receiving appropriate knowledge about ED and its treatment options, which may be facilitated by improved communication. This will arguably allow men to make informed choices about their care. It is particularly important that this is done so within the context of the individual's culture and how cultural beliefs may impact on perceptions about the effectiveness and safety of ED treatments. This further emphasises the need for culturally competent service provision (Campinha-Bacote, 2002).

## **Clinical Implications**

This systematic review highlighted similarities in the illness perceptions of men with ED, both within and across cultures, across the age range and in men with different comorbid health conditions. However, it has also demonstrated differences in illness perceptions between men with ED. This emphasises the variations in men's coherence of this condition, which may be influenced by the above factors. As such, the importance of communication about ED was expressed, with a particular emphasis on the initiation of discussions about ED by healthcare professionals.

In consideration of the above, healthcare professionals need to initiate conversations about ED with men, particularly where men may be embarrassed to come forward themselves. This will not only allow men to gain greater coherence of their condition, but will grant the healthcare professional the opportunity to better understand the illness perceptions of these men. The pertinence of this is that illness perceptions regulate coping and health behaviours (Leventhal, Nerenz, & Steele, 1984). Thus, with better communication between men with ED and healthcare professionals, men can be better informed about their condition, such that they have sufficient knowledge about how they may be treated and supported.

However, this systematic review highlighted that healthcare professionals seldom initiated dialogues about ED. Research has shown that some healthcare professionals do not feel confident, knowledgeable or adequately trained with regard to sexual difficulties (Byrne, Doherty, McGee, & Murphy, 2010). Thus, it is important that healthcare professionals are sufficiently trained to approach the subject of sexual difficulties such as ED.

The DIRECT communication model (Cawthorn, 2009, cited in Lee, Jacklin, & Boyer, 2012) can be utilised to determine the sexual needs of individuals. DIRECT is an acronym for the steps taken and skills involved which allow the healthcare professional to discuss sexual concerns. These include; developing an alliance, initiating a dialogue, reflecting an inclination to be consulted about sexual concerns, eliciting as well as analysing these concerns, communicating and treatment and/or therapy (Cawthorn, 2009, cited in Lee, Jacklin, & Boyer, 2012). In light of the variations in illness coherence that men with ED may have about their condition, it is important that healthcare providers tailor their services to cater to individual needs. Thus, healthcare providers need to ensure culturally competent (Campinha-Bacote, 2002) service provision.

### **Limitations**

The findings and conclusions drawn from this systematic review need to be considered in light of its limitations. The studies eligible for review were heterogeneous in their aims, methods as well as in their measure of ED. As such, the validity of the review is questionable, as although all of the studies reported aspects of men's perceptions about ED, there was no consistent definition of this construct. This appeared evident as not all of the studies aimed to investigate men's perceptions, but rather these were a by-product of the research. It is therefore difficult to draw consistent and reliable conclusions. However, although a limitation of the review, it highlights the paucity of literature specifically exploring the illness perceptions of men with ED, utilising valid measures and comparable methods.

Due to the heterogeneous nature of the literature which reports on the illness perceptions of men with ED, this systematic review intended to be exploratory.

As such, strict inclusion and exclusion criteria were employed in order that the scope of the review was not too broad, whilst ensuring that the findings were generalisable to different populations of men with ED. Thus, only studies which reported a minimum of two aspects of men's perceptions about ED in their abstract were included. This ensured that men's perceptions were considered a main finding and that the scope of perceptions reported was widened. Additionally, the review aimed to enhance generalisability of the findings by excluding studies that investigated men with ED of a specific health population e.g. DM. However, by employing these criteria, the scope of the review was narrowed and arguably restricted generalisability to specific health populations.

It was difficult to make comparisons between the quality of the quantitative and qualitative studies reviewed, as two separate quality assessment measures were used for each. Although the majority of quantitative studies were deemed high quality, only one of the qualitative studies was, despite the additional qualitative studies achieving above 75% of the total achievable score. This highlights the limitations of using the mean quality assessment score for determining the cut-off for high quality. Additionally, high quality is only determined by comparison to the quality of the other studies which utilise the same methodology. As such, the method for determining quality is not objective. Considerable inter-rater reliability was found for the quality assessment of quantitative studies, with a Cohen's Kappa of 0.68. However, there was only a 'fair agreement' found for the quality assessment of qualitative studies, with a Cohen's Kappa of 0.36. This may reflect the limitations of the quality assessment tool employed for qualitative studies, whose items were arguably open to subjective interpretation. The quality assessment tool employed for quantitative studies was also limited, in that not all items were applicable to all studies being assessed. These studies were scored positively in this instance, which may have resulted in higher quality assessment scores.

However, the inter-rater reliability was substantial for the quality assessment of quantitative studies, which may suggest that the tool employed was less susceptible to bias via subjective interpretation. Finally, the second independent rater only assessed the quality of four of the quantitative studies and so it is difficult to ascertain if the inter-rater reliability may have differed with the inclusion of inter-rater quality assessment scores for all studies.

### **Future Research**

This systematic literature review highlighted a number of avenues for future research. There is a clear need for research that specifically aims to investigate the illness perceptions of men with ED. Future studies should employ valid and reliable illness perception measures and should define ‘illness perceptions’ utilising an underpinning theory. One study in this review did so, utilising Leventhal’s Self-Regulatory Model (1984) (Stamogiannou et al., 2005). If research studies can look to define ‘illness perceptions’ in this way, the findings would arguably be more comparable across studies, resulting in more reliable and valid conclusions. This could be applied to both quantitative and qualitative research.

The current review aimed to be exploratory, thus incorporating a wide scope of heterogeneous literature. The rationale for this was to increase the generalisability of the findings to men with ED from different cultures, of varying ages and from different health populations. However, the review identified some variations in perceptions of men with ED across cultures, the age range and health populations. Therefore, future reviews may wish to consider the illness perceptions of men with ED from specific health populations, ages and cultures. Future research may need to be conducted in these areas initially, in order that there was the scope to conduct such a review.



## **Conclusion**

This systematic review explored the illness perceptions of men with ED. Men were found to have varied perceptions about different aspects of ED including its severity, timeline, communication, cause/s, consequences and treatments. Healthcare professionals need to initiate communication about this condition and an exploration of men's individual illness perceptions in a culturally competent way. This will facilitate an understanding of the impact of these perceptions on men's willingness to discuss ED and thus seek help for this condition. Future research needs to further explore the illness perceptions of men with ED utilising valid and reliable measures of illness perceptions and to do so within specific health populations.

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Please note: References marked with an (\*) are those that were included in the systematic review.

Part Two:  
Empirical Paper

The experiences of South Asian men with diabetes mellitus and erectile  
dysfunction

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Please see Appendix A for the Guideline for Authors

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## Abstract

**Objectives:** To explore the experiences of South Asian men with diabetes mellitus (DM) and erectile dysfunction (ED), with reference to illness perceptions and the impact on quality of life (QoL).

**Method:** Qualitative Interpretative Phenomenological Analysis (IPA) methodology was employed. Semi-structured interviews based on Leventhal's Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984) were conducted with six South Asian men with DM and ED.

**Results:** Four superordinate and ten subordinate themes emerged. Participants conveyed ED as enduring and restrictive, limiting perceived control. Participants expressed ED to have a relational impact, but with partner support buffering this effect. Participants conveyed acceptance of ED, prioritising other duties e.g. DM management, but were hopeful of treatment. Participants expressed uncertainty about ED. Discussing ED with a healthcare professional (HCP) was emphasised, to gain information about treatment.

**Conclusion:** HCPs need to routinely assess for ED in men with DM and to provide appropriate information about treatment options.

*Short Title: DM and ED in South Asian men*

*Keywords: South Asian; men; diabetes mellitus; erectile dysfunction; experiences; illness perceptions*

## **Introduction**

The World Health Organisation has proposed that there are currently approximately 3 million individuals residing in the UK with a diagnosis of diabetes mellitus (DM) (Diabetes.co.uk., 2014<sub>a</sub>). The prevalence of DM has continued to increase over the past few years, with a rise from 1.4 million individuals with this health condition in 1996. It is predicted that by the year 2025, there will be a further increase in the number of individuals in the UK with DM, with a rise of up to 5 million people (Diabetes UK, 2012<sub>a</sub>). Four percent of the UK population consists of South Asian individuals (Khunti, Kumar, & Brodie, 2009). South Asian people have a 6 times greater likelihood of developing DM (NHS Choices, 2014). Therefore, where 4% of the UK population consists of South Asian individuals who are more likely to develop DM, South Asian communities will be significantly impacted on by the increase in prevalence of DM. Thus, these individuals will be more likely to develop the associated complications of DM (Khunti, Kumar, & Brodie, 2009).

## **DM**

DM is a long-term, commonly occurring health condition. Approximately 630,000 individuals in the UK have DM but are unaware of their diagnosis (Diabetes UK, 2012<sub>b</sub>). DM results from the inability of the body's cells to utilise glucose and this may occur for a number of reasons (Diabetes UK, 2012<sub>b</sub>). In Type 1 DM (T1DM), the pancreas is unable to produce the hormone insulin (Diabetes UK, 2012<sub>c</sub>). In T2DM, insufficient insulin is produced or the insulin that is produced does not work effectively (Diabetes UK, 2012<sub>d</sub>). As a result, glucose absorption is impaired and blood glucose levels are high. The body is unable to use this glucose as fuel to generate the energy that individuals need in their everyday lives (Diabetes UK, 2012<sub>b</sub>).

T1DM most commonly presents itself in childhood and in people under 40 years old.

A tenth of adults with DM have the form T1DM. Regular exercise, a healthy diet and the use of insulin injections are treatments for T1DM (Diabetes UK, 2012<sub>c</sub>).

T2DM is most commonly found in individuals over the age of 40. However, for South Asian individuals, who have an increased likelihood of developing DM, onset can be as early as 25 years old. The prevalence of T2DM is increasing amongst children and young people. Eighty-five to ninety-five percent of people who have DM have T2DM. Similar treatments are used for T2DM as for T1DM, as well as the use of medication if required (Diabetes UK, 2012<sub>d</sub>).

If DM is left untreated, or blood glucose levels are poorly controlled or regulated, individuals may experience any number of short or long-term complications. These can include; hypoglycaemia<sup>16</sup>, diabetic ketoacidosis<sup>17</sup>, hyperosmolar hyperglycaemic state<sup>18</sup>, retinopathy<sup>19</sup>, cardiovascular disease<sup>20</sup>, nephropathy<sup>21</sup> and neuropathy<sup>22</sup> (Diabetes UK, 2012<sub>e</sub>). Additionally, men with DM may experience erectile dysfunction (ED) (Diabetes.co.uk, 2014<sub>b</sub>).

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<sup>16</sup> Blood glucose levels are low (National Institute of Diabetes and Digestive and Kidney Diseases, 2012)

<sup>17</sup> Very limited insulin in the body to gain energy from glucose, thus energy is gained via broken down body tissues. As a consequence, ketones develop. These are poisonous chemicals which can result in the body being acidic (Diabetes UK, 2012<sub>f</sub>).

<sup>18</sup> This can develop in those with T2DM with very high blood glucose, due to the amalgamation of illness and dehydration (Diabetes UK, 2012<sub>g</sub>).

<sup>19</sup> Impairment to a part of the eye called the retina (Diabetes UK, 2012<sub>h</sub>).

<sup>20</sup> Diseases that are associated with the heart and blood circulation (British Heart Foundation, n.d.).

<sup>21</sup> Kidney disease (Diabetes UK, 2012<sub>i</sub>).

<sup>22</sup> Nerve damage resulting from high blood glucose (Diabetes UK, 2012<sub>j</sub>).

ED is an important complication of DM, with a high worldwide prevalence, which is predicted to rise with the ageing of the worldwide population (Nehra & Kulaksizoglu, 2002).

ED occurs when a male is unable to obtain and/or sustain an erection, in order that sexual intercourse is deemed satisfactory. It is also referred to as 'impotence' (NHS Choices, 2012<sub>a</sub>). There are many known causes of ED including physical, vasculogenic, neurogenic, hormonal and anatomical. Additionally, ED may result from medicinal, psychological and other causes inclusive of drug-taking, alcohol consumption and fatigue or any combination of these (NHS Choices, 2012<sub>b</sub>). Fifty percent of men aged from 40 years to 70 years will experience ED to some extent in their lifetime (NHS Choices, 2012<sub>a</sub>).

### **DM and ED**

Seventy percent of all cases of ED are caused by an underlying health condition such as DM and approximately fifty percent of men who have DM will experience ED (UK Health Centre, 2014). DM is both a vasculogenic and neurogenic condition that can result in ED. Where there is excess blood glucose with DM, this can restrict blood getting to the penis, and can impact on the penis nerve endings (NHS Choices, 2012<sub>b</sub>). There is a greater prevalence of undiagnosed and unidentified DM in men experiencing ED compared with men in the general population (Sairam, Kulinskaya, Boustead, Hanbury & McNicholas, 2001). Men with DM are three times more likely to experience ED than men without DM (Dey & Shepherd, 2002).

Research suggests that for men in sexual relationships, ED is perceived as an important complication of DM (Rance et al., 2003). These men perceived ED to be more important than other DM complications, inclusive of sleeping problems and foot ulcers and ED was only viewed as less important in comparison to complications such as kidney disease and blindness (Rance et al., 2003). This group of men perceived ED to be more important than other participant groups including; healthy male controls, men with DM but without ED and single men with DM and ED (Rance et al., 2003). Men with DM and ED proposed a greater willingness to pay for treatment of ED, compared to other participant groups (Rance et al., 2003). A study by Eardley et al. (2007) found that men with DM and ED had a greater likelihood of perceiving their ED as permanent and severe, compared to men with ED but without DM. Additionally, this comorbid group had a greater likelihood of talking to a healthcare professional about their ED (Eardley et al., 2007).

ED has been shown to impact negatively on quality of life (QoL), particularly for men with a diagnosis of DM (Avasthi et al., 2011; Penson et al., 2003). Avasthi et al. (2011) investigated QoL of individuals with DM alone and those with DM and ED. ED was found to exacerbate poor QoL in men with T2DM (Avasthi et al., 2011). A study by Penson et al. (2003) investigated differences in health-related QoL (HRQoL) between men with comorbid DM (15% had T1DM and 85% had T2DM) and ED and those with ED alone. They found that men with both DM and ED experienced poorer intercourse satisfaction, as well as erectile function. Moreover, the emotional lives of men with DM were affected more by ED, than men without DM. Poorer disease-specific HRQoL was experienced by men with comorbid DM and ED. Despite functional and HRQoL improvements in men with DM and ED after receiving ED treatment, these effects were not lasting (Penson et al., 2003).



Both outcomes deteriorated one year from baseline and were significantly poorer than in men with ED alone. It was therefore proposed that treatments for ED may not be as effective long-term for men with DM (Penson et al., 2003). These studies suggest that comorbid DM and ED have a greater impact on QoL than either condition alone (e.g. Avasthi et al., 2011) and that ED is perceived to be an important complication of DM. Therefore, it is important to consider the perceptions that men hold about ED and DM and the possible impact of these perceptions.

### **Illness Perceptions**

Leventhal's Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984) posits that an individual will generate a cognitive belief system about their illness which is used to comprehend their illness and to coordinate their health behaviours. These beliefs are termed illness perceptions or representations. It has been proposed that illness perceptions consist of five domains including; identity, causal beliefs, time-line, consequences and cure/control. Identity refers to the beliefs that one holds about diagnosis and symptoms. Causal beliefs are concerned with an individual's thoughts about the root of their illness. Time-line refers to an individual's beliefs about how long they will have their illness for. The consequences domain is concerned with an individual's beliefs about how severe the illness is. Moreover, the perceptions they hold about the effect their illness will have on aspects of functioning including; physical, psychological and social. Finally, cure/control refers to the degree to which an individual believes that there is a cure for their illness and/or that it can be controlled (Leventhal, Nerenz & Steele, 1984).

Two additions have been made to this model since its development. These include ‘coherence’ and an emotion domain. The coherence domain is concerned with the knowledge that one holds about their illness and to what extent they can make sense of it. The emotion dimension refers to the affective/emotional reaction that an individual’s illness elicits (Moss-Morris et al., 2002).

Coping strategies will be utilised in light of the perceived health/illness threat posed. An emotion or problem-focused coping strategy will be utilised, dependent upon the individual’s response to the illness threat (Leventhal, 1997).

Research has shown illness perceptions of DM impact on a number of physical and psychological health outcomes (e.g. Hudson, Bundy, Coventry, & Dickens, 2014; Eiser, Riazi, Eiser, Hammersley, & Tooke, 2001; Hart & Grindel, 2010). Eiser et al. (2001) found that for men and women with either T1DM or T2DM, psychological well-being was predicted by the extent to which they believed they could self-manage their DM and moreover, the degree to which individuals could control the onset of DM-related complications. Psychological well-being was found to be worse for those who perceived their DM to impede their everyday activities (Eiser et al., 2001). For individuals with T1DM, there was an association between well-being and the degree to which they believed their DM to affect their lives. For those with T2DM, amount of complications was predictive of well-being. Therefore, for both T1DM and T2DM, an individual’s illness perceptions can predict psychological well-being. In particular, beliefs about control and ability to self-manage DM to deter the development of complications impact on well-being (Eiser et al., 2001).

Hart and Grindel (2010) found illness perceptions to influence the effectiveness of coping, self-care behaviour and health outcomes in individuals with T2DM. Those with greater perceived individual and treatment control over DM, as well as with greater coherence of DM, were also better able to cope. Greater self-care was found for those who thought their DM less likely to be chronic and cyclical, to have fewer consequences and less emotional distress (Hart & Grindel, 2010). Those with greater coherence of their DM were more likely to engage in self-care. Those with greater social support and who better utilised problem-solving strategies were more likely to engage in self-care behaviours, thus aiding health outcomes (Hart & Grindel, 2010).

While the evidence base investigating perceptions of DM is growing, less evidence exists which explores perceptions of men with ED. One study by Stamogiannou, Grunfeld, Denison and Muir (2005) investigated the perceptions men had about their ED, based on the Self-Regulatory Model (Leventhal et al., 1984). This study found a significant association between QoL and each of the following factors; masculinity, emotions, sexual functioning and the perception of ED consequences. Better QoL was most strongly predicted by greater sexual functioning. Second to this, it was best predicted by greater positive beliefs regarding the impact of ED on masculinity. However, most of the men in the above study were White (Stamogiannou et al., 2005) and therefore the findings are not necessarily applicable to South Asian men.

As the current study looked to investigate the illness perceptions<sup>23</sup> of South Asian men with DM and ED specifically, it seemed important to consider the impact of South Asian cultural beliefs on health behaviours.

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<sup>23</sup> The terms illness ‘perceptions’ and ‘representations’ have been used interchangeably in the literature. For the purpose of the current study, the term ‘perceptions’ is adopted, to encompass wider illness perceptions of men that are not necessarily restricted to those incorporated in Leventhal’s Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984).

Research has found South Asian cultural beliefs to impact on health behaviour change in South Asian individuals (Lawton, Ahmad, Hanna, Douglas, & Hallowell, 2006).

Lawton et al. (2006) found that for Indian and Pakistani individuals with T2DM, the norms and social expectations of their culture impacted on their engagement in physical activity in association with their DM management.

British South Asian individuals will more likely be affected by the predicted increase in prevalence of DM in the UK by 2025 (Diabetes UK, 2012<sub>a</sub>; Khunti, Kumar & Brodie, 2009) and thus also affected by associated complications, such as ED (Diabetes.co.uk, 2014<sub>b</sub>). Based on research to date, illness perceptions will likely influence health behaviours, coping strategies and thus health outcomes for South Asian men; both physiological and psychological. Therefore, it is important that illness perceptions are explored, such that service providers have a greater understanding of how best to support and treat these individuals.

Therefore, this study aimed to explore the experiences of South Asian men with DM and ED, specifically to elucidate illness perceptions and how they may impact on QoL.

The research questions were:

1. What are the experiences of South Asian men with DM and ED?
2. What illness perceptions do these men have and how do they impact on QoL?

## Method

### Design

Qualitative methodology was employed in this study and data was collected via semi-structured interviews. Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was used to analyse and interpret data. [See Appendix F for the Epistemological Statement].

### Participants

Participants were recruited from an ED service for men with DM within a teaching hospital in the North of England. The service gets between approximately five to six new referrals a month. Fifteen men expressed an interest in the study and consented to being contacted by the researcher to further discuss the study and potential participation. Seven men consented to participate in the study, however one participant was deemed unsuitable for participation as evident at the start of the interview and subsequently withdrew. Six men in total participated in the study. The inclusion criteria for participation were; men (18 years+), South Asian ethnicity, diagnosis of DM (T1DM or T2DM) and ED, willingness to discuss their ED and English-speaking. Men who did not have ED but who experienced another form of sexual dysfunction alone, such as premature ejaculation, were excluded<sup>24</sup>. However, if men experienced multiple sexual dysfunctions, including ED, they were included.

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<sup>24</sup> The rationale for recruiting men with ED and excluding the recruitment of men with other forms of sexual dysfunction alone, is that ED has been reported to be a complication of DM (Diabetes.co.uk, 2014<sub>b</sub>).

## Measures

The study employed a semi-structured interview which was produced for this study based on Leventhal's Self-Regulatory Model (Leventhal, Nerenz, & Steele, 1984; Moss-Morris et al., 2002; Leventhal, 1997) [see Appendix G], consistent with the recommended form of data collection for IPA. Semi-structured interviews are flexible, the interview schedule allows the researcher to initiate a dialogue with the participant, but it can also be adapted according to participant responses (Smith & Osborn, 2003). This allows the researcher to further explore participants' experiences based on the responses provided during the interview, so important information relevant to the participant's experience is not missed as a result of a stricter and structured interview schedule (Smith & Osborn, 2003). The interview schedule was refined according to service-user feedback from individuals attending a local DM support group [see Appendix H for more information].

The following descriptive data was collected; ethnicity, age, DM type, onset/duration of DM, onset/duration of ED, other health difficulties/conditions/sexual dysfunctions, treatments tried for ED (successful or not) and whether participants were sexually active and if not, whether they wanted to be.

## Procedure

Ethical approval and Research and Development (R&D) approval was obtained [see Appendix I]. Men who attended the ED clinic were approached about participating in the study if they met the inclusion criteria, by a Diabetes Specialist Nurse. Potential participants were provided with a participant information sheet [see Appendix J] and were given the opportunity to read this through and discuss and ask any questions about the study with their Diabetes Specialist Nurse.

Potential participants were then given the opportunity to take time alone in the waiting area to indicate whether or not they would like to be contacted or make further contact about participating in the study. This was to ensure they did not feel pressured to participate in the presence of the Diabetes Specialist Nurse. The researcher was then provided with the contact details of men who indicated that they would like to be contacted by the researcher. Potential participants were contacted, where possible, within one week of having been approached. At the point of contact with the researcher, potential participants were given the opportunity to further discuss and/or ask any questions about the research study. If the potential participant agreed to take part, a date, time and place to conduct the interview was arranged.

Interviews were conducted within the ED clinic setting. This ensured that if any risk issues and/or concerns arose, the participants' Diabetes Specialist Nurses could be consulted. Participants were given the opportunity and encouraged to ask any further questions before the interview began. Following this, participants completed and signed a written consent form [see Appendix K]. Once consent was obtained, the researcher gathered descriptive data [see Appendix L]. Following this, the researcher conducted the audio-taped semi-structured interview. The duration of participant interviews lasted between approximately 37 and 59 minutes. On completion of the interview, the researcher provided the participant with the opportunity to request to be informed of the main findings of the study [see Appendix M]. Participants who requested this were provided this information in writing, once data collection and analysis was completed.

**Data analysis procedure**

Interviews were transcribed verbatim and IPA was used to analyse data [see Appendix N for an example of IPA].

In order to increase reliability of findings, an independent rater, a Consultant Clinical Health Psychologist, completed stage 1 and 2 of the IPA process for three out of six transcripts. The contributions of this independent rater were incorporated into the analysis.



## **Results**

### **Summary of Participant Demographics and Characteristics**

A total of six men participated, ranging in age from 41-70 years, with a mean age of 59.5 years. The ethnicity of all participants was Pakistani. Five of the six men who took part were T2DM and one was T1DM. Participants had been living with DM between 5 and 24 years and with ED for 2 to 23 years. A variation in the onset of ED relative to the onset of DM was found. Some participants began to experience ED after the onset of their DM, the same time as or before. All participants reported a history of or current comorbid health conditions, as well as ED and DM. These included; heart failure, heart attack, depression, high blood pressure, underactive thyroid, prostate operation, constipation and low levels of testosterone. Two participants experienced premature ejaculation (PE) as well as ED. All participants had tried treatments for ED, some of which were successful and others unsuccessful. These included; medication e.g. Viagra, hormone treatment, injection and use of a pump. Participants were not able to provide specific names of medications at times, other than Viagra. Half of the participants were sexually active and the half that were not reported that they would like to be.

Table 1.

*Participant demographics and characteristics associated with their health status, sexual life and treatments tried for ED.*

Participant	Ethnicity	Age Range (Years)	DM Type (1 or 2)	Onset/duration of DM (Years)	Onset/duration of ED (Years)	Other health difficulties/conditions/sexual dysfunction	Treatment tried for ED (successful/unsuccessful)	Is participant sexually active? If not, do they want to be?
1	Pakistani	50-60	DMT2 (50 + years at onset)	5+	5+	<ul style="list-style-type: none"> <li>• Depression</li> <li>• High blood pressure</li> <li>• Underactive thyroid</li> <li>• Prostate operation (9 weeks prior)</li> <li>• Constipation</li> <li>• Testosterone level low</li> </ul>	<ul style="list-style-type: none"> <li>• Viagra (unsuccessful)</li> <li>• Hormone treatment (successful)</li> <li>• Injection (successful)</li> <li>• Currently taking treatment</li> </ul>	No, would like to be.

2	Pakistani	65-75	DMT2	6/7	9	<ul style="list-style-type: none"> <li>• Heart attack</li> <li>• PE</li> </ul>	<ul style="list-style-type: none"> <li>• Tablets similar to Viagra (successful but stopped use as difficult to obtain and expensive; wanted professional advice)</li> <li>• No further treatments.</li> </ul>	No, would like to be.
					Year 2009, ED worsened after heart attack and bypass operation.			
3	Pakistani	60-70	DMT2	10+	5	<ul style="list-style-type: none"> <li>• High blood pressure</li> </ul>	<ul style="list-style-type: none"> <li>• Tadalafil (not specified). Not successful to date; full erection not achieved.</li> <li>• Recent use of pump (more successful than medication)</li> <li>• Viagra: initially successful but less so as DM worsened.</li> </ul>	Yes, sexually active.

4	Pakistani	40-50	DMT1	21	Approximately 22/23	<ul style="list-style-type: none"> <li>• Heart attack 2014</li> <li>• PE</li> </ul>	<ul style="list-style-type: none"> <li>• Pump recommended but not tried to date.</li> <li>• Viagra: not successful</li> <li>• 2006: Injections; partial success, with an erection lasting for a few minutes, but was not able to achieve a full erection.</li> </ul>	Yes, sexually active.
5	Pakistani	50-60	DMT2	10+	2/3	<ul style="list-style-type: none"> <li>• High blood pressure</li> </ul>	<ul style="list-style-type: none"> <li>• Viagra: successful for 2/3 years but now unsuccessful.</li> <li>• Pump (had been trying in last few weeks prior to interview): not very effective.</li> </ul>	Yes, sexually active.

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6	Pakistani	60-70	DMT2	24	4	<ul style="list-style-type: none"> <li>Heart problem 1997: heart failure.</li> </ul>	<ul style="list-style-type: none"> <li>Injection: 2 years (unsuccessful)</li> <li>Medicine, capsules gels: medicines designed to increase testosterone levels (unsuccessful).</li> </ul>	No, would like to be.
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## Themes

Data analysis generated ten subordinate themes, encompassed by four superordinate themes and these are shown in Table 2.

Table 2.

*Superordinate and Subordinate themes generated from IPA analysis.*

Superordinate Themes	Subordinate Themes
Significance of ED	The Meaning of Sex
	The Power of ED
Control	Acceptance Vs. Hope
	DM Vs. The Self
	Prioritisation
Relational Impact	Duty
	Isolation
	Judgement Vs. Support
Understanding ED	Uncertainty
	Discussing ED

## Significance of ED

### The Meaning of Sex

The significance of ED was paralleled with participants' reflections on the meaning of sex. Many participants emphasised the importance of sex as natural and gratifying. As such, ED was conveyed as an obstacle restricting access to the very essence of life.

*'...basic need of a man, if a man doesn't have this one, mean he's gonna be affected in lot of ways...' (Participant 4, 60-61).*

*'...life is not sweet, you know...I think it's like er, perfume without, flower without perfume...It's like, my life is, is you know, plastic flowers...Real flowers have perfumes.' (Participant 2, 389-395).*

Some participants portrayed sex as a benefit, an additional enjoyment or pleasure, rather than a necessity.

*'Well I thought this is the bonus, you see, you know, if you, if you can, you know, get through, you know, so you can have a both lives, you see, with your wife, with your childrens, you know, within the family...' (Participant 5, 104-107).*

However, it was evident that there was some ambivalence about the significance of sex. One participant expressed that although not necessary, sex is an element of life, that without, can render dissatisfaction or displeasure.

*'...without sex, I can live.'* (Participant 6, 32)

Vs.

*'...sex is a part of life, and if you take one part away, you, you can't feel comfortable...'*  
(Participant 6, 401-403)

### **The Power of ED**

The depiction of the nature of ED by participants was somewhat conflicted. The extent of its power and control was associated with its severity and chronicity, an affliction resulting in the helplessness of participants.

*'But I think the damage has been done.'* (Participant 3, 77)<sup>25</sup>.

*'Because ermm, without m, medication, I did not feel any changes even if I have feelings, for having sex with someone, but, that doesn't work...that doesn't work, so, there's a big chances of, this thing that, my erectile dysfunction will last forever.'*  
(Participant 4, 295-300).

*'I never have that, never even a morning reaction, never'* (Participant 1, 615).

The inevitability of ED was also conveyed, in connection with concepts inclusive of increasing age, DM and its treatment and the finite nature of sex. This arguably reinforced the helplessness and powerlessness of participants; unable to prevent the onset of ED.

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<sup>25</sup> Participant 3 conveyed a perception that his ED was irreversible, as despite his DM being well-controlled, he continued to experience ED. Participant 3 had reported the perception that his ED may have resulted from his DM and management of DM.



*'One is the age, second is...diabetic situation, you're on in, insulin, you're on tablets...it bounds to happen.'* (Participant 3, 91-92).

*'And er, for example, if there is a...twenty kilo water in the tank, sometimes people use it, all in one go, couple of months time, or sometime they spread it all over the year, you see, you know. But there is a twenty kilo there, you see...So either you do it with once or you will, spread it...for a longer time, you see, you know. So this is my thought, you know, I think...I've got enough...'* (Participant 5, 165-173)<sup>26</sup>.

On the contrary, one participant felt as though ED was not inevitable and that men should be able to continue to experience adequate erectile functioning despite increasing age. Thus, questioning the omnipotence of ED and proposed limits of sexual capacity.

*'And if I have to live for long, at least another ten, fifteen years...live happy life, sex life, you know...I think people do live good sex life, after eight, eighty-five, you know.'*  
(Participant 2, 338-343).

ED was perceived as an absence of power, a reduction of energy and a weakness.

*'...there is nothing there.'* (Participant 1, 386)<sup>27</sup>

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<sup>26</sup> Participant 5 expressed the concept that one has a limited sexual capacity. Therefore, one can choose to use up his capacity within a short amount of time or use it more sparingly over a longer time, so that it is longer-lasting over a number of years. This conveyed a sense that ED was therefore inevitable, with the perception that one cannot have the capacity to have sex infinitely.

<sup>27</sup> Participant 1 expressed a perception that there is a depletion of power, resulting in his inability to achieve an erection. As such, this conveyed a sense that erectile functioning almost results from a power, strength or energy in the penis that allows it to become erect.

*‘...when they increase insulin, then all my energies is also going down as well you see, you know. Then I get the problem with erectile and everything...’ (Participant 5, 582-584).*

*‘There’s no feeling...No feeling at all.’ (Participant 6, 229-231).<sup>28</sup>*

ED was thus conceptualised along a power continuum. Power was conveyed by the perceived severity, chronicity and inevitability of ED. It was also identified as an affliction marked by absences of functioning, energy and power, thus conveyed as a weakness.

## **Control**

### **Acceptance Vs. Hope**

Many participants expressed an acceptance that they had ED. Acceptance appeared to be a response to a perceived lack of individual control. Participants expressed an external locus of control with regard to the onset and management of ED, viewing it as an inevitable affliction due to factors such as age and DM.

*‘Even if I tried to do sex, right, I know that I can’t do it’ (Participant 1, 593).*

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<sup>28</sup> Participant 6 conveyed a perception that ED consists of a lack of physiological feeling, thus characterising ED as an absence of certain qualities that may contribute to satisfactory erectile functioning.

*'Well, I was used to be, you know, when I...age of twenty and between thirty...I enjoy myself, you see, with my wife and I mean...every couple of times, you know, we do...have intercourse but you know when the time pass by, you know...for example I'm nearly forty\* years of age, so that's why you know, I'm try to, move away from these things because, I can't do it, I can't manage it, you see, you know. And there's no a strength, you know.'* (Participant 5, 74-82).

*'Well, I have accepted that the reality is the sugar is there, I'm a diabetic. So this is part and parcel of it.'* (Participant 3, 237-238).<sup>29</sup>

Acceptance for some participants appeared to serve as a stoic coping strategy, continuing on in the absence of personal control, yet in spite of psychological pain. However, although participants were prepared to accept ED and continue on with life, they were hopeful of treatments for it. This emphasised an external locus of control and hope facilitated by external influences.

*'Well...it does, er, felt er, I don't know what to say, it does, you feel hurt. But then, you say to yourself you're a diabetic, what can you do? And you can't stop the tablets and insulin. So, one has to live with it. I mean, I don't know what other, therapies or what else is available in the market or in this medical world. Er, I don't have that knowledge. Sure it will be interesting to know, there is something available to help this situation.'*  
(Participant 3, 255-259).

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<sup>29</sup> Participant 3 conveyed ED as an inevitable consequence of his DM, thus suggesting DM to be a cause of ED.

Despite hope, there was an acceptance that treatments may not be effective or available.

*'...something you can't get, you have to leave it, you see.'* (Participant 5, 117).

*'If there is not any treatment, can live without that. I can live without that* (Participant 6, 109-110).

### **DM Vs. The Self**

Participants portrayed DM as a controlling and restrictive illness, governing and impeding on other aspects of life and requiring careful management. However, participants appeared to be engaged in a 'reciprocal role' (Ryle & Kerr, 2002) with DM. Despite its controlling nature, participants were able to seize personal control over the management of their illness. An internal locus of control was employed, where participants took responsibility for their health outcomes. Thus, a struggle for control between DM and the individual was depicted.

*'But diabetes, it affect everythings. Even you can't, sometimes you can't have other treatment for other problems, because diabetes. So like me, as a heart patient, diabetes very bad. Very serious. For that reason, I can't eat what I like to eat. I have control myself. And er, I have to be active.'* (Participant 2, 542-546).

*'With diabetes, have to be, I have to be careful ermm, ermm, doing things and to make sure all the time, twenty four hours a day, that I should be in the normal range, because if I'm not in the normal range there could be a, big problem for me.'* (Participant 4, 723-727).

## Prioritisation

Along with the acceptance of ED, some participants regained control via prioritisation. They chose to focus on other aspects of their lives, inclusive of family and DM. Prioritisation appeared to stem from a number of factors. One participant in particular expressed that with increasing age, one should shift their focus from ED and their sexual life to making the family happy.

*‘What is gone...gone and now you should look for the future, you know, for the best interests for the family, you see.’ (Participant 5, 468-470).<sup>30</sup>*

Other participants emphasised a need to prioritise the management of their DM over their ED.

*‘As long as its go, try to keep myself physically fit, walking and try to keep...level low. This is m, my...main aim is, not my main aim is having a sex.’ (Participant 6, 152-154).*

One participant expressed a lack of choice over this hierarchy of health issues. They felt obliged to prioritise DM management, despite their belief that insulin and DM medications contributed to their ED.

*‘Well, my feelings are that these are the two reasons for this dysfunction, but then, I say to myself, what option I have?...That’s my first priority should be control the sugar level, everything else should be second...’ (Participant 3, 136-140).*

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<sup>30</sup> Participant 5 conveyed that one should not dwell on what they no longer have, which in this case would be satisfactory erectile functioning. As such, he emphasised the importance of focusing on the future and shifting one’s priorities e.g. focusing on the best interests of the family, rather than the ED.

Some participants expressed that rumination and/or self-pressure was futile, acting to potentially exacerbate the impacts of ED. They chose to refrain from this and instead prioritised a sense of gratefulness for that which was positive in their lives.

*‘...if you putting too much in your mind, doing this and doing that...forcing yourself...can’t get any gain from that.’ (Participant 6, 198-201).*

*‘I mean...mostly, the, the people, when they get married, they have a, they, they want to get a family and that family is complete when you have children...And er, I’ve got them.*

*So because of that I’m, I’m happy.’ (Participant 4, 782-788).*

*‘...I think, thanks God, at least you are giving, giving me a two pair of hands, pair of, you know, everything is OK, there is nothing wrong with my body...So, I’m not thinking something on the negative here, but I’m thinking on the positive.’ (Participant 5, 306-318).*

## **Relational Impact**

### **Duty**

Participants expressed that they had a duty to sexually satisfy and provide for their partners, but that ED restricted fulfilment of this. Some participants appeared to possess gender stereotypes about the responsibility of men within the sexual relationship. There was an expectation that man provides for the woman, emphasising the importance of adequate erectile functioning in order to do so.

*‘She should get and I should help her and give her what she like to do.’ (Participant 2, 418-419).*

*'I mean...you know...womans, you know, have no reaction, you know what I mean, a man have a reaction, right?' (Participant 1, 539-540).<sup>31</sup>*

*'...nothing do with the woman, you see. The woman is always ready there, you see.'*  
*(Participant 5, 516-517).<sup>32</sup>*

Participants recognised the impact that a lack of sexual fulfilment may have on their partners and disclosed feelings of shame, guilt and self-blame at not being able to provide for them.

*'Yeh, well, if she is not satisfied with...you know, I'm already gone and then a bit makes me little shame, you know...'* (Participant 5, 428-430).

*'...psychologically, yes its, it is in your mind, its little bit burden on you. It is, feeling on you that, yes you're not able to, perform.'* (Participant 3, 275-276).

*'But there is a feeling that, I, that, the, the things she should deserve that I cannot provide her that, and that really kills me a lot.'* (Participant 4, 117-118).

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<sup>31</sup> Participant 1 emphasised the perceived responsibility of the man to provide for the woman sexually, as he has to physically achieve an erection in order that intercourse can occur, whereas it was perceived that a woman has no such physical preparation to make for intercourse.

<sup>32</sup> Please refer to footnote 31.

### **Isolation**

A theme of isolation was present throughout participants' interviews. This incorporated ideas about one being isolated from the norm, their cultural community or in their experience of ED. Participants expressed that ED equated to an 'abnormal' self, in a sense restricting one's ability to live a normal life. ED was depicted as a private problem, one which was difficult for some to initially discuss with others, due to feelings of embarrassment and shame. At times, this could hinder help-seeking.

*'This is the thing that er, you cannot share with, with, with, with friends or with people or with anybody, so I was just getting...in, in myself.'* (Participant 4, 95-97).

*'Thing is, if I come to the, professional...few years ago, I may not suffer all this problem at all...You know, as, as I say, embarrassment and thing like that.'* (Participant 2, 312-314).

*'So this is what I'm looking, you know. For...from them to help me with that, you know, to get my rest of my life, you know, normal...'* (Participant 5, 691-693).

### **Judgment Vs. Support**

Participants expressed a fear of the negative judgments of others, regarding their ED, thus impacting on one's self-esteem, in anticipation of what others were thinking of them. These judgments were associated with the function of different relationships and the expectations within those. For some, fear of judgment was linked to the inability of the man to fulfil his sexual duty to his partner and how this then reflected on him as a person.



*'So, so, so she would be fed up. She would be fed up and she would be bad thought about the man...About the man...the he, he is useless, you know what I mean?'*

*(Participant 1, 548-551).*

This was particularly poignant for Participant 1, who expressed cultural expectations about the monogamist nature of Pakistani relationships. Hence, emphasising the importance of duty fulfilment, as the partner cannot seek sexual satisfaction from elsewhere.

*'And we, we don't go out, you know, to find, err, somebody else.'* (Participant 1, 319).

One participant expressed having had a sexual partner for a number of years, whose critical judgment of ED was associated with the function of this relationship.

*'I said she discouraged me, for this, the friend of mine...Because, why I wasted my time here, I come for y<sup>33</sup>, come to you...and I've wasted my time.'* (Participant 6, 512-517).

One participant feared the judgment of his community, if they knew that he had ED and emphasised the psychological impact that this would have.

*'Obviously, you know that nobody will ev-er say to me on, on the face, that you are like this, but they'll be thinking and that, that kind of, er, thinking that y<sup>34</sup>, you're thinking that people are thinking like this about you, that, that, really affects you a lot...mentally.'* (Participant 4, 191-194).

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<sup>33</sup> Participant verbalisation

<sup>34</sup> Participant verbalisation

However, despite concerns that participants had about the negative judgments of others and the subsequent impact on their self-esteem, many found that their partners were supportive, encouraging and accepting of their ED. They conveyed the support of others as a buffer against any additional negative impacts of ED. This emphasised the importance of interpersonal collaboration in accepting and managing ED, helping to prevent isolation from others.

*'I mean luckily in my case, er, I didn't have a problem with my partner. She accepted the reality and er, we're just managing...Otherwise, that could have been a problem if that was the, if er, er, if she wouldn't have accepted it. That could have serious consequences in the life.'* (Participant 3, 305-309).

*'...if a man doesn't have this one, mean he's gonna be affected in lot of ways. Yeh. But, only the thing I'm, I'm, I'm really, er, feeling ermm, lucky about that, I've got a very good partner and ermm, we are, we are going very good with each others.'* (Participant 4, 60-64).

*'Sometime, you know...in my opinion, if you don't have a, sexual life good with your wife it, they just leave the house, leave the children, they just gone, runaway. Or they throw you out and they bring someone else in, you see, you know. It does happen sometimes, you know. But it didn't happen in my family...we are quite happy, you know.'* (Participant 5, 392-397).

## Understanding ED

### Uncertainty

A theme of ambivalence was evident throughout the interviews, with participants speculating about many issues relating to ED, but appearing to lack concrete knowledge and understanding. Participants had a variety of beliefs about the causes of ED, including those of an organic and psychological nature, but there was apparent uncertainty of such causes.

*'Actually how it started is er, really psychological and er, ermm, in, in, in, in medical ways, I don't know whether to associate this problem with that...' (Participant 4, 77-79).*

*'I don't know what to do...What I think, you know, I think it is a...it is, it is a, a circ...,it is a circulation...problem. Might be, might be, you know, I'm not sure.' (Participant 1, 98-99).*

One participant questioned why he had ED over others who were arguably more deserving of it, conveying a sense of injustice.

*'Yeh, do bad things, you know. They rape woman, they drink, you know what I mean? They drink, they have a fight, they have a everything, you know, but they're ok. Th, their health is ok.' (Participant 1, 757-759).*

Although they had some information about the treatments available, some participants appeared uncertain as to the reasons for treatment ineffectiveness or of help-seeking/treatment options.

*'...I surprised you know...I surprised you know...why, why medicine is not working on me?' (Participant 1, 17-18).*

*'...maybe there's something else available, which I'm not aware of. So, one has to accept.' (Participant 3, 464).*

### **Discussing ED**

The importance of discussing ED within a professional context was emphasised throughout the interviews. In some cases, ED was not directly assessed and was thus inadvertently discovered in the pursuit of other health agendas. Some participants conveyed the importance of healthcare professionals assessing for ED, such that men could receive information about and support for this condition as early as possible.

*'And I think that should be picked up early because some people, might not know, who to ask. ...So if somebody's diabetic after whatever time...or wherever he's going, that particular person, that particular doctor should ask him, do you have that problem. If you don't, that's good...If you do, he should be helped at very early stages. But two years down the line, you don't know who to go to. But that's one thing I feel, if it can be improved, er, that's great...' (Participant 3, 577-583).*

One participant expressed that the television programme 'Embarrassing Bodies' (Eglin, Harris, & Jones, 2008) provided him with encouragement to seek help as well, overcoming his embarrassment to discuss ED. There was an emphasis on the normalising of ED, to prevent one from feeling isolated and alone with the condition.

*'Well er...I was very embarrassed, feeling embarrass...to discuss anyone's, even the doctor, but er, as I said, seeing that programme on TV and then, er, suddenly, I go for a, diabetes review, and nurse ask me question...and I say ah yes I have problem and she ask me if I, had any help or, a, see doctor and I said no. Why? Because embarrassment, she said no, should not. You are not alone. So she, you know, encouraged me, see doctor.'* (Participant 2, 497-502).

Within a professional healthcare context, participants were more comfortable discussing their ED. They expressed the view that in a respectful and confidential environment such as this, discussion could aid treatment-seeking and understanding.

*'But now I'm more worse, I'm looking for more help, you see. So that's why I try to, contact most of the people...So I can have a open word...and they will understand my problem...'* (Participant 5, 800-806).

*'...I'm not shy, you know, to talk with a, doctors or you lot, you know, I'm not telling anybody else, no, no. I'm not telling anybody outside.'* (Participant 1, 670-671).

*'Everything is confidential so, no, no there's no problem. I, I, I will discussed and I can discuss with, with doctors er, regarding, these matters.'* (Participant 4, 638-640).

In summary, participants have expressed the significance of ED as a restrictive and enduring condition, one which they have limited control over. This results in an acceptance of ED, prioritising other aspects of life e.g. the family or DM management. However, participants express hope for treatment and emphasise the importance of the initiation of communication by healthcare professionals in order to facilitate this. Despite the relational impact of ED perceived by participants, support is viewed as a buffer to further negative consequences.

## **Discussion**

This study aimed to explore the experiences of South Asian men with DM and ED. It utilised qualitative methodology, employing in-depth semi-structured interviews, based on Leventhal's Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984) and specifically considered illness representations. The findings have been synthesised into hypotheses as to how South Asian men with DM may make sense of ED and its impact on them.

### **Interpretations of findings**

#### **Significance of ED**

Themes of the 'Meaning of Sex' and 'Power of ED' depicted the significance of ED to the men experiencing it. ED was portrayed as a restrictive and enduring condition. It was deemed an obstacle to the pleasure of sex, which was viewed by some as an important and natural part of life, whether as a basic need or an additional bonus. There was also some ambivalence, with a suggestion that one can live without sex, although its absence renders life uncomfortable. Aspects of ED were perceived along a power continuum. It was conveyed as a weakness and a lack of power in nature, paralleled to the powerlessness and weakness of the men experiencing it. Yet, it was also viewed as a somewhat powerful condition, for some being severe, potentially permanent and inevitable in light of factors such as increasing age, DM and its medication and for one man, the perception that one has a finite sexual capacity. One man questioned age and sexual capacity as limits to the ability to have sex.

Maslow (1943, 1954) postulated that human beings possess motivation to seek fulfilment of various basic and growth needs. These needs are situated in a hierarchy, such that when the needs at the bottom of this are met, one can look to meet the next need. In ascension of the hierarchy, individuals are seeking to fulfil the growth need of self-actualisation, which is recognition of one's potential and self-fulfilment (Maslow, 1943; 1954). Arguably, the men in this study perceived sex as an important part of life, and thus a basic physiological need that one would seek to fulfil. However, the perception of ED as powerful and thus restricting fulfilment of this need suggests ED to be an obstacle in the ascension towards self-actualisation.

Research has shown that men with ED can vary in their perceptions of the meaning and importance of sex (Pontin, Porter, & McDonagh, 2002). Pontin et al. (2002) interviewed nine men with ED in the United Kingdom (UK) and found differences in their views about the meaning of sex. Some men conveyed sex as a means of demonstrating love to their partners. Others posited that sex was a bonus and that penetrative intercourse was not the only means by which love could be demonstrated (Pontin et al., 2002). Low, Ng, Choo and Tan (2006) interviewed 17 Malaysian men with ED and found that men perceived sex as important, despite one's age. Additionally, research has shown that men with ED across various countries generally disagree with the concept that they are too old to be having sex (Perelman, Shabsigh, Seftel, Althof, & Lockhart, 2005). This emphasises that healthcare professionals should not make assumptions about men's perceptions of sexual functioning based on age.



The World Health Organization has emphasised the negative impact of sexual dysfunction on QoL. They proposed that research has been conducted cross-culturally, in countries such as Pakistan and has shown that there is a link between sexual dysfunction and poorer QoL outcomes, as well as with psychological conditions such as depression (World Health Organisation, 2010). Healthcare professionals need to recognise ED as a significant condition and therefore initiate discussions about it.

### **Control**

The perceived limitations of personal control resulted in an acceptance of ED. However, hope of help from external sources, arguably resulted in participants demonstrating problem-focused coping (Lazarus & Folkman, 1984) via help-seeking. Therefore, even having adopted an external locus of control, participants were still able to demonstrate personal control in the form of help-seeking, which was driven by their hope for treatment from external healthcare sources. Problem-focused coping has been found to be positively associated with beneficial health outcomes (Penley, Tomaka, & Wiebe, 2002).

Participants demonstrated an internal locus of control in their prioritisation of other aspects of life such as family and DM management. Research has indicated that South Asian men demonstrate an obligation towards family over the pursuit of individual needs (Patel, Phillips-Caesar, Boutin-Foster, 2012). Additionally, despite participants' perceptions that DM was a restrictive and somewhat controlling condition, they themselves took responsibility for the management of it. As such, participants could be described as being engaged in a 'reciprocal role' (Ryle & Kerr, 2002) with their DM, adopting the 'controlled' pole due to restrictions that DM places on their lives and 'controlling' pole in their management of their DM.

Active acceptance is defined as an individual's recognition of an adverse event or situation, which they subsequently deal with in an effective manner. As such, futile endeavours to control or change a situation are abandoned. The individual finds meaning in other areas of life and seeks to achieve valuable goals. As a result, the individual experiences a steady emotional balance. Thus, active acceptance is an efficient means of coping when an individual has no control (Nakamura & Orth, 2005).

Research has shown that active acceptance has resulted in better health outcomes, adaptive coping, QoL and psychosocial adjustment in individuals with chronic kidney disease and/or dialysis (Chan, 2013). Illness acceptance has also been found to be associated with QoL in individuals with DM (Lewko et al., 2007). However, not all forms of acceptance are deemed adaptive, including that of resigning acceptance (Nakamura & Orth, 2005). This form of acceptance is defined by an individual's passiveness, resignation and hopelessness, with prospects of the future being negative. Unlike active acceptance, the individual does not pursue additional goals and thus passiveness ensues in all realms of life (Nakamura & Orth, 2005).

Arguably, the participants in the current study demonstrated active acceptance (Nakamura & Orth, 2005). They proposed acceptance of their ED, due to a perceived lack of personal control, but with a pursuit of other goals via prioritisation e.g. DM management and family life. Also, rather than resort to complete passiveness, they actively engaged in help-seeking by attending clinic, as a product of their hope for treatment of their ED. Similarly to the participants in the current study, Pontin et al. (2002) found that the men that they interviewed in the UK were hopeful that their ED could be solved, whilst accepting that this may not be possible.

Perelman et al. (2005) found that 47.2% of participants from across six countries concurred with the notion that they should accept their ED. However, those least likely to accept their ED were in the UK and US (Perelman et al., 2005).

Along with the findings of the current study, this research highlights that men with ED from a variety of different countries and cultures are accepting of their ED (Perelman et al., 2005). Healthcare professionals need to collaboratively engage men with ED to find ways of managing or improving their condition.

### **Relational Impact**

Participants in the current study conveyed a sense of duty to provide for their partners within the sexual relationship, with some suggesting that this was the responsibility of the man, thus assuming gender stereotypes. As such, participants expressed feelings of shame, guilt and self-blame due to their attributed responsibility to fulfil this role and inability to do so due to the restrictions of their ED. This evident impact on self-esteem was further impacted on by participants' concern for the negative judgements of others, at times related to the lack of duty fulfilment and thus how this conveyed participants' worth. Arguably linked to the impact on self-esteem, participants reported experiencing isolation from others, as well as what it means to be 'normal'. Additionally, some participants disclosed a sense of embarrassment to discuss their ED, hindering help-seeking and arguably reinforcing a sense of isolation. However, participants perceived that with the support of others, there existed a buffer against further negative consequences of ED.

Gender roles within the South Asian home highlight that the man is perceived to be the dominant member of the household, who makes the decisions (Patel, et al., 2012).

Pakistani and Indian men have expressed a responsibility to prioritise the family above individual pursuits, thus demonstrating a social duty (Lawton et al., 2006). The findings of the current study concur with this, as participants perceived ED to have a significant relational impact, lack of duty fulfilment, isolation and concerns about the critical judgements of others.

Rogers (1959) proposed that in order for individuals to be self-actualised, they must experience congruence between their perceived self and the self that they would ideally be. He posited that this process could be aided by ‘unconditional positive regard’, where the individual feels accepted and supported by the significant people in their lives, regardless of their actions or disclosures (Rogers, 1959). The findings of the current study can be conceptualised within this theory, highlighting the impact that one’s relational roles and experiences can have on one’s sense of self (Rogers, 1959). This is reflected in participants’ perceptions that the support of their partners was an important buffer against further consequences of ED.

Most Pakistani individuals are Muslim and to act in accordance with principled masculine values, men are expected to provide for and respect the family as well as to restrict sexual activity to the marriage (Walle, 2004). Furthermore, sexuality within the marriage is viewed as an entitlement and obligation for both man and woman, with duty being achieved when the woman gives birth (Walle, 2004). The men in the current study expressed that they had a duty and responsibility to provide for their partners in the context of the sexual relationship, which corresponds to the proposed masculine attributes suggested above, in which the man should provide for the family, over individual pursuits (Walle, 2004).

Not only does the man perceive not to be able to have sex, with sex having been expressed as a privilege within the marriage for Muslim couples but arguably the man is unable to allow for fulfilment of the duty of reproduction (Walle, 2004). As such, men may perceive ED to impact on their ability to uphold such masculine values and so there is arguably an incongruence between their perceived self and the self that they would ideally be (Rogers, 1959). However, with participants having expressed that the support of their partners is a buffer to further negative consequences of ED, it is possible that these men can achieve 'self-actualisation' (Rogers, 1959) despite not fulfilling what they perceive to be a part of their masculine duties. Therefore, men experiencing ED, who are without a partner or a good relationship (one where the individual feels supported and accepted by their partner), may be at greater risk of distress.

Research has shown that men perceive ED to impact negatively on their relationships (Low et al., 2006) and on their partners (Pontin et al., 2002; Perelman et al., 2005), across a variety of cultures. Men with ED in Malaysia have expressed reduced confidence as well as insecurity in their ability to preserve a gratifying partner relationship (Low et al., 2006). Men with ED interviewed in the UK have reported worries about whether they will have full erections, as a means of satisfying the sexual needs of their partners (Pontin et al., 2002). However, Pontin et al. (2002) found that for men below the age of sixty, their partners were perceived as accepting, attributing no blame to the man.

Whilst the participants of the current study conveyed that they were supported by their partners, it is possible that their feelings of shame, guilt and self-blame were associated with their inability to fulfil their duty to their partners. This appeared particularly poignant where some participants expressed that their partners had not sought sexual gratification elsewhere.

However, men with ED interviewed in the UK have expressed concerns that their partners may do just this (Pontin et al., 2002). This highlights that guilt for South Asian men with ED may be worse, as they may have less of an expectation that their partner will seek sexual gratification elsewhere. This is particularly poignant where Pakistani and Indian men have reported that they have a duty to others above themselves (Lawton et al., 2006). Therapeutic interventions such as Compassion-Focused Therapy may help these men to enhance their self-compassion (Gilbert, 2009), in light of the self-blame, guilt and shame that they may experience as a result of ED.

### **Understanding ED**

Participants in the current study expressed uncertainty about a number of ED-related factors, including causes and treatment of the condition. They proposed a variety of potential causes, including those both psychological and organic in nature, with most citing DM as a potential cause. Despite being currently engaged in treatment-seeking, participants seemed unsure of the reasons for treatment ineffectiveness or of the availability of treatment options. With a limited knowledge base about ED evident amongst participants, they emphasised the importance of healthcare professionals initiating a direct discussion about ED to facilitate timely help-seeking.

Participants expressed no concerns in discussing ED within a professional and confidential context, for the purpose of seeking help. Again, this emphasises that healthcare professionals need to be asking about ED.

Cummings, Meeking, Warburton and Alexander (1997) found 90% of their participants, who had DM, were unable to accurately define ED. Thirty percent did not know that ED could result from DM, whilst 42% believed ED to be inevitable with increasing age. Forty-seven percent had no knowledge of treatment options (Cummings et al., 1997).

For participants with an understanding that DM could result in ED and of treatment options, this knowledge was less likely received from healthcare professionals. This study highlighted that men with DM had not conversed with a healthcare professional about ED, even though 50% of the participants experienced this condition. More than 90% of the participants were encouraged to seek support if they experienced ED, following involvement in the study (Cummings et al., 1997). Additional research has found that perceptions about cause and options for treatment of ED can impact on men's help-seeking behaviour for this condition (Shabsigh, Perelman, Laumann, & Lockhart, 2004). The issues around a lack of knowledge about and understanding of ED may be more evident for South Asian men due to potential language barriers. Therefore, healthcare professionals need to initiate discussions about ED and provide information about the condition that is culturally appropriate.

There is evident cross-cultural willingness of men to discuss their ED with healthcare professionals (Perelman et al., 2005). Similarly to the participants in the current study, participants in the Pontin et al. (2002) study expressed a willingness to discuss their ED with a healthcare professional, without preference for gender, whilst emphasising professionalism and confidentiality (Pontin et al., 2002). Perelman et al. (2005) found that men across six countries were amenable to discussing ED with their doctor. However, for others, embarrassment hindered consultation with a healthcare professional about ED and thus help-seeking (Shabsigh et al., 2004; Perelman et al., 2005).

There appears to be cross-cultural agreement of men with ED that discussion about the condition should be initiated by healthcare professionals (Gülpinar, Haliloglu, Abdulmajed, Boga, & Yaman, 2012; Lyngdorf & Hemmingsen, 2004).

This may be a particularly important consideration in light of some men (9-35%) perceiving that their doctors may not be comfortable discussing ED (Perelman et al., 2005).

The coherence domain of the Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984; Moss-Morris et al., 2002) is concerned with an individual's understanding of their illness. Research has shown a significant link between low illness coherence (reduced comprehension of the illness) and greater psychological distress (van Os, Norton, Hughes, & Chilcot, 2012). A link between greater illness coherence and increased psychosocial outcomes has also been reported (Sawicki, Sellers, & Robinson, 2011). This highlights the impact that an individual's understanding of their illness may have on health outcomes, thus emphasising the importance that men are well-educated and informed about their illness. Healthcare professionals should therefore ensure that they initiate a discussion and provide information about ED in men with DM, particularly where men may be embarrassed to come forward.

### **Clinical Implications**

Findings from this study have a number of implications for clinical practice. South Asian men with DM and ED perceived their ED to have a significant impact on their QoL. In particular, ED had a relational impact. South Asian men have expressed obligations to provide for others, above the pursuit of individual needs, which has been found to hinder elements of physical management of DM (Lawton et al., 2006).

In another health population, Indian and Pakistani men have proposed the importance of having knowledge and understanding, as well as an obligation to their families and individual health (Galdas, Cheater, & Marshall, 2007). These factors were perceived as important masculine characteristics, which encouraged men to seek help for cardiac chest pain (Galdas et al., 2007).



This emphasises the importance of culturally competent healthcare services, particularly where the cultural values of men may influence their perception of ED, its impact and expectations of treatment.

NICE Guidelines (2009<sub>a</sub>) propose that the cultural needs of individuals with DM should be considered in the provision of information, treatment and care that they receive. A model for the development of cultural competence within healthcare services has been proposed (Campinha-Bacote, 2002). Cultural competence is defined as a continuous process, with healthcare services aiming to operate efficiently in consideration of the client's cultural context. This requires a synthesis of cultural awareness, knowledge, skills, encounters and desire. Cultural competence has been suggested as necessary, in order for healthcare services to be culturally receptive (Campinha-Bacote, 2002).

Healthcare services should ensure, in accordance with NICE Guidelines (2009<sub>b</sub>) that they assess men with DM for ED, and inform them about the potential origins of and also treatment options for this condition. It is particularly important that healthcare professionals initiate this discussion and provide appropriate education, as embarrassment may hinder help-seeking behaviour initially. Additionally, despite men in this study demonstrating acceptance of ED and limited control, they expressed hope for treatments, although they were unclear of the effectiveness or availability of these.

As such, it is the responsibility of the healthcare provider to empower men to seek help, through education about ED, particularly when South Asian men with DM appear to adopt an external locus of control regarding their ED.

There are implications to be considered in light of the differences in ethnicity, gender and age between participants and the researcher. Due to these differences, in that the researcher was White British, female and of a younger age than participants, the researcher made assumptions about aspects of the research. She had anticipated that older men, with potentially variable cultural beliefs and practices to herself, may find it difficult or uncomfortable discussing as sensitive a subject as ED with her. As ED is a condition only experienced by males, she assumed that men may feel more comfortable discussing their experience of this condition with another male, who they may have felt could have better related to this experience. As such, the researcher anticipated that these differences could be a potential obstacle to recruitment.

As recruitment began and the study progressed, men were willing to discuss their ED with the researcher and thus participated in the study, despite her difference in age, gender and ethnicity. Participants appeared comfortable discussing ED with the researcher, expressing no embarrassment but emphasising the professional context of such discussions. As such, the differences between the researcher and the participants allowed what may be common assumptions about conducting research in sensitive subject areas to be challenged. By not conforming to these assumptions, the researcher was able to demonstrate that although some men may feel uncomfortable discussing ED with a female, who is younger and of a different culture, that others do not. Although there were men who declined to take part in the current study, one cannot assume that this was due to the researcher's gender, age or ethnicity. Therefore, healthcare professionals who directly support men with DM should not make assumptions about the willingness of men to discuss ED, based on age, gender or culture. As such, these healthcare professionals should initiate conversations about ED, to explore the individual's experience and perceptions about ED, including that of discussing ED, thus avoiding generalised assumptions about these discussions.

The semi-structured interview developed for this study was informed by Leventhal's Self-Regulatory Model (Leventhal, Nerenz, & Steele, 1984; Moss-Morris et al., 2002; Leventhal, 1997) as a means of utilising an underpinning theoretical model to understand the experiences of South Asian men with DM and ED. This model was a useful framework from which to explore these experiences, as it offered an understanding of the perceptions that these men had about their health conditions as well as how these perceptions may subsequently impact on their coping and health behaviours (Leventhal, Nerenz, & Steele, 1984; Moss-Morris et al., 2002; Leventhal, 1997) e.g. willingness to discuss ED or seek treatment. As such, it guided useful clinical implications such as the initiation of ED discussions by healthcare professionals working with men with DM. However, the exploration of the experiences of South Asian men with DM and ED was arguably restricted by the specific focus and scope of one theoretical model. Despite this limitation, the current study highlighted the utility of employing an underpinning model, as a means of structurally guiding the exploration of experiences such that important clinical implications could be theoretically supported.

### **Study Limitations**

There are a number of limitations to the current study. Firstly, it aimed to explore the experiences of South Asian men with DM and ED. The ethnicity of the men that chose to participate in this study was Pakistani and thus it is difficult to generalise the findings to British South Asian men with DM and ED in other South Asian communities. This is important to consider, as there will exist heterogeneity in the health beliefs of South Asian men (Lucas, Murray & Kinra, 2013). As such, there are limitations to the use of the term 'South Asian' in the current study, as it homogenises a group of individuals who differ in their country of origin, their cultures (NHS Choices, 2014) and who therefore may have different health beliefs (Lucas et al. 2013).

However, the term ‘South Asian’ encompasses the homogenous qualities of this group of individuals e.g. increased risk of developing health conditions such as DM (NHS Choices, 2014) and as such the findings of the current study may be generalised to a wider population of men who are at greater risk of developing DM (NHS Choices, 2014) and arguably therefore ED (Diabetes.co.uk, 2014<sub>b</sub>). Additionally, the findings cannot be generalised to men with DM and ED in other cultural populations. However, the rationale for only including South Asian men in the current study was that there appears to be no existing literature that investigates the experiences of these men, who are more likely to develop DM (NHS Choices, 2014) and arguably ED as a subsequent complication (Diabetes.co.uk, 2014<sub>b</sub>).

Although all participants were English-speaking, there were times throughout the interviews when individuals struggled to comprehend the questions being asked of them, such that the researcher had to re-phrase them in order to facilitate a better understanding. IPA adopts a double hermeneutic, such that the researcher attempts to make sense of the ways in which the individual makes sense of their experiences (Smith & Osborn, 2003). Therefore, one must consider the impact of misinterpretation on the validity of the analysis, particularly where there were potential language barriers. IPA adopts a subjective interpretation of qualitative data (Smith & Osborn, 2003). A relativist stance posits that there exists no absolute truth, but that reality is known through subjective experience, thus shaped by culture (Rorty, 1991).

The researcher’s subjective assumptions and experiences of reality may have arguably impacted on the interpretation of the data, throwing into question the reliability of the findings. However, the researcher attempted to address this issue with the involvement of a qualified Consultant Clinical Health Psychologist, who reviewed three of the six interview transcripts.

Participants were recruited from a DM and ED clinic, thus they were all actively help-seeking. It is therefore difficult to ascertain to what extent the findings of this study could be generalised to South Asian men with DM and ED, who are not actively treatment-seeking for their ED. This is particularly poignant as research has shown that men's perceptions about ED can impact on help-seeking (Shabsigh et al., 2004). Additionally, participants volunteered to participate in the current study and were therefore willing to discuss their ED with the researcher. As such, the findings cannot be generalised to South Asian men with DM and ED who are not willing to discuss their ED. The findings of the current study cannot be generalised to younger men, as participants were aged forty plus. Additionally, the majority of participants were T2DM, with only one participant being T1DM. Therefore, consideration should be given to the generalisability of the findings to men with ED and T1DM.

The current study has adopted a medical view of ED, in that it has been defined as a medical condition that can be assessed for and treated in men. Medically defining ED is arguably useful, as it conveys to men that they can approach healthcare services to receive information about this condition as well as medical treatment for it. However, by defining ED as a medical condition, it is possibly less normalising for men, despite it being a commonly occurring condition in men between the ages of forty and seventy (NHS Choices, 2012<sub>a</sub>) and one which is predicted to increase in prevalence with the ageing population (Nehra & Kulaksizoglu, 2002). Therefore, defining ED in this way may enhance any stigma or embarrassment surrounding this condition, as well as reinforce ED as a 'problem' to be solved via the support of external sources. This may arguably result in men perceiving to have limited personal control over the condition, despite the varied organic and psychological causes of ED (Aikey, 1992).

### **Future research**

The direction of future research can be informed by limitations of the current study. To further build on the generalisability of current findings, future research could look to investigate these experiences in men with DM and ED, from additional South Asian communities. The rationale for doing this is that there has been argued to be more intra- than inter-ethnic diversity existent (Campinha-Bacote, 2002), as well as proposed differences in health beliefs amongst South Asian men (Lucas, Murray & Kinra, 2013). Having a greater understanding of the potentially variable experiences and illness perceptions of South Asian men with DM and ED could contribute to the evolving cultural competence of healthcare providers (Campinha-Bacote, 2002) and inform culturally appropriate service provision.

Future research could attempt to explore the experiences of South Asian men with DM and ED who are not actively help-seeking, as these men may have different experiences and perceptions of ED. This is poignant, as Leventhal's Self-Regulatory Model (Leventhal, Nerenz & Steele, 1984) posits that illness perceptions inform subsequent health behaviours and research has highlighted the impact that perceptions of ED can have on help-seeking behaviour (Shabsigh et al., 2004).

Finally, future research should also look to explore the above recommendations, but across a wider age range than was employed within the current study. As the findings of the current study showed that South Asian men may perceive ED to be inevitable due to increasing age, it would be beneficial to investigate the perceptions of men of a younger age. Overall, future research could provide greater scope of the experiences of South Asian men with DM and ED, of a variety of ages, from different communities and who may or may not be help-seeking for their ED. Additionally, the experiences of South Asian men with ED and T2DM or ED and T1DM could be explored.

## **Conclusion**

Findings suggest that ED has a significant impact on the QoL of South Asian men with DM. These men described having limited control over what is perceived to be an enduring condition. They demonstrated acceptance of their ED, whilst remaining hopeful of treatment. Although they appeared to have some knowledge about the potential causes of and treatment options for ED, these men expressed uncertainties. They emphasised the importance of education and knowledge about ED for those with DM, as well as the initiation of a discussion about ED by healthcare professionals. Healthcare providers should consider the impact that ED can have on the experiences of South Asian men with DM. Assessment of and education about ED for men with DM should be initiated by those healthcare professionals who directly support men with DM. These healthcare professionals should do so during their initial consultations with these men. Healthcare providers should focus on the development of culturally competent service provision, issuing men with DM appropriate information about ED and options for treatment.

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## Appendix A – Guideline for Authors for the Journal of Clinical Psychology

### **Manuscript Submission**

Manuscripts for submission to *The Journal of Clinical Psychology* should be forwarded to the Editor as follows:

1. Go to your Internet browser (e.g., Netscape, Internet Explorer).
2. Go to the URL <http://mc.manuscriptcentral.com/jclp>
3. Register (if you have not done so already).
4. Go to the Author Center and follow the instructions to submit your paper.
5. Please upload the following as separate documents: the title page (with identifying information), the body of your manuscript (containing no identifying information), each table, and each figure.
6. Please note that this journal's workflow is double-blinded. Authors must prepare and submit files for the body of the manuscript that are anonymous for review (containing no name or institutional information that may reveal author identity).
7. All related files will be concatenated automatically into a single .PDF file by the system during upload. This is the file that will be used for review. Please scan your files for viruses before you send them, and keep a copy of what you send in a safe place in case any of the files need to be replaced.

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## **Manuscript Preparation**

**Format** . Number all pages of the manuscript sequentially. Manuscripts should contain each of the following elements in sequence: 1) Title page 2) Abstract 3) Text 4) Acknowledgments 5) References 6) Tables 7) Figures 8) Figure Legends 9) Permissions. Start each element on a new page. Because the Journal of Clinical Psychology utilizes an anonymous peer-review process, authors' names and affiliations should appear ONLY on the title page of the manuscript. Please submit the title page as a separate document within the attachment to facilitate the anonymous peer review process.

**Style** . Please follow the stylistic guidelines detailed in the Publication Manual of the American Psychological Association, Sixth Edition, available from the American Psychological Association, Washington, D.C. Webster's New World Dictionary of American English, 3rd College Edition , is the accepted source for spelling. Define unusual abbreviations at the first mention in the text. The text should be written in a uniform style, and its contents as submitted for consideration should be deemed by the author to be final and suitable for publication.

**Reference Style and EndNote** . EndNote is a software product that we recommend to our journal authors to help simplify and streamline the research process. Using EndNote's bibliographic management tools, you can search bibliographic databases, build and organize your reference collection, and then instantly output your bibliography in any Wiley journal style. Download Reference Style for this Journal: If you already use EndNote, you can download the reference style for this journal. How to Order: To learn more about EndNote, or to purchase your own copy, click here . Technical Support: If you need assistance using EndNote, contact [endnote@isiresearchsoft.com](mailto:endnote@isiresearchsoft.com) , or visit [www.endnote.com/support](http://www.endnote.com/support) .

**Title Page** . The title page should contain the complete title of the manuscript, names and affiliations of all authors, institution(s) at which the work was performed, and name, address (including e-mail address), telephone and telefax numbers of the author responsible for correspondence. Authors should also provide a short title of not more than 45 characters (including spaces), and five to ten key words, that will highlight the subject matter of the article. Please submit the title page as a separate document within the attachment to facilitate the anonymous peer review process.

**Abstract**. Abstracts are required for research articles, review articles, commentaries, and notes from the field. A structured abstract is required and should be 150 words or less. The headings that are required are:  
 Objective(s): Succinctly state the reason, aims or hypotheses of the study.  
 Method (or Design): Describe the sample (including size, gender and average age), setting, and research design of the study.  
 Results: Succinctly report the results that pertain to the expressed objective(s).  
 Conclusions: State the important conclusions and implications of the findings.

In addition, for systematic reviews and meta-analyses the following headings can be used, Context; Objective; Methods (data sources, data extraction); Results; Conclusion. For Clinical reviews: Context; Methods (evidence acquisition); Results (evidence synthesis); Conclusion.

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**Final Revised Manuscript** . A final version of your accepted manuscript should be submitted electronically, using the instructions for electronic submission detailed above.

**Artwork Files** . Figures should be provided in separate high-resolution EPS or TIFF files and should not be embedded in a Word document for best quality reproduction in the printed publication. Journal quality reproduction will require gray scale and color files at resolutions yielding approximately 300 ppi. Bitmapped line art should be submitted at resolutions yielding 600-1200 ppi. These resolutions refer to the output size of the file; if you anticipate that your images will be enlarged or reduced, resolutions should be adjusted accordingly. All print reproduction requires files for full-color images to be in a CMYK color space. If possible, ICC or ColorSync profiles of your output device should accompany all digital image submissions. All illustration files should be in TIFF or EPS (with preview) formats. Do not submit native application formats.

**Software and Format** . Microsoft Word is preferred, although manuscripts prepared with any other microcomputer word processor are acceptable. Refrain from complex formatting; the Publisher will style your manuscript according to the journal design specifications. Do not use desktop publishing software such as PageMaker or Quark XPress. If you prepared your manuscript with one of these programs, export the text to a word processing format. Please make sure your word processing program's "fast save" feature is turned off.

Please do not deliver files that contain hidden text: for example, do not use your word processor's automated features to create footnotes or reference lists.

## **Article Types**

**Research Articles** . Research articles may include quantitative or qualitative investigations, or single-case research. They should contain Introduction, Methods, Results, Discussion, and Conclusion sections conforming to standard scientific reporting style (where appropriate, Results and Discussion may be combined).

**Review Articles** . Review articles should focus on the clinical implications of theoretical perspectives, diagnostic approaches, or innovative strategies for assessment or treatment. Articles should provide a critical review and interpretation of the literature. Although subdivisions (e.g., introduction, methods, results) are not required, the text should flow smoothly, and be divided logically by topical headings.

**Commentaries** . Occasionally, the editor will invite one or more individuals to write a commentary on a research report.

**Editorials** . Unsolicited editorials are also considered for publication.

**Notes From the Field.** Notes From the Field offers a forum for brief descriptions of advances in clinical training; innovative treatment methods or community based initiatives; developments in service delivery; or the presentation of data from research projects which have progressed to a point where preliminary observations should be disseminated (e.g., pilot studies, significant findings in need of replication). Articles submitted for this section should be limited to a maximum of 10 manuscript pages, and contain logical topical subheadings.

**News and Notes.** This section offers a vehicle for readers to stay abreast of major awards, grants, training initiatives; research projects; and conferences in clinical psychology. Items for this section should be summarized in 200 words or less. The Editors reserve the right to determine which News and Notes submissions are appropriate for inclusion in the journal.

### **Editorial Policy**

Manuscripts for consideration by the *Journal of Clinical Psychology* must be submitted solely to this journal, and may not have been published in another publication of any type, professional or lay. This policy covers both duplicate and fragmented (piecemeal) publication. Although, on occasion it may be appropriate to publish several reports referring to the same data base, authors should inform the editors at the time of submission about all previously published or submitted reports stemming from the data set, so that the editors can judge if the article represents a new contribution. If the article is accepted for publication in the journal, the article must include a citation to all reports using the same data and methods or the same sample. Upon acceptance of a manuscript for publication, the corresponding author will be required to sign an agreement transferring copyright to the Publisher; copies of the Copyright Transfer form are available from the editorial office. All accepted manuscripts become the property of the Publisher. No material published in the journal may be reproduced or published elsewhere without written permission from the Publisher, who reserves copyright.

Any possible conflict of interest, financial or otherwise, related to the submitted work must be clearly indicated in the manuscript and in a cover letter accompanying the submission. Research performed on human participants must be accompanied by a statement of compliance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and the standards established by the author's Institutional Review Board and granting agency. Informed consent statements, if applicable, should be included with the manuscript stating that informed consent was obtained from the research participants after the nature of the experimental procedures was explained.

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## Appendix B - Quality assessment tool for quantitative studies

### Quality Assessment Tool for Quantitative Studies

A 'Yes' response is awarded a score of '1'.

A 'No' response is awarded a score of '0'.

If the answer to an item is 'Unsure/Unable to determine', this is also awarded a score of '0'.

Maximum quality score = 19

1. Is a clear rationale for the study presented?
2. Is the aim/objective of the study clearly described?

#### External Validity

##### *Source Population*

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

##### *Description of eligibility*

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

##### *Participants and non-responders*

6. Is the response rate specified, >70, or is information on non-responders sufficient to make inference on the representativeness of the sample?

##### *Description of study period?*

7. Is the study period specified?

##### *Description of study population?*

8. Are important population characteristics<sup>a</sup> 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<sup>b</sup> clearly specified?
11. Is the measurement instrument described and/or its psychometric properties reported?

### ***Definitions***

12. Is a definition of erectile dysfunction stated?

### ***Data analysis and reporting***

13. Do the statistics add clarity/increase confidence in the data?  
 14. Have actual probability values been reported (e.g. 0.035 rather than  $<0.05$ ) for the main outcomes, except where the probability value is less than 0.001? <sup>c</sup>

### ***Informativity***

15. Are the findings of the study described with reference to the original aims of the study?  
 16. Are the conclusions clearly supported by the data reported or with reference to previous research?  
 17. Are the implications of the findings discussed and any limitations considered?<sup>d</sup>  
 18. Has further research needed been identified?

### ***Ethical Approval***

19. Has the study stated that it has gained ethical approval?

<sup>a</sup>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.

<sup>b</sup>Questionnaire, interview, focus groups.

<sup>c</sup>If not applicable, score '1' by default.

<sup>d</sup>Must include both implications and limitations to score '1'.

This quality assessment tool was adapted from the adapted version of Prins et al. (2002) Criteria for methodological quality assessment of prevalence studies by Orchard (2008). Elements of the Down's and Black (1998) quality assessment checklist were also incorporated into the above quality assessment tool.

## Appendix B - Quality assessment tool for quantitative studies

<b>Quality Assessment Item Quantitative Studies</b>	<b>Zhang, Yu, He &amp; Jin (2014)</b>	<b>Matic &amp; McCabe (2008)</b>	<b>Gülpinar, Haliloglu, Abdulmajed, Boga &amp; Yaman (2012)</b>	<b>Stamogiannou, Grunfeld, Denison &amp; Muir (2005)</b>	<b>Perelman, Shabsigh, Seftel, Althof &amp; Lockhart (2005)</b>	<b>Giuliano et al. (2002)</b>	<b>Lyngdorf &amp; Hemmingsen (2004)</b>	<b>Shabsigh, Perelman, Laumann &amp; Lockhart (2004)</b>	<b>Fisher, Rosen, Eardley, Niederberger, Nadel, Kaufman &amp; Sand (2004)</b>	<b>Wong, Tan, Low &amp; Ng (2008)</b>
1. Rationale										
2. Aim/objective										
3. Representative sample										
4. Age Range										
5. Inclusion/ Exclusion Criteria										
6. Response rate										
7. Study period										
8. Population characteristics										
9. Country of population										
10. Data collection method										

11. Measurement instrument										
12. ED definition										
13. Clarity of statistics										
14. Probability values										
15. Study findings										
16. Conclusions										
17. Implications/ Limitations										
18. Further research										
19. Ethical approval										
<b>Total Quality Score</b>										

Appendix C - Quality assessment tool for qualitative studies

A 'Yes' response is awarded a score of '1'.

A 'No' response is awarded a score of '0'.

If the answer to an item is 'Unsure'/'Unable to determine', this is also awarded a score of '0'.

Maximum score = 34.

		<b>Quality Assessment Item</b>	<b>Low, Ng, Choo &amp; Tan (2006)</b>	<b>Tomlinson &amp; Wright (2004)</b>	<b>Pontin, Porter &amp; McDonagh (2002)</b>
<b>Theoretical approach:</b>	<b>Is a qualitative approach appropriate?</b>	Does the research question seek to understand processes and structure, or to highlight subjective experience or meanings?			
	<b>Is the study clear in what it seeks to do?</b>	Are there clear aims/objectives/research questions?			
		Is there adequate/appropriate reference to literature?			
		Are underpinning assumptions/values/theories discussed?			
<b>Study Design:</b>	<b>How defensible/rigorous is the research design/methodology?</b>	Is the design appropriate to the research question?			
		Is a rationale provided for the use of a qualitative approach?			
		Are there clear rationales/justifications for the sampling, data collection and data analysis methods used?			



<b>Data Collection:</b>	<b>How well was the data collection carried out?</b>	Is there a clear description of the data collection methods?			
		Was the data collected appropriate to answer the research question(s)?			
<b>Validity:</b>	<b>Is the role of the researcher clearly described?</b>	Has the relationship between the researcher and participant been adequately considered?			
		Does the study describe how the research was explained and presented to participants?			
	<b>Is the context clearly described?</b>	Are the characteristics of the participants clearly defined?			
		Are the inclusion and exclusion criteria for participation clearly described?			
		Is the sample representative of the population of interest?			
		Are the characteristics of the settings clearly described?			
		Was context bias considered? (E.g. did the author consider the influence of the setting of the study?)			
	<b>Were the methods reliable?</b>	Were data collected by more than one method?			
		Do the methods investigate what they claim to?			
<b>Analysis</b>	<b>Is the data analysis sufficiently rigorous?</b>	Is the procedure for data analysis clear?			
		Is the analysis systematic/reliable/dependable?			

		Is it clear how the themes and concepts were derived from the data?			
	<b>Is the data ‘rich’?</b>	Is the data ‘rich’? (E.g. has the diversity of perspective and content been explored? How well have the detail and depth been demonstrated?)			
	<b>Is the analysis reliable?</b>	Did more than one researcher theme and code transcripts/data?			
	<b>Are the findings clearly presented?</b>	Are the findings clearly presented?			
		Are extracts from the original data included?			
		Are the data appropriately referenced?			
		Is the reporting clear and coherent?			
		Are the findings relevant to the aims of the study?			
		Are there clear links between data, interpretation and conclusion?			
		Are the conclusions plausible?			
		Does this study enhance understanding of the research subject?			
		Are the implications of the study clearly defined?			
		Is there adequate discussion of limitation encountered?			
<b>Ethics</b>	<b>Ethical Approval</b>	Is there a statement about Ethical Approval?			
		<b>Total Quality Assessment Score</b>			

### Appendix D - Quality assessment scores for quantitative studies

Quality Assessment Item	Zhang, Yu, He & Jin (2014)	Matic & McCabe (2008)	Gülpinar, Haliloglu, Abdulmajed, Boga & Yaman (2012)	Stamogiannou, Grunfeld, Denison & Muir (2005)	Giuliano et al. (2002)	Perelman, Shabsigh, Seftel, Althof & Lockhart (2005)	Lyngdorf & Hemmingsen (2004)	Shabsigh, Perelman, Laumann & Lockhart (2004)	Fisher, Rosen, Eardley, Niederberger, Nadel, Kaufman & Sand (2004)	Wong, Tan, Low & Ng (2008)
1. Rationale	1/1	1/1	1/1	1/0	1	1	1	1	1	1
2. Aim/objective	1/1	1/1	1/1	1/1	1	1	1	1	1	1
3. Representative sample	0/0	0/0	0/0	0/0	1	0	0	0	1	0
4. Age Range	1/1	1/1	1/1	1/1	0	1	1	1	1	1
5. Inclusion/ Exclusion Criteria	0/0	1/0	1/0	0/0	0	0	0	0	0	0
6. Response rate	0/0	0/0	0/1	1/1	0	0	0	0	0	0
7. Study period	1/1	0/0	0/1	0/0	1	0	0	1	1	0
8. Population characteristics	1/1	1/0	1/1	1/1	1	1	1	1	1	1
9. Country of population	1/1	1/1	1/1	1/1	1	1	1	1	1	1
10. Data collection method	1/1	1/1	1/1	1/1	1	1	1	1	1	1

11. Measurement instrument	1/1	1/1	1/1	1/1	1	1	1	1	1	1
12. ED definition	0/0	0/0	0/0	1/1	1	1	1	1	1	0
13. Clarity of statistics	0/1	1/1	1/1	1/1	1	1	1	1	1	1
14. Probability values	1/1	0/0	1/1	1/0	0	1	0	1	1	1
15. Study findings	1/1	1/1	1/1	1/1	1	1	1	1	1	1
16. Conclusions	1/1	1/1	1/1	1/1	1	1	1	1	1	1
17. Implications/ Limitations	1/1	1/0	1/1	1/1	1	1	0	1	1	1
18. Further research	1/0	1/1	0/0	0/0	0	1	0	1	1	1
19. Ethical approval	1/1	0/0	1/1	1/1	1	0	0	0	0	0
<b>Total Quality Score</b>	<b>14/15</b>	<b>13/10</b>	<b>14/15</b>	<b>15/13</b>	<b>14</b>	<b>14</b>	<b>11</b>	<b>15</b>	<b>16</b>	<b>13</b>

For those studies whose quality was rated by both independent raters, such that they were given two scores, the score issued by the second rater is the score on the right.

# Appendix E - Quality assessment scores for qualitative studies

A 'Yes' response is awarded a score of '1'.

A 'No' response is awarded a score of '0'.

If the answer to an item is 'Unsure', this is also awarded a score of '0'.

Maximum score = 34.

		Quality Assessment Item	Low, Ng, Choo & Tan (2006) [11]	Tomlinson & Wright (2004) [12]	Pontin, Porter & McDonagh (2002) [13]
<b>Theoretical approach:</b>	<b>Is a qualitative approach appropriate?</b>	Does the research question seek to understand processes and structure, or to highlight subjective experience or meanings?	1/1	1/1	1/1
	<b>Is the study clear in what it seeks to do?</b>	Are there clear aims/objectives/research questions?	1/1	1/1	1/1
		Is there adequate/appropriate reference to literature?	1/1	1/1	1/1
		Are underpinning assumptions/values/theories discussed?	1/0	1/1	1/0
<b>Study Design:</b>	<b>How defensible/rigorous is the research design/methodology?</b>	Is the design appropriate to the research question?	1/1	1/1	1/1
		Is a rationale provided for the use of a qualitative approach?	1/1	1/1	0/1
		Are there clear rationales/justifications for the sampling, data collection and data analysis methods used?	0/0	1/1	0/1

<b>Data Collection:</b>	<b>How well was the data collection carried out?</b>	Is there a clear description of the data collection methods?	1/1	1/1	1/1
		Was the data collected appropriate to answer the research question(s)?	1/1	1/1	1/1
<b>Validity:</b>	<b>Is the role of the researcher clearly described?</b>	Has the relationship between the researcher and participant been adequately considered?	0/1	1/0	1/0
		Does the study describe how the research was explained and presented to participants?	0/1	1/1	1/0
	<b>Is the context clearly described?</b>	Are the characteristics of the participants clearly defined?	1/0	1/1	1/1
		Are the inclusion and exclusion criteria for participation clearly described?	1/0	1/0	0/1
		Is the sample representative of the population of interest?	0/0	0/0	0/0
		Are the characteristics of the settings clearly described?	0/1	1/1	0/0
		Was context bias considered? (E.g. did the author consider the influence of the setting of the study?)	0/1	0/0	0/1
	<b>Were the methods reliable?</b>	Were data collected by more than one method?	0/0	0/0	0/0
		Do the methods investigate what they claim to?	1/1	1/1	1/1
<b>Analysis</b>	<b>Is the data analysis sufficiently rigorous?</b>	Is the procedure for data analysis clear?	1/1	1/1	1/1
		Is the analysis systematic/reliable/dependable?	1/1	1/1	1/1
		Is it clear how the themes and concepts were derived from the data?	1/1	1/1	1/1

	<b>Is the data ‘rich’?</b>	Is the data ‘rich’? (E.g. has the diversity of perspective and content been explored? How well have the detail and depth been demonstrated?)	1/1	1/1	1/1
	<b>Is the analysis reliable?</b>	Did more than one researcher theme and code transcripts/data?	1/0	1/1	0/1
	<b>Are the findings clearly presented?</b>	Are the findings clearly presented?	1/1	1/1	1/1
		Are extracts from the original data included?	1/1	1/1	1/1
		Are the data appropriately referenced?	1/1	0/1	1/1
		Is the reporting clear and coherent?	1/1	1/1	1/1
		Are the findings relevant to the aims of the study?	1/1	1/1	1/1
		Are there clear links between data, interpretation and conclusion?	1/1	1/1	1/1
		Are the conclusions plausible?	1/1	1/1	1/1
		Does this study enhance understanding of the research subject?	1/1	1/1	1/1
		Are the implications of the study clearly defined?	1/1	1/1	1/1
		Is there adequate discussion of limitation encountered?	0/1	0/0	1/0
<b>Ethics</b>	<b>Ethical Approval</b>	Is there a statement about Ethical Approval?	1/0	0/0	1/1
		<b>Total Quality Assessment Score</b>	<b>26/26</b>	<b>28/27</b>	<b>26/27</b>

Adapted version of the NICE qualitative research quality assessment tool (2009).

Quality assessment scores on the right are those that were issued by the second independent rater.

## Appendix F – Epistemological statement

Epistemology is an aspect of philosophy that focuses on the understanding of knowledge, particularly with regard to what and by which means one can know something (Willig, 2001). It contemplates the essence of knowledge (BonJour, 2010), in as much as its breadth and the extent to which it can be considered reliable or valid (Willig, 2001).

Before embarking on the research process, one must endorse an epistemological viewpoint. In doing so, one considers what it is that the research is looking to investigate and the feasibility of acquiring such knowledge. As such, it is important to have a rationale for the research methodology employed, as this aids the quest of seeking answers to the research question/s proposed (Willig, 2001).

The current study aimed to investigate the experiences of South Asian men with diabetes mellitus (DM) and erectile dysfunction (ED). In approaching this question, a relativist stance was adopted, which posits that the means by which truth or reality is known is subject to the individual's experience (Rorty, 1991). Therefore, there exists no absolute truth and thus the experience of reality may vary between individuals and cultures (Rorty, 1991). Therefore, with a view to exploring individual's experiences and interpretations of their subjective world, the adoption of qualitative methodology was deemed most appropriate (Ashworth, 2008). Following from this, interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009) was the specific qualitative methodology of choice.



IPA is concerned with the ways in which individuals comprehend their subjective world, with a view to understanding the significance attached to their experiences (Smith & Osborn, 2008).

IPA has a number of underlying theoretical assumptions. The first is phenomenology, which is concerned with the significant factors that contribute to the lived experience of human beings. The second is hermeneutics, which is concerned with interpretation. IPA has been proposed to employ a double hermeneutic in that the researcher attempts to make sense of the means by which the individual makes sense of their experiences. The third is idiography, which focuses on that which is particular. This refers to IPA's attention to detail and analytical depth, as well as its attempt to comprehend the means by which particular individuals within a particular situation understand a particular experience (Smith, Flowers, & Larkin, 2009).

Although the above qualitative approach was deemed most appropriate, the hermeneutic assumption had to be considered. IPA is subject to the researcher's individual interpretation of the participant's experience. In consideration of this potential bias, the decision not to include South Asian men who could not speak English was made, as the use of an interpreter in interviews would have introduced a treble hermeneutic. Thus, this ensured that only a double hermeneutic remained (Smith, Flowers, & Larkin, 2009).

IPA was deemed the most appropriate qualitative methodology to employ, allowing the exploration of the experiences of South Asian men with DM and ED. IPA has previously been utilised for the study of individual's experiences of health and illness (Smith, Flowers, & Larkin, 2009).

This approach was also appropriate as it requires recruitment of small numbers of participants (Smith, Flowers, & Larkin, 2009) and it was anticipated that recruitment would be difficult due to the sensitive nature of the research area. However, it allowed for an in-depth exploration of experiences, arguably providing avenues for future research.

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## Appendix G – Semi-structured interview schedule

Interview Schedule

1. What thoughts do you have about your diagnosis and symptoms of erectile dysfunction?
2. What are your thoughts about the cause/causes of your erectile dysfunction?
3. How long do you think you will experience your erectile dysfunction for?
4. What are the consequences of your erectile dysfunction for you?  
(Physical, psychological, social functioning)
5. To what extent do you believe that you are in control of your erectile dysfunction?
6. To what extent do you believe that your erectile dysfunction can be treated?
7. How does having erectile dysfunction make you feel?
8. How do you cope with your erectile dysfunction?
9. Have you felt embarrassed when discussing erectile dysfunction with another person i.e. a health professional, partner etc?
10. How does having both diabetes mellitus and erectile dysfunction impact on your quality of life?

This interview schedule was developed for this study based on The Self-Regulatory Model and its later additions (Leventhal, Nerenz, & Steele, 1984; Moss-Morris et al., 2002; Leventhal, 1997). It was also informed by service-user feedback.

## Appendix H – Service-user involvement

The researcher attended a meeting held by a local DM support group on 15<sup>th</sup> November 2012 to discuss the aims, design and methodology of the current study. In attendance were both men and women, including those with DM and spouses of those with DM. During this meeting, the researcher was able to share the originally constructed semi-structured interview schedule with members of the group and to ask for feedback regarding the appropriateness of the questions listed. Many group members had no comments to make, whilst others commented that the questions appeared appropriate and most importantly there were no objections to any of the questions being asked. This was important to consider, given the sensitive nature of the study.

One member of the group proposed that the first original question presented (*'Please describe what you know about erectile dysfunction.'*) felt as though one's knowledge was being tested and so this question was removed from the interview schedule. Use of the word "beliefs" in the question *'What beliefs do you have about your diagnosis and symptoms of erectile dysfunction?'* was suggested to be confusing, as it was thought to be referring to religious beliefs. The researcher amended the question to *"What are your thoughts about the cause/causes of your erectile dysfunction?"* One member expressed that question 2 be deleted due to its similarity to the first original question. However, question one was removed instead, due to the feedback that it stood to test one's knowledge of ED. It was suggested that "a question regarding patient embarrassment of speaking to either a health professional or to even a partner?" be featured. Therefore, the question *'Have you felt embarrassed when discussing erectile dysfunction with another person i.e. a health professional, partner etc.?'* was added to the interview schedule.

## Appendix I – Documentation for Ethical Approval

*Removed for hard binding*

## Appendix J – Participant information sheet

### **The experiences of South Asian men with diabetes mellitus and erectile dysfunction.**

I would like to invite you to take part in my research study. Before you agree to take part, I would like you to understand why the research is being done and what you will be asked to do if you choose to take part. Your Diabetes Specialist Nurse in the BEDDS clinic will go through this information sheet with you and answer any questions that you might have. Please talk to others about the study if you wish.

#### **Purpose and aims of the research**

This research study is being conducted as part of the Doctorate in Clinical Psychology programme at the University of Hull.

The World Health Organisation suggests that within the UK, there are 2.9 million people with diabetes mellitus (DM). This is predicted to rise by 47% by the year 2025. South Asian people are more likely to develop DM than people who are white British and so will be greatly affected by the rise of DM in the population, including its associated complications. A complication of DM is erectile dysfunction (ED).

Research has shown that men with DM and ED think that their ED is important. For men with DM, ED can negatively affect their lives if left untreated. What these men think about their DM and ED can affect how they feel.

It is therefore important to have a better understanding of what South Asian men think about their DM and ED, how this may affect how they feel and how it may affect their lives. This may then help healthcare staff to provide better services to meet peoples' needs.

#### **How the research will be carried out**

This research study will involve you taking part in an interview which will be about 1 hour long and will be audio-recorded. During the interview, you will be asked to talk about your DM and ED and how they have affected how you feel and your life. The data collected during the interview will be transcribed, which means that the information audio-recorded from the interview will be changed into a written format. We will then analyse this information, along with other people's, to see the main things that people say about how their DM and ED has affected how they feel and their lives.

If you agree to take part in the research study, you will be asked to sign a form that you consent (agree) to take part. You will be asked some information about yourself, including the treatments you have tried.

All of the personal and sensitive data and information obtained about you during the study will be made anonymous and will be kept confidential. This means that the information about you will not be shared with other people. However, in the event that you disclose a criminal offence, intent to harm yourself or others, I will have to share this information with appropriate others. This will be discussed with you if this occurs. You have the right to withdraw from the study at any point. You have the right to withdraw your personal and sensitive information and data from the study, up until the point of transcription, if you wish to. This would not affect the standard of care that you receive.

### **Why have I been asked?**

You have been invited to take part in this study, as you are of South Asian ethnicity and you have a diagnosis of DM and ED. Your Diabetes Specialist Nurse in the BEDDS clinic has identified you as a potential participant of the study. You are receiving information about the study so that you can decide if you would like to take part. It is completely your decision as to whether you decide to take part in this study.

### **What will happen?**

Once you have read this information sheet, if you decide that you do not wish to take part in this study, you can choose this option below. However, if you are unsure or would like the chance to ask some more questions about the study, we will contact you in the next week of you having received and read this information sheet. You can indicate below whether you would like to be contacted by a Diabetes Specialist Nurse in the BEDDS clinic or the researcher. When contact is made, you will be given the opportunity to ask any further questions. If you decide at this point that you would like to take part in the study, then a date and time to take part in the interview will be agreed with you.

On the day that you come to take part in the study, before the interview begins, you will be asked some information about yourself such as your age and you will be asked to sign a form to consent (agree) to take part. The interview will last for about 1 hour. You will be asked to talk about your DM and ED and how they have affected how you feel and your life. If any concerns arise during the interview, about your mental or physical health, with your consent (agreement), this information will be passed onto a Diabetes Specialist Nurse in the BEDDS clinic, who will be able to offer you support and advice. This will be at the time of the interview if a Diabetes Specialist Nurse in the BEDDS clinic is available or a time will be arranged.

Once the interview has finished, you will be asked if you would like to be informed of the findings of the study. If you decide that you would like to be informed, you will be asked to provide an address for the findings to be sent to you in writing.

### **How will the research be used?**

This research is being carried out as part of a Doctorate in Clinical Psychology course at the University of Hull. The research submitted will be anonymised to ensure the confidentiality of the information provided.

You are free to withdraw your data from the study, up until the point of transcription. After this, information is completely anonymous. This research will be submitted to be published. If the research is published then it will be accessible to anyone who may be interested in reading it, although no-one will be able to be identified from it in any way.

### **Potential advantages/disadvantages of participating in this study**

A potential disadvantage to you participating in this study is that you may experience some distress when discussing how your DM and ED may be affecting you. If this happens you are free to stop the interview at any time and/or you will be able to access support and advice from a Diabetes Specialist Nurse in the BEDDS clinic after the interview.

If you do choose to take part in this study, your experiences will hopefully help to provide a greater understanding of how DM and ED may be affecting the lives of South Asian men. If your experiences are better understood, it is hoped that this will help healthcare staff to provide better services to meet peoples' needs. Additionally, you may find discussing how your DM and ED has affected your life helpful.

**What will happen if concerns/problems arise?**

If you experience any problems whilst you are taking part in the study, please feel free to contact me on the details provided below. I will do the best that I can to answer any questions that you have. If you wish to make any formal complaint during the course of the study, you can do this by contacting the NHS Patient Advice and Liaison Service (PALS).

**How is this research funded?**

This research is funded by the University of Hull, as part of the Doctorate in Clinical Psychology course.

**Who is reviewing this research study?**

Research that is carried out within the NHS must be approved by a Research Ethics Committee. This is in order to protect the interests of anyone taking part in the research. This research study has been reviewed and has been given a favourable opinion by Yorkshire and The Humber: Sheffield Research Ethics Committee.

**What happens now?**

We would like to know if you would be interested in taking part in this study. Please indicate below how you would prefer to be contacted by ticking the appropriate box:

☐

I would like a Diabetes Specialist Nurse in the BEDDS clinic to telephone/email me

☐

I would like the researcher to contact me directly

☐

I would like to contact the researcher directly via telephone

☐

I would not like to be contacted as I do not wish to take part in the study

If you would like to contact the researcher directly, as well to ask any questions about the study, please contact her on the telephone contact number below.

If you would like a Diabetes Specialist Nurse in the BEDDS clinic or the researcher to contact you, please indicate below if you have a preferred day and/or time to be contacted and your preferred telephone contact number and/or email address.

Name:

Telephone number:

Preferred day/time:

Email:



If you decide that you would like to take part in the study, a date, time and place for interview will be agreed.

Thank you for your time.

If you wish to contact me at any point, please do not hesitate to do so using any of the contact details below:

**Researcher:** Chloe O'Brien

**Telephone Contact Number:** 07936525920

**Contact Address:**

Department of Clinical Psychology and Psychological Therapies,  
Hertford Building  
The University of Hull  
Cottingham Road  
Hull  
HU6 7RX

**Email:** C.O'Brien@2011.hull.ac.uk

## Appendix K - Participant consent form

**Consent Form****Title of Project:**

The experiences of South Asian men with diabetes mellitus and erectile dysfunction

**Name of Researcher:**

Chloe O'Brien, Trainee Clinical Psychologist

PLEASE INITIAL  
BOX

1. I confirm that I have read and understand the information sheet dated 27/06/13 (version 2) for the above study. I have had the opportunity to consider the information, and if I have had any questions, these have been answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to a Diabetes Specialist Nurse in the BEDDS clinic being informed of any concerns that arise regarding my well-being so that they can best support me and provide me with advice. ☐
4. I agree to the interview being audio-taped and to the use of verbatim quotation from my interview. ☐
5. I agree to take part in the above study ☐

Name of participant: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Name of person taking consent: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Appendix L - Participant descriptive data collection sheet

Ethnicity	Age	DM Type (1 or 2)	Onset/duration of DM	Onset/duration of ED	Other health condition/difficulties/sexual dysfunction	Treatments tried for ED (successful or not?)	Sexually active? If no, do you want to be?

## Appendix M - Participant request to be informed of the study findings

**Request to be informed of the findings of the study****Name of Researcher:**

Chloe O'Brien, Trainee Clinical Psychologist

**Title of the research study:**

The experiences of South Asian men with diabetes mellitus and erectile dysfunction

If you would like to be informed of the findings of the study, please tick the appropriate box below.

- ☐ I would like to be informed of the findings of the study
- ☐ I would *not* like to receive any further information about the findings of the study

If you have requested to receive further information about the findings of the study, this will be provided in writing by post.

Please provide the address you would like this information sent to.

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You will be contacted with the requested information when data collection and data analysis is complete, which could be anytime between the date of your participation in the study and May 2014.

Name:

Signature:

Date:

## Appendix N - Example of Interpretative Phenomenological Analysis

In stage 1 of the IPA analysis, transcripts were read through, in order that the researcher could immerse themselves in the data. This first stage permits the researcher to actively engage with the data and to initially access the participant's reality. Stage 2 involved the researcher making initial notes on each transcript, including descriptive, linguistic and conceptual comments of interest. Thus, the researcher provides a description of content, analysis of the language utilised and an inquisitive and conceptual exploration of the data respectively. This stage not only allows the researcher to engage with the participant's dialogue in greater detail, but to begin exploring the meaning of it, from an interpretative stance. In stage 3, the researcher identified themes that emerged from the exploratory notes made (Smith, Flowers, & Larkin, 2009).

Emergent themes	Extracts from transcript Participant 4	Initial commentary
<p>ED prevents sexual activity</p> <p>Help-seeking</p>	<p><b><i>Extract one:</i></b></p> <p><i>R: ...what thoughts do you have about your diagnosis and your symptoms of erectile dysfunction?</i></p> <p>P: What do I think about that?</p> <p><i>R: Yeh.</i></p> <p>P: Yeh.</p> <p><i>R: Umm</i></p> <p>P: Yeh, err, I think that ermm, is, is, it's <u>not in good condition physically</u>, yeh. Er, I cannot, er, go ahead w, with the sexual activities, 'cos of this <u>problem</u>. So I just want to, get that <u>sorted really</u>. In a, <u>in any possible way</u>.</p> <p><i>R: Umm</i></p> <p>P: Yeh</p> <p><i>R: Can you tell me a bit more about the thoughts that you have about you, you getting your diagnosis of erectile dysfunction and...</i></p> <p>P: Like, how I've got, how, how I got this problem? You want to...?</p>	<p>ED- physical problem with function – preventing sexual activity. Willing to try <u>any</u> treatments – wants help.</p>

Impact of ED on life	<i>R: [Researcher overlaps with participant's speech] How, yeh what are your thoughts about it? What do you think about it?</i>	ED impacts on life. A
Impact of ED on relationship	P: [Pause] There <u>is lots of thing to think about</u> . Er, <u>they say</u> , because the, that's the <u>kind of thing that effect, effects your life...</u>	lot to think about with ED – big impact? → Who? Does <i>he</i> think this?
Support and protective factors	<i>R: Umm</i> P: ...in a way. But <u>fortunately</u> , er, ermm, <u>I've got wife and she's very friendly and very, very good</u> with me and we've got very, very good relationship, [inaudible verbalisation]...so there's no problem [over?] there. Even we, we, we got in, ah, activities previous night [inaudible] so <u>everything is fine</u> .	ED has not impacted on relationship with wife – participant feel lucky – wife supportive. This is not a problem.
ED as a problem for the sex life.	<i>R: Umm</i> P: But ah, when there's a, but when there's, <u>the matter of sex comes</u> , then er, this, this, <u>this problem</u> , erect, <u>erectile dysfunction affects me a lot and I cannot</u>	ED = problem. ED has a big impact as unable to have sex as a result. Would like help for this.
Impact of ED.	<u>do that</u> , any, any, any further thing. So, just <u>need some help regarding this matter</u> .	No control. → Repetition – emphasis?
Control: ED and solving it.		
Help-seeking.		

	<p><b>Extract two:</b></p> <p><i>R: ...Have you felt embarrassed when discussing erectile dysfunction with another person? So for example, a health professional, or partner, so your wife for example?</i></p>	
Discussion of ED.	<p>P: Errr, no, because we are in the <u>same</u>, same er, er, kind of er, <u>mentality</u>.</p> <p><i>R: Umm</i></p>	No embarrassment to discuss with HCP due to professionalism.
Professionalism as a buffer against embarrassment.	<p>P: So, ermm, there's no problem, psychologically with, with, with her. So everything is OK. Er, as long as the matter, regards the er, <u>discussing the problem with the doctors</u>, I've no problem.</p> <p><i>R: Umm</i></p> <p>P: Yeh, so I can <u>openly</u>, er, discuss this, this problem with the doctors. And er, with <u>the family and friends</u>, never <u>discussed</u>.</p>	<p>Happy to discuss ED with HCP.</p> <p>Not happy to discuss with non-professionals.</p>

In stage 4, the researcher established evident connections between the initial themes.

These patterns enabled the researcher to form clusters of themes, which formed the subordinate themes. Quotes were found to support the themes. Subordinate themes were then organised into overarching superordinate themes (Smith, Flowers, & Larkin, 2009).



Examples of subordinate themes	Supporting Quotes
The Meaning of Sex	<p><i>‘...basic need of a man, if a man doesn’t have this one, mean he’s gonna be affected in lot of ways...’</i></p>
DM vs. The Self	<p><i>‘With diabetes, have to be, I have to be careful ermm, ermm, doing things and to make sure all the time, twenty four hours a day, that I should be in the normal range, because if I’m not in the normal range there could be a, big problem for me.’</i></p>
Judgement Vs. Support	<p><i>‘...if a man doesn’t have this one, mean he’s gonna be affected in lot of ways. Yeh. But, only the thing I’m, I’m, I’m, er, feeling ermm, lucky about that, I’ve got a very good partner and ermm, we are, we are going very good with each others.’</i></p>
Discussing ED	<p><i>‘Everything is confidential so, no, no there’s no problem. I, I, I will discussed and I can discuss with, with doctors er, regarding, these matters.’</i></p>

### Appendix O - Reflective statement

I think back to the departmental Research Fair in my fourth year, terrified at the prospect of having to finalise an area of research for my thesis. Research had never been a great interest of mine. I was far more passionate about the clinical and academic experiences that I was due to endeavour whilst on this three year doctorate. The whole research process from start to finish has been extremely daunting for me and by far the most challenging element of the course. I anticipated that I would be pulled from my comfort zone and invited to really test myself; that I have been. I fully underestimated the time, commitment, motivation, drive and attention to detail that such work requires and demands. Although this has been by far one of the most difficult and all-consuming projects that I have ever embarked on, I have never learnt more about myself and my capabilities. The most important lesson I have learned however, is that patience and determination are key, as research can be uncertain and unpredictable. Throughout the research process over the last three years, I have continued to follow my supervisor's sound advice to "paddle my own canoe". Although a rocky journey for me, I eventually reached my finish line and the experience was wholly worthwhile.

### **The Empirical Paper**

One of my first thoughts pre- Research Proposal One was that I had very little experience in research and thus had no confidence in being able to generate an idea for an empirical research study. We had been encouraged to consider an area of personal interest, as this would be an ongoing piece of work over three years and so it was important that we were passionate about it. I was interested in the area of health psychology, but had no real idea as to a specific research avenue. Considering areas of personal significance to me, I began to consider a study which explored the experiences of siblings of children with physical disabilities.

I approached two supervisors about this idea, but soon came to realise that there were no meaningful gaps in the literature that I could fill. From this point, my current research supervisor suggested that I look at the existing literature around men who have diabetes mellitus (DM) and erectile dysfunction (ED). At this point, I had very limited knowledge of either health condition. I soon realised that there was a gap in the literature investigating the experiences of men with both conditions, from a qualitative stance, as from what I could gather, there had been some quantitative research conducted. From further discussion with my supervisor, we concluded that it would be meaningful to investigate the experiences of South Asian men with DM and ED, as South Asian individuals are more likely to develop DM (NHS Choices, 2014) and thus experience ED (Diabetes.co.uk, 2014<sub>b</sub>).

Having finalised my research question, I felt more contained. Due to other academic pressures in the fourth and fifth years, research was put on the back burner. Initially, it had not been a priority to me, as I naively perceived to have an abundance of time. Fortunately, my supervisor kept me on track and focused on Research Proposals one through four, amidst the many other course demands and pressures. The outcome of my fourth Research Proposal was a positive one, which encouraged me to narrow my focus on research and start the Ethics process. Applying for Ethical Approval was a completely novel and anxiety-provoking experience. I had felt particularly downheartened when I learned that I would have to attend an Ethics Committee meeting about my research proposal, as the subject of my research was too sensitive in order to be considered for Proportionate Review. This threw me into a panic, as none of my peers at this point had had to do this.

I anticipated many obstacles to gaining ethical approval, including the sensitive nature of my area of study. However, it was a very positive and rewarding experience and overall, the Ethics process was smoother than expected.

Gaining Ethical Approval was a paradoxical experience. I was anxiously wishing to gain approval quickly, in the hope that I could start recruitment as soon as possible. However, once gained, I suddenly became extremely nervous about conducting the research and very aware of the assumptions that I held in relation to it. I was apprehensive about travelling to a new area to conduct a piece of work that was completely novel to me and with a client group that I had never worked with before. I had many fears and assumptions. Foremost, I had concerns about recruitment. I made assumptions that being a female researcher, of a different culture and gender to the men whose experiences I was interested to learn of, that individuals would not feel comfortable talking to me about such a sensitive health concern. I had aired these worries in supervision, where my supervisor emphasised that perhaps these assumptions have been obstacles to such research being conducted up until now. Recruitment has been a struggle and a slow process. However, my approach to recruitment was to maintain good communication and enthusiasm within the research team, as well as to be patient but persistent. I learnt that recruitment can be an unpredictable process and that one cannot guess when individuals will be interested to take part in your study. On finishing recruitment, I was able to dispel some of the assumptions that I had made and appreciate that professionalism and respect can be valued above the gender and culture of the researcher.

I decided to choose a qualitative methodology, as with the paucity of literature in this specific area, I wanted to gain an in-depth understanding of the experiences of South Asian men with DM and ED.

As the current study was exploratory in nature, I felt the use of semi-structured interviews would be most appropriate, as a quantitative approach may have been more restrictive in the expression of men's experiences. Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was the method of data analysis employed, as it allows the researcher to attempt to understand how individuals make sense of their experiences and what meaning these experiences hold for them (Smith, Flowers & Larkin, 2009). It is more concerned with an individual's subjective and personal perceptions of phenomena or events, as opposed to attempting to objectively record such events. This form of analysis was deemed appropriate for two reasons; to provide richer data on the experiences of South Asian men with DM and ED, which to my knowledge, had not previously been conducted and secondly, given my epistemological stance. I adopted a relativist stance, which proposes that there exists no absolute truth, but that the concept of truth may vary between individuals and cultures. Therefore, suggesting that multiple realities or truths may be known, relative to the individual experiencing it (Rorty, 1991).

On reflection, there were limitations to the epistemological stance that I adopted. Although I was able to consider the individual experiences of South Asian men with ED and DM, arguably a relativist stance questions the generalisability of these experiences to other South Asian men. However, the use of IPA enables the researcher to identify common themes in these experiences, thus highlighting a shared experience or perception of reality, which may be generalised to other men.

It was important to reflect on the impact that my own experiences and assumptions may have had on the interpretation of the data, as I too have constructed a perception of reality as influenced by my interaction with the social world and my culture.

However, involving a Consultant Clinical Health Psychologist to analyse three of the transcripts was intended to help reduce my individual bias in interpretation of the data collected.

I had underestimated the time and attention that was necessary in order to complete data analysis. I had anticipated that emergent themes would be fairly evident and thus the generation of superordinate and subordinate themes relatively straight-forward. I have learnt that in utilising IPA, one must really immerse themselves in the data and go beyond a descriptive and explicit interpretation of individual's experiences. This was difficult, as there was a lot of data to consider. I soon realised that there were many evident themes that could have been grouped under various superordinate themes and that all categories could in some way be linked. This made organisation of themes challenging, but highlighted a coherent narrative of participant's experiences.

### **The Systematic Literature Review (SLR)**

My initial assumption about the SLR was that it would be a fairly straight-forward piece of work. I mistakenly presumed that it would be more manageable than the empirical paper, as it did not require me to venture out and recruit participants, but merely search for relevant literature on a topic of my choice, from the comfort of my home. On reflection, I was extremely naïve. This paper was the most difficult to initiate, organise and conduct. I have encountered many difficulties with the SLR, born out of my inexperience and ignorance of what is required to conduct one.

Generating a question came easily to me. Having chosen an empirical research question that was very focused and specific, it was apparent that a broader investigation of the perceptions of men with ED would sufficiently inform my empirical inquiry.

As such, it was hoped that the findings of this paper could be used to compare and contrast those of the empirical paper, which focused specifically on the experiences of South Asian with DM as well as ED.

Due to the paucity of specific literature in the research area under investigation, including SLRs, I choose to utilise a combination of search terms generated in other SLRs. I used the search terms from one previously conducted SLR that was focused on illness perceptions in another health population, to capture relevant literature on the illness perceptions (Foxwell, Morley, & Frizelle, 2013). The search terms that I used to capture literature concerned with men with ED were from an SLR looking at the help-seeking behaviours of men with ED (Orchard, 2008). Together, selected search terms were combined to capture the relevant literature on the illness perceptions of men with ED.

The process of conducting a systematic search, I found, required attention to detail and efficient organisation. On a number of occasions, I realised that I had lost track of why I had excluded certain studies and why I had included others, resulting in me having to conduct my search from the beginning. As the review question was broad, I soon realised that I was going to have to be very explicit about how I defined the perceptions of men with ED, as a means of aiding my inclusion criteria. This was challenging, as there appeared to be a paucity of literature that clearly defined the illness perceptions of men with ED. Additionally, for research that did consider the perceptions of men with ED, this was not their main aim.

Thus, there were no consistent methodologies or measures for perceptions of men with ED. I had considered, for greater consistency, to conduct a review utilising qualitative studies only. However, there was such limited qualitative research available, that it would not have been feasible to conduct the review on these alone. Through this process, I learnt the importance of clearly defining the concepts under investigation in the review, as well as specifying the inclusion and exclusion criteria. Without this, it is difficult to provide a rationale for the studies included under review, which in turn could question not only the validity but reliability of the review.

I found generating meaningful conclusions from the findings of the SLR difficult, due to the heterogeneity of the study aims, measures, methodologies and participants. The most useful way for me to do this was to highlight the limitations of the review based on the above, whilst considering themes that were evident in the perceptions of men with ED under investigation. I viewed these themes as a means of illustrating what is known about the illness perceptions of men with ED, whilst emphasising the need for further research to consider investigating the illness perceptions of men with ED with consistent and homogenous measures and methodologies.

### **Concluding reflections**

I have always been an individual who likes to know when things will come to fruition and so the uncertainty and unpredictability of the research process was truly a challenge for me. However, this experience has emphasised the importance of patience and enthusiasm, as well as the encouragement of a persistent research team. I have learnt to challenge my assumptions. By doing so, I have been able to step outside of my comfort zone and engage in the acquisition of knowledge of a research area that was previously unfamiliar to me, as well as of myself.



I now look forward to further developing these skills within my clinical work, challenging myself to be curious, to be passionate, persistent and yet patient in my approach to research.

### **Rationale for Journal choice**

I chose to submit both the Systematic Literature Review and the Empirical Paper to the *Journal of Clinical Psychology*. This journal encompasses research within the field of clinical health psychology and behavioural medicine. It therefore catered to the multifaceted dimensions of the current research, which investigated the experiences and illness perceptions of men with comorbid health conditions, as well as considering the impact that these may have on health behaviours and quality of life. The breadth of this journal's research interests was thought to best capture the focus of this research as a whole.

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