

THE UNIVERSITY OF HULL

Perceived influences of the self and others in diabetes

being a dissertation submitted in partial fulfilment of the requirements for the degree of
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by

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“If you're going through hell, keep going.”

This thesis is dedicated to Françoise; my true kindred spirit.

Overview

This portfolio has three parts. Part one is a systematic literature review, in which the existing research literature is reviewed for evidence of diabetes related social anxiety in adolescents. Part two is an empirical paper, which explores individuals' experiences and perceptions of influence around amputations related to type 2 diabetes. Part three comprises the appendices, containing supporting information for the systematic literature review and empirical paper, in addition to an epistemological and a reflective statement.

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Part One: Systematic Literature Review

This paper is written in the format ready for submission to *Qualitative Health Research*.

Please see Appendix A for submission guidelines.

Word count: 8,366 (excluding tables, figures and references)

Diabetes related social anxiety in adolescents

A systematic mixed studies review

Abstract

Objective Adolescents with type 1 diabetes demonstrate greater levels of social anxiety than their peers. This review investigated whether (and how) adolescents with diabetes experience social anxiety in relation to diabetes. **Methods** A systematic mixed method study review was undertaken. Results from eighteen quantitative, qualitative and mixed method studies were subject to convergent thematic synthesis, with themes based on Clark and Wells' (1995) cognitive model of social anxiety. **Results** Adolescents and significant others reported (1) underlying beliefs and assumptions, (2) feared social situations, (3) somatic and cognitive symptoms and (4) safety behaviours consistent with social anxiety directly related to diabetes. Avoidance of diabetes related tasks or discussions in peer situations was a common safety behaviour. **Conclusions** Certain diabetes related situations can be perceived as socially dangerous by adolescents. This has implications for psychological and physical wellbeing (especially self-management adherence), and existing research on social anxiety in this group.

Keywords: diabetes; adolescents; social anxiety; self-management; stigma

Introduction

Type 1 diabetes (hereafter referred to as diabetes) is a chronic health condition in which the body is unable to produce insulin, the hormone required to break down blood glucose. Without insulin, glucose acquired from food remains in the bloodstream rather than being converted into energy, putting those with diabetes at risk of a number of serious health complications that can result from excessive blood glucose¹. Consequently, individuals with diabetes require regular extraneous insulin to manage their condition (usually in the form of multiple daily injections or a subcutaneous pump system), which is used in addition to other self-management behaviours such as blood glucose testing and dietary monitoring to keep blood glucose levels within the normal range. In the UK, the estimated prevalence of diabetes in children and young people under the age of 19 is 1 in 430-530, with the peak of diagnosis occurring between 10-14 years of age (Diabetes UK, 2014; NHS, 2007).

In addition to being the most frequent period of diagnosis, there are a number of ways in which the adolescent years (between ages 10-19; Canadian Paediatric Society, 2003) can be uniquely challenging for those with diabetes. In relation to diabetes, adolescence has been associated both with a period of unstable and unpredictable metabolic change due to puberty, requiring frequent changes to diabetes management plans (Tfayli & Arslanian, 2007), and an expected transition towards autonomy in self-management, which may previously have been assisted by family or other adult carers (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008). As such, the adolescent with diabetes often finds him or herself adopting daily responsibility for managing their condition at a time when it can be intrinsically difficult to manage. Importantly, these substantial health concerns

¹ Including short term complications related to acutely high and low blood sugars (with symptoms such as tiredness/fainting), and long term damage to the eyes, heart, kidneys and feet.

occur not in a psychosocial void, but rather within a developmental stage acknowledged to involve significant personal transitions and challenges.

One prominent transition in adolescence is the change in social orientation from the family unit to the peer group (Holmbeck, 2002; Fuligni, Eccles, Barber, & Clements, 2001); a phenomenon which has been suggested to underlie the concurrent escalation of social anxiety at this stage of development (Bruce & Saeed, 1999; Velting & Albano, 2001). Social anxiety, which has been defined as the fear and avoidance of social situations in which a person might be exposed to negative evaluation by others, is closely linked with the construct of shame, having further been described as the fear of feeling ashamed, or the fear of being shamed, or both (Veale, 2003). In adolescence, it is suggested that the peer group begin to serve as a prominent forum for social evaluation (actual or perceived), paving the way for potential anxiety (Velting & Albano, 2001). Whilst some clinicians primarily consider social anxiety within the formal diagnoses of ‘social anxiety disorder’ or ‘social phobia’, there is a growing consensus that social anxiety is better considered on a continuum (McNeil, 2001; Bögels et al, 2010); ranging from the absence of social fear, to occasional feelings of embarrassment in certain situations, to severe, functionally impairing and generalised presentations.

Various models have been proposed to explain the psychosocial mechanisms behind social anxiety. One prominent model is Clark and Wells’ (1995) cognitive model of social anxiety, which is widely used in its therapeutic conceptualisation and treatment (Veale, 2003). Clark and Wells (1995) define the six components of social anxiety as: (1) underlying social assumptions and beliefs (i.e. “I’m weird; I must appear to fit in with others”) which are activated by (2) current or imagined social situations; (3) perceptions and appraisals of such situations as posing “social danger” (i.e. “I will be rejected”); and responses to this danger including (4) somatic and cognitive symptoms associated with perceived social danger, (5) safety behaviours employed to reduce the social danger (i.e.

avoidance), and (6) the monitoring of the self as a “social object” (see figure 1). Fundamentally, the model suggests that social anxiety stems from personally held standards or rules about how one should (not) be or appear to others, with the belief that failing to adhere to these standards will result in negative evaluation.

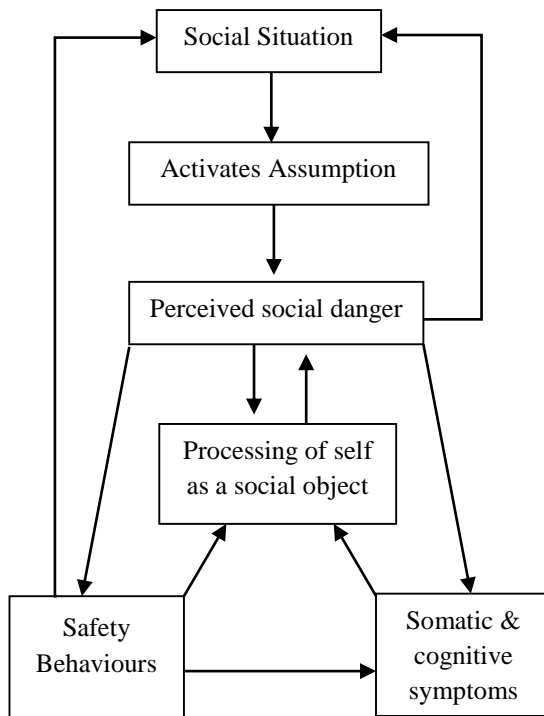


Figure 1. Clark and Wells’ (1995) cognitive model of social anxiety

Whilst heightened preoccupation with expected social standards appears to be normal in adolescence- particularly in reference to the peer group- the extent to which individual adolescents fear or expect negative evaluation varies. Whilst Clark and Wells’ (1995) model emphasises the belief that one is socially unusual over actual and objective social discrepancy (i.e. believing one is ‘different’ vs. exhibiting an objective difference), individuals who are objectively different from others on a socially significant domain may be more likely to appraise themselves as such- and, consequently, to experience more or greater social anxiety. Furthermore, such individuals may actually experience more negative evaluation from others. One such domain of social difference is health and illness. Significantly, adolescents with chronic health problems have been found to both

experience and perceive more stigma and victimisation than their healthy counterparts (Vishwanath, 2014; Pinqart & Shen, 2011; Fernandes et al, 2007); a finding which has been attributed to the increased incidence of social anxiety in this population (i.e. De Boer, Mula, & Sander, 2008; Devine et al, 2008).

Whilst adolescents with diabetes have often been included in such studies, and whilst elevated levels of social anxiety in adolescents with the disease have been noted (i.e. de Ornelas Maia, de Azevedo Braga, Brouwers, Nardi & de Oliveira e Silva, 2012; Storch et al, 2004; McCarroll, Lindsey, MacKinnon-Lewis, Chambers & Frabutt, 2009), few studies have directly explored adolescents' specific experience of social anxiety in relation to diabetes. Although studies of social anxiety in adolescents with chronic health difficulties elicit broad themes and experiences which may apply to those with diabetes (such as stigma), certain aspects of diabetes (i.e. the frequent need to self-manage and the invisibility of the disease in the absence of acute presentations such as hypoglycaemia²) may confer unique experiences in relation to social anxiety. Additionally, whilst studies suggest that adolescents with diabetes are more socially anxious than their peers, there has been little consideration as to whether any such anxiety is experienced in relation to the disease itself (i.e. whether feared social situations include those specific to diabetes and/or self-management behaviours).

Since psychological wellbeing is widely acknowledged to affect health outcomes in diabetes (Diabetes UK, 2008), and since physical and psychological wellbeing are vital to quality of life, exploring the possibility and profile of diabetes related social anxiety in adolescents is important. Furthermore, by exploring whether social anxiety might directly impact diabetes *care* (i.e. by causing embarrassment and thus avoidance of self-management), we might begin to understand and later seek to reduce possible barriers to

² Low blood glucose; resulting in symptoms such as shakiness, fainting, confusion and mood changes

self-management compliance- with non-compliance being particularly pronounced in this age group (Hanna & Outhrle,1999; McConnell, Harper, Campbell & Nelson, 2001). Consequently, the current systematic literature review sought to answer the following questions: (i) Is diabetes specific social anxiety in adolescents documented in the literature; and if so, (ii) how is it experienced? The review utilised Clark and Wells' (1995) model of social anxiety as the framework for organising and synthesising findings.

Methods

Search Strategy

A systematic search was conducted using the following predetermined search terms, based on existing keywords related to social anxiety and adolescent health: *diabet**, *adolesc**, *teen**, *youth**, *young*, *social* anxi**, *social* phobi**, *stigma**, *embarrass** and **shame**. Databases searched included Web of Science, PsycINFO, PsycARTICLES and MEDLINE, in order to access articles from a broad range of research and clinical specialties (given the variety of professionals who come into contact with adolescents with diabetes). The reference sections of articles meeting inclusion criteria were also searched for relevant studies (the 'ancestry' method). In order to maximise findings pertaining to diabetes related social anxiety, both quantitative and qualitative studies were included in the review.

Inclusion Criteria

In accordance with the Cochrane Collaboration's recommendations for conducting systematic reviews, a protocol was developed and explicit inclusion criteria were defined (Lefebvre, Manheimer & Glanville, 2011). These criteria were as follows: (i) publication date between January 1994 and August 2014 (i.e. the past 20 years; limiting the review to studies relevant to current practice given advancement in self-management techniques); (ii) publication in a peer-reviewed journal; (iii) written in the English

language; (iv) study population included adolescents (10-19 years) with type 1 diabetes; (v) study was qualitative, quantitative or of mixed methods, and included measures or discussion around the experience of social anxiety specifically concerned with diabetes or diabetes related activities (i.e. self-management). Studies concerned simply with measuring symptomatic levels of general 'social anxiety' in adolescents with diabetes were not included, as it was not possible to infer from these whether such anxiety was experienced in direct relation to diabetes. Studies were excluded if the focus was on a family member's experience of having a child with diabetes, and did not include the adolescent's perspective. A total of 18 studies (8 quantitative, 9 qualitative, 1 mixed methods) were ultimately selected for review (see figure 2).

Quality Review

The quality of each article was assessed using the Mixed Methods Appraisal Tool (MMAT [see Appendices B and C]), a scoring system appropriate for mixed-studies reviews (Pluye, Gagnon, Griffiths & Johnson-Lafleur, 2009). The tool allows concomitant appraisal of qualitative and quantitative approaches, whose epistemological and methodological differences preclude the use of a single quality appraisal instrument. Using the MMAT, the methodological quality of each study was calculated by totalling all relevant items on the instrument for each study, yielding a score from 0% (indicating a study of low quality) to 100% (indicating a study of high quality). In order to determine inter-rater reliability, a third party researcher independently scored a subset of 7 papers (38.8% of the dataset [see Appendix D]). Cohen's Kappa was used to determine inter-rater agreement between scores awarded for every appropriate assessment criterion across the papers, yielding a value indicating moderate agreement between item ratings ($\kappa = .574$ (95% CI = .310 to .843), $p < .0001$). These quality assessment scores were consulted in relation to the legitimacy of results inferred from each study (i.e. whether the domain in which quality was poor impacted on the rigour of findings included within the synthesis).

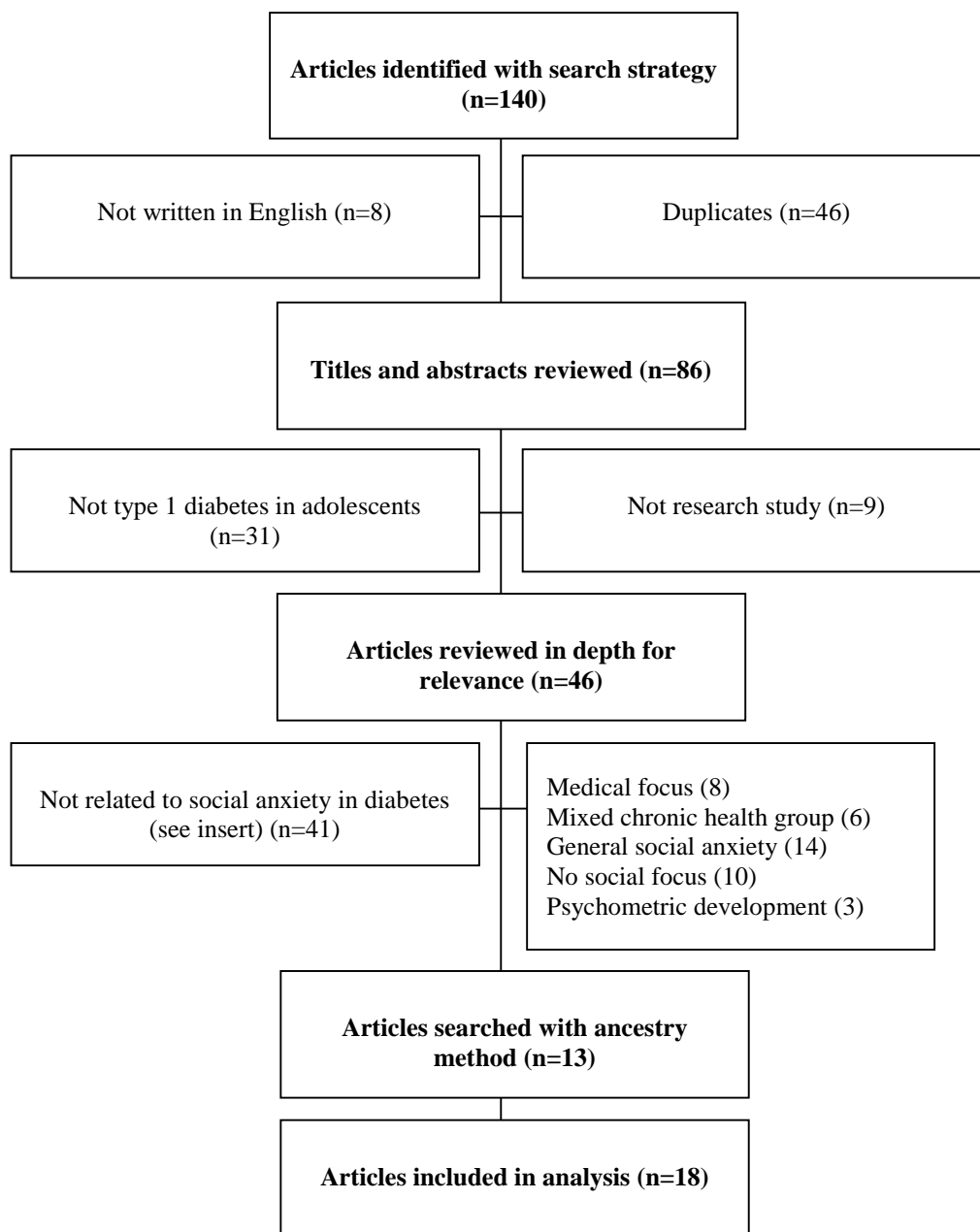


Figure 2. Flowchart detailing the selection of studies for review (in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PRISMA, 2015)

Synthesis

The results of the review were synthesised using convergent thematic analysis³, with heterogeneous and idiosyncratic approaches within the quantitative studies rendering

³ In convergent thematic analysis, data is sorted into pre-determined (rather than emergent) themes

meta-analysis inappropriate. Thematic analysis was deemed an appropriate and valuable approach for exploring studies with different designs, as it provides a qualitative synthesis that captures common themes irrespective of study methodology (Fereday & Muir-Cochrane, 2006). As this review aimed to explore the occurrence of a previously defined psychological phenomenon (social anxiety), themes were deductively derived from the components of Clark and Wells' (1995) cognitive model of social anxiety. Data display matrices were developed, where significant data, statements and experiences were independently coded, grouped into categories, and assimilated within appropriate themes [see Appendix E].

Results

Overview of literature

A summary of the papers included in the review can be found in table 1. No studies were found which directly sought to explore the concept of diabetes related social anxiety in adolescents. Rather, results and findings relevant to this concept were identified within studies explicitly focussing on other psychosocial aspects of adolescent diabetes. The stated areas of exploration (and methodology) within the studies varied, and included topics which were both specific (i.e. barriers to self-management) and more general (i.e. the lived experience of diabetes). Typically, the studies included adolescents with diabetes as the sole participants (in 13 out of 18 papers included), although a small number included parents (3) and friends/peers (2). The majority of studies (10) were from North America, although some originated from Europe (5), Asia (2) and Africa (1).

Quality assessment

The span of possible scores on the MMAT ranged from 0% to 100% (i.e. from zero to four of four method specific criteria being fulfilled). The papers in this review obtained

scores of 25% (n = 1), 50% (n = 7), 75% (n = 6) and 100% (n = 3) respectively, demonstrating a range of quality from somewhat poor to very good. This illustrates that in addition to the stated topics of exploration, the methodological qualities of the papers reviewed were notably heterogeneous.

For the purposes of this review, no articles were excluded based on quality, as results of low quality studies were consistent with results of high quality studies. Additionally, the domains in which studies scored poorly on the MMAT were appraised as having minimal impact on the credibility of the findings assimilated. For example, two of the poorest scoring domains across the papers- a lack of consideration of researcher or contextual influence in qualitative studies, and the question of population representativeness in quantitative studies- did not contraindicate the relevance of either direct quotes from study participants or idiographic agreement with statements relevant to social anxiety, since the primary concern of this review was to identify the presence, rather than prevalence, of such phenomena. However, these methodological shortcomings do negate any interpretation of population/context generalisability, in that the finding that X% of a particular adolescent sample with unknown population representativeness indicated feeling embarrassed in relation to diabetes can be used to conclude only that feeling is present to some degree within the adolescent population at large, but not that X% of the overall adolescent population can be estimated to experience this. Nonetheless, the findings of this review are an important preliminary step in assimilating evidence relating to diabetes related social anxiety from a literature base which varies in focus and quality.

Themes

1. Underlying assumptions and beliefs

The self as different; difference as unwelcome.

In numerous studies, reference was made to overarching assumptions and beliefs about the socially embedded self. In particular, a common narrative amongst the studies

Table 1. Summary of included studies

Study/Location	Focus	Study type	Data/Measures used	Participants and ages	MMAT Score
1. Berlin et al, 2006 (USA)	Difficult situations faced by adolescents using an insulin pump and their parents	Quantitative: Correlational, Comparative	Structured interview transcripts; Difficulty ratings; HBA1C	AwD* (n=20): 14.04 Parents (n=34): 44.09	75%
2. Buchbinder et al, 2005 (USA/Canada)	The illness experience of adolescents with diabetes	Qualitative: Video Intervention/Prevention Assessment	Self-recorded video footage; structured interview transcripts	AwD (n=5): 13-18	50%
3. Davidson, Penney, Muller & Grey, 2004 (USA)	Stressors and self-management challenges reported by adolescents with diabetes	Qualitative: Content Analysis	Coping skills group transcripts	AwD (n=6): 13.0-17.7	50%
4. Di Battista, Hart, Greco & Glozier, 2009 (Canada)	Associations between (general) social anxiety, self-management, quality of life and fear of hypoglycaemia.	Quantitative: Correlational, Comparative	Social Anxiety Scale for Adolescents; Diabetes Quality of Life Scale; Summary of Diabetes Self Care Activities; Hypoglycaemia Fear Survey; HBA1C	AwD (n=76): 15.9	100%
5. Dickinson & O'Reilly, 2004 (USA)	The lived experience of female adolescents with diabetes	Qualitative Phenomenological analysis (Van Manen)	Semi-structured interview transcripts	AwD (n=10): 16-17	50%

*Adolescents with diabetes

Table 1. Summary of included studies

Study/Location	Focus	Study type	Data/Measures used	Participants and ages	MMAT Score
6. Hains, Berlin, Hobart Davies, Parton & Alemzadeh, 2006 (USA)	The relationship(s) between negative attributions of friend reactions within a social context, anticipated adherence difficulties, diabetes stress & metabolic control.	Quantitative: Path Analysis	Negative Friend Attribution Scale; Anticipated Adherence Scale ; Diabetes Stress Questionnaire; HBA1C	AwD (n=104): 13.94	75%
7. Hains et al 2007 (USA)	The relationship(s) between negative attributions of friend/peer reactions within a social context, anticipated adherence difficulties, diabetes stress & metabolic control.	Quantitative: Path analysis	Negative Attribution of Friend Scale; Negative Attribution of Peer Scale; Anticipated Adherence Scale; Diabetes Stress Questionnaire; Diabetes Social Support Questionnaire; HBA1C	AwD (n=102): 13.87	75%
8. Hussein & Abdel Sadek, 2014 (Egypt)	Perceived hindrances to diabetes self-management according to adolescents and their mothers	Quantitative: Correlational, Comparative	Structured interview responses; Diabetes knowledge questionnaire (adolescents only); Hindering factors questionnaire	AwD (n=250): 12.63 Mothers (250): 35.98	25%
9. Huus & Enskär, 2007 (Sweden)	The lived experience of adolescents with diabetes	Qualitative: Phenomenological analysis (Giorgio)	Semi-structured interview transcripts	AwD (n=8): 14-18	50%
10. Karlsson, Arman & Wikblad, 2006 (Sweden)	The transition towards autonomy in self-management	Qualitative: Phenomenological analysis (Vancouver)	Semi-structured interview transcripts	AwD (n=32): 14.5	75%
11. Lehmkuhl, et al, 2009 (USA)	Perceptions of diabetes amongst affected youth and their peers	Mixed methods: Embedded Design	Talking About Diabetes Survey	AwD (n=45): ? Peers (n=25): ? Overall age: 11-16	50%

Table 1. Summary of included studies

Study/Location	Focus	Study type	Data/Measures used	Participants and ages	MMAT Score
12. Mulvaney et al, 2011 (USA)	Processes associated with an online problem solving skills tool for adolescents with diabetes	Quantitative: Correlational, Comparative	Semi-structured interview transcripts; frequency of online activity; HBA1C	AwD (n=41): 15.1	75%
13. Peters, Nawijn & van Kesteren, 2014 (Netherlands)	Perspectives of adolescents with diabetes and their friends on the positive social support that friends can offer	Qualitative: Content Analysis	Semi-structured interview transcripts	<i>Study 1:</i> AwD (n=28): 12-15 <i>Study 2:</i> AwD (n=11): 13-17 Friends (n=11): 13-19 AwD (n=10): 13.60	75%
14. Salamon, Hains, Fleischman, Hobart Davies & Kichler, 2009 (USA)	Pilot evaluation of a problem solving intervention for self-management around peers	Quantitative: Intervention	Self Care around Friends Questionnaire; Diabetes Stress Questionnaire (Peer and adverse interpersonal reactions subscales)	AwD (n=10): 13.60	75%
15. Skinner, Petzing & Johnson, 1999 (UK)	The role of peers in supporting adolescents' diabetes management	Quantitative: Correlational, Comparative	Diabetes Social Support Interview; Glycated haemoglobin assays	AwD (n=27): 15.8	50%
16. Wang, Brown & Horner, 2010 (Taiwan)	School based lived experiences of adolescents with diabetes (preliminary study)	Qualitative: Phenomenological analysis (Heidegger)	Semi-structured interview transcripts	AwD (n=2): 14-15	100%
17. Wang, Brown & Horner, 2013 (Taiwan)	School based lived experiences of adolescents with diabetes (preliminary study)	Qualitative: Phenomenological analysis (Heidegger)	Semi-structured interview transcripts	AwD (n=14): 14.20	100%
18. Williams, 1999 (UK)	The interaction between gender and adolescence in the lived experience of diabetes	Qualitative: Grounded theory	Semi-structured interview transcripts	AwD (n=20): 15-18 Mothers (n=20): ?	50%

involved the consideration of the self as ‘different’ to others. In some cases, self-perceived difference was regarded with ambivalence, or even positively. For example, adolescents in three studies discussed feeling different in the sense that their diabetes had made them more independent, responsible, mature or empathic than their peers (Huus & Enskär, 2007; Wang, Brown & Horner, 2013; Dickinson & O’Reilly, 2004), with more general feelings of difference being dismissed (i.e. “*I don’t consider myself differently from anybody*”; Dickinson & O’Reilly, 2004). Similarly, adolescents in some studies discussed their difference in terms of the objective lifestyle differences they faced in comparison to others (i.e. “*I feel differently from everybody else. All others can live as they want, but I have to adjust to my diabetes, for instance, when I am with my friends and I have to have a sandwich in my pocket*”; Huus & Enskär, 2007), rather than in terms of general identity. In other studies such as that by Lehmkuhl et al (2009), where 31% of adolescents noted that their regimen interfered with social activities by making them feel different from peers, the use of the term ‘difference’ was ambiguous.

For many other adolescents, however, being perceived as different- by themselves or others- was a more fundamental and/or negative concept. In some cases, this negative appraisal was demonstrated in regards to feeling different (i.e. believing the self to be fundamentally different to others). For example, in an interview excerpt from Wang et al (2013), a female adolescent says “Although my classmates don’t say anything, I still feel that I’m different from them”- followed by weeping and silence. In other cases, the experience of appearing different was emphasised, as in an excerpt from Peters, Nawijn and van Kesteren’s (2014) study- “I find it annoying when I’m different and I’d rather never show it”. Such experiences of internal or external difference are not necessarily mutually exclusive, and both share similarities. In both cases, individuals appeared to hold the appraisal that difference is bad, and the assumption that it is preferable to be (or appear) ‘normal’. This preference for normality was made explicit by mothers of

adolescents in Williams (1999)- “He wants to be normal” / “Once he goes out of the door [without his self-management kit]...he’s no different to anybody else, which is good really”. The latter quote highlights the propensity for asymptomatic diabetes- and thus difference- to be concealed from others, which many of those concerned with difference saw as appealing- “At school I try to avoid anything related to this [disease] because I want to be like others” (Wang et al, 2013). This attraction was summarised succinctly by Davidson, Penney, Muller and Grey (2004) as a dilemma faced by those with diabetes: ‘To act normal or reveal difference’. Such beliefs and assumptions concerning difference- an innately relational concern- are fundamental to the experience of social anxiety, where an individual evaluates themselves as falling short of an expected and desired social standard.

2. *Feared social situations/responses*

‘Standing out and being watched’

In fitting with the values held about feeling or being seen as ‘normal’, the social situations adolescents described as being uncomfortable or problematic involved revealing or drawing attention to their diabetes (and thus their difference). Although these situations are inherently ambiguous, and were indeed perceived without threat by many adolescents (i.e. “*There will be people looking, thinking ‘What’s she doing that for?’ , but I don’t care*”; Williams, 1999), they were regarded as anxiety provoking by a number of other adolescents across the studies. The general essence of these situations echoed the ‘standing out and being watched’ theme identified by Dickinson and O’Reilly (2004), as extraneous attention from others was the common experience described.

The first type of situation described involved eating or (more frequently) self-managing in front of peers, and their accompanying interest in this. The interest from peers was variously described as ‘attention’, ‘watching’, ‘staring’ or ‘looking’, and ‘curiosity’ or

‘questioning’ (Davidson et al, 2004; Dickinson & O’Reilly, 2004; Wang et al, 2013; Wang, Brown & Horner, 2010; Peters et al, 2014; Williams, 1999). Whilst some adolescents discussed such situations ambiguously or as an annoyance (i.e. regarding questioning: “It gets very annoying. It’s just constant; everybody asks. You should just tattoo it on my forehead so they can just read it”; Dickinson & O’Reilly, 2004), others described them as anxiety provoking. For example, one adolescent in Wang et al’s (2010) study said “If I want to test, I test, but at school I feel some stress. I don’t like my classmates watching”. Self-managing in front of those outside of the peer group, such as family, was not referred to as anxiety provoking in any of the studies, with one adolescent saying “*My father and mother never watch me like people at school, but my classmate always stare, looking very curious*” (Wang et al, 2013). Anxiety in self-management situations was ubiquitous in Hussein and Abdel Sadek’s (2014) study, with 90.4% of adolescents ‘agreeing’ with the statement ‘*I feel embarrassed when I take my medication in front of my friends*’, and the remaining 9.6% indicating that they felt like this ‘sometimes’. Questioning, either in regards to self-management or otherwise, was similarly a universal source of discomfort, with 90.4% ‘agreeing’ with the statement ‘I mind if my friends bring up my illness or ask me questions about it’, and 9.6% indicating that they felt this way sometimes (Hussein and Abdel Sadek, 2014).

The second type of situation described revolved around purposeful diabetes-related effort, involvement or ‘support’ offered by others. Some studies referred to adolescents being ‘singled out’ (Dickinson & O’Reilly, 2004; Lehmkuhl et al, 2009) or ‘treated differently’ (Peters et al, 2014; Huus & Enskär, 2007) by friends, teachers or parents, with examples including being asked that parents attend school trips (Wang et al, 2013) and being questioned about snacks by teachers and coaches (Dickinson & O’Reilly, 2004). Whilst again some adolescents regarded these kind of situations with annoyance rather than anxiety (i.e. “*They also treat me differently... I sometimes find that annoying. I just want*

to be treated like everyone else. I can take care of myself"; Peters et al, 2014), for others having people 'making a big deal' or 'overreacting' about diabetes was anxiety provoking (Wang et al, 2013). In Peters et al's (2014) study, adolescents were described in terms of two 'types' of social response to diabetes, with 'type a' individuals (a minority) typically perceiving support as a threat rather than welcoming it. Friends of those in this study recognised the importance of not 'making a big deal' about their friends' diabetes- "*As a friend you just try to act normal. I mean you don't say "gosh, how awful"... Just don't overreact*". Adolescents in Lehmkuhl et al's (2009) study also cited not 'making a big deal' about their diabetes as a way in which friends could improve their support, though this was only a minority (4.6%) of the sample. Conversely, however, some adolescents stated that they did not like it when friends *underappreciated* the seriousness of diabetes (Peters et al, 2014), again highlighting that appraisals of active effort from others varied.

3. Social danger

The social danger experienced or anticipated in regards to feared situations came in two forms. Firstly, there were feared *cognitive* reactions from others (i.e. what others would think of them). Secondly, there were feared *behavioural* reactions from others (i.e. what others would do or say). These are detailed below.

a. Feared perceptions (cognitive)

"They might not think of you the same, if they know".

Whilst some adolescents spoke ambiguously about the expected cognitive response of others (i.e. that they wouldn't 'understand'; Lehmkuhl et al, 2009; Peters et al, 2014; Wang et al, 2013), some of the perceptions feared or described were unequivocally negative. In some instances (Karlsson, Arman & Wikblad, 2006; Huus & Enskär, 2007), the past negative responses which adolescents described were broad and vague ("*At first*

they almost looked down on me, like: wondered what kind of a person I was who had diabetes"; Karlsson et al, 2006), with others making similarly vague comments about hypothetical future perceptions that might be made (*"They might not think of you the same, if they know"*; *"I don't know, and I don't want to find out"*; Lehmkuhl et al, 2009; Williams, 1999). However, other adolescents were far more specific about what they believed others thought (or might think) suggesting being perceived as 'needy' or 'a burden' (Peters et al, 2014); 'special', 'weird' or 'strange' (Wang et al, 2013); or a 'problem' (Wang et al, 2013). Adolescents were primarily concerned with the perceptions of friends and peers, rather than adults.

Negative attributions of the perceptions of friends and peers were investigated in two studies exploring the relationship between such attributions and metabolic control (Hains, Berlin, Hobart Davies, Parton & Azmeldeh, 2006; Hains et al, 2007). The negative attribution scales constructed for these studies included various self-management scenarios followed by Likert scale ratings for the following perception related statements: *'I'd think my friends would understand and be supportive'* / *'I'd think my friends wouldn't care'* / *'I'd think my friends wouldn't like me anymore'*. Participating adolescents varied regarding the extent of negative attributions made, suggesting that not all adolescents with diabetes are inclined to make such attributions. Indeed, some adolescents reported that their peers regarded their diabetes in a *positive* light (i.e. cool or interesting; Lehmkuhl et al, 2009). Relevant to the concept of negative attributions, a third of the friends who took part in Lehmkuhl et al's (2009) study reported having no strong response to finding out that their friend had diabetes, suggesting that the uniformly negative perceptions predicted by some adolescents are not necessarily corroborated. Furthermore, friends of adolescents with diabetes in Peters et al's (2014) study described that they were wary of offering support or discussing diabetes only because their friend was not open about the

matter. It is thus possible that some adolescents may ascribe negative attributions to friends' neutral actions, when the motivations underlying these may in fact be supportive.

Finally, a more specific negative perception raised in two separate studies concerned disgust or fear from others in response to the use of needles (Lehmkuhl et al, 2009; Buchbinder et al, 2006). Although this was typically not raised in the context of it being particularly upsetting for the adolescents themselves (i.e. “[*My friends*] don't normally pay attention, most of them don't like blood”; Lehmkuhl, 2009), it is significant in terms of adding to the cumulative unfavourable social perceptions that are potentially faced by adolescents with diabetes.

b. Feared reactions (behavioural)

“Some people just stop talking to me”.

In some cases, the anticipated negative reactions voiced were hypothetical. For example, in two studies, anxiety about potential gossip/rumours (*“Some people in school like to gossip or spread rumors, so I would rather not let them know I have this problem”*; Wang et al, 2013) or bullying (*“I'm afraid some people... may say something mean to me”*; Wang et al, 2010) were clearly speculative. Such speculative reactions were also captured in the negative attribution scales used by Hains et al (2006) and Hains et al (2007), within the predictions *‘I'd think my friends would get mad or frustrated’/‘I'd think my friends wouldn't invite me anymore’*. In isolation, these comments may suggest an irrational anxiety- a feared outcome for which there is no evidence.

However, evidence of negative reactions from others was prolific throughout the studies. Regarding negative experiences with friends and other peers, some of the past experiences described were quite general. For example, mocking/teasing (*“Some classmates ...purposefully used food to provoke me”*- Wang et al, 2013), gossip (*“One girl once said*

behind my back 'Oh, I wish she wouldn't do injections in the lunch break'"- Williams, 1999), rumours and bullying ("*Some of my elementary classmates spread rumors and bullied me*"- Wang et al, 2010). In Hussein and Abdel Sadek's (2014) study, these kind of generally negative experiences were familiar to the majority of adolescents, with 44.4% 'agreeing' with the statement '*My friends mock me when I take my medications*', and 44% indicating this happened 'sometimes'. In other cases, the negative responses from peers described were more specific. These included peers refusing to talk to them ("*Some people just stop talking to me*"; Lehmkuhl et al, 2009), refusing to play with them ("*Some students said that I might have hypoglycemia, therefore I cannot play with them*"; Wang et al, 2010), saying that diabetes was a contagious disease or caused by eating "*too much candy*" (Wang et al, 2010), asking the adolescent to leave a tent to inject their insulin when on a camping trip, and calling them things like 'druggie' (Skinner, Petzing & Johnston, 1999).

Less often, negative reactions from adults were also described. In two studies, adolescents spoke of adults mistaking insulin injections for illicit drug use (Dickinson & O'Reilly, 2004; Buchbinder et al, 2006). In one case, this resulted in a woman calling security when an adolescent administered insulin in a shopping mall. A further study detailed adolescents being asked to abstain from races and exercise activities, and being denied their right to serve as class leaders by teachers (Wang et al, 2013). The punitive experience of these responses stood in contrast to the usual complaints about 'nagging' that many adolescents voiced, which were associated with annoyance rather than any other negative emotion (i.e. Huus & Enskär, 2007; Peters et al, 2014). However, the emphasis on described negative experiences seemed to be with the peer group. Although some described peers gradually becoming more accepting over time (i.e. Karlsson et al, 2006; Wang et al, 2013), the potential sum of these sort of negative reactions was summarised by Wang et al (2013), who wrote: '*Many described experiencing*

unforgettable emotional trauma because of classmates' ignorant or naive responses... emotions remained vivid in their memories and prevented them from handling T1DM more openly. ' Indeed, as detailed below, concealment was often adolescents' behavioural response to such experiences.

4. Somatic and cognitive symptoms associated with social danger

Anxiety, embarrassment and upset

Somatic and cognitive symptoms experienced in response to such situations and perceived social danger were not explicitly detailed in any of the studies, but rather encapsulated in the broader description of emotions described (i.e. where individuals described anxiety, the somatic and cognitive components which constitute anxiety could be inferred). Adolescents reported experiencing various emotional states (and thus various somatic and cognitive symptoms) in relation to such situations. Occasionally, adolescents spoke of emotions associated with the anxious *anticipation* of the situations, namely stress or fear (i.e. *"I'm afraid that..."*; Wang et al, 2010; Wang et al, 2013). More frequently however, adolescents indicated experiencing embarrassment or 'discomfort' when faced with social situations- particularly when self-managing in front of peers (Dickinson & O'Reilly, 2004; Huus & Enskär, 2007; Mulvaney et al, 2011; Wang et al, 2010; Skinner et al, 1999). The experience of embarrassment was universal across Hussein and Abdel Sadek's (2014) sample, where 90.4% 'agreed' with the statement *'I feel embarrassed when I take my medication in front of my friends'* and the remaining 9.6% indicated feeling this way 'sometimes'. Additionally, Buchbinder et al (2006) commented that all adolescents in their study *'reported being upset by friends' and strangers' reaction to their diabetes'*. Whilst it is unclear whether this 'upset' was experienced during these reactions, in reflection upon them, or both, this comment adds another dimension to the emotional experience of such challenging situations. This

assortment of negative emotions seems distinguishable from non-anxious negative emotions experienced by some adolescents- namely annoyance or frustration.

As the somatic symptoms associated with such anxiety were not explicitly documented in any of the reviewed studies, it is not directly evident whether these might be visibly apparent to others. However, some studies suggest that such anxiety may have been somewhat underestimated by parents- suggesting that it may not be wholly visible. In Berlin et al's (2006) study, parents of adolescents using insulin pumps indicated feeling that the most frequently encountered 'problematic situations' were related to the family context, with social and peer contexts being rated as considerably less problematic. However, the adolescents themselves considered the latter context the most problematic of all. Similarly, the mothers of adolescents in Hussein & Abdel Sadek's (2014) study demonstrated lower agreement with statements about the experience of embarrassment than their children did. This parental underestimation of the anxiety experienced is summarised in Wang et al's 2010 study, where one adolescent commented "*My mom always told me that... I shouldn't be afraid of other people paying attention. But she is not me. She cannot understand*". However, some parents may be aware of their children's anxiety, as demonstrated by a mother in Williams' (1999) study, who agreed to manage her son's diabetes entirely from home to preserve his 'normality' at school. Similarly, friends in Peters et al's (2014) study indicated their reserve in offering more support due to their friends seeming to 'mind'. However, in both of these cases, it may be that others are aware of any anxiety because it was disclosed to them, rather than visibly evident.

5. Safety behaviours

"At school I try to avoid anything related to this [disease]"

Throughout the studies, the 'safety behaviour' of choice for adolescents was the *avoidance* of situations which drew attention to their diabetes in a peer group setting-

particularly in terms of self-management and discussing/disclosing their diabetes. This avoidance took various forms. In a few cases, adolescents discussed *concealing* their self-management (i.e. blood glucose testing and insulin administration) from others (Davison et al, 2004; Peters et al, 2014; Wang et al, 2010; Wang et al, 2013). In one case, an adolescent described concealing blood glucose testing whilst remaining in the classroom (“*Now, when I test my sugar in the classroom, I look to make sure no one is watching me, and then I will do a quick test on my thighs. I would never put the meter on my desk*”; Wang et al, 2010). In two other cases regarding insulin administration rather than blood glucose testing, adolescents described seeking private locations as they did not feel comfortable doing this in the classroom (i.e. “*I would rather go hide in the restroom to inject my insulin*”; Wang et al, 2010).

Alternatively, adolescents described entirely omitting self-management in school as a result of anxiety. For some, this was an occasional occurrence (Wang et al, 2010; Huus & Enskär, 2007). One female adolescent described such an occasion of ‘skipping’ in the face of hypoglycaemic symptoms: “*I saw everyone was sleeping and I was just sitting there short of breath... Because everyone was sleeping, I didn’t want to be seen walking out and through the corridor*” (Wang et al, 2010). Others, however, demonstrated a more complete avoidance of self-management at school (Wang et al, 2013; Williams, 1999; Skinner et al, 1999). One mother in Williams’ (1999) study said of her son: “*He won't do them [blood sugars] at school now, he absolutely refuses, he won't even do an injection at school*”. In some cases, parents and healthcare staff were aware of and complicit in this avoidance. Regimens were agreed that omitted the need for injections at school (i.e. being on a regimen of two injections a day, rather than four). The mother of one adolescent in Williams’ (1999) study was supportive of this arrangement, saying “*his diabetes is managed purely from here- once he goes out of the door... he’s no different to anyone else, which is good, really*”. In other cases, it was unclear whether adults were aware.

It is salient to note that many adolescents who omitted self-management activities did this despite explicitly acknowledging and understanding the physical risks posed to themselves (Dickinson & O'Reilly, 2004; Wang et al, 2010; Wang et al, 2013; Huus & Enskär, 2007; Hains et al, 2007), suggesting a conscious and informed neglect of their self-care needs rather than forgetfulness or ignorance. As summarised by Wang et al (2013), *'Appearing normal was more important than physical comfort or possible health risks'*. Others maintained that they were able to self-manage effectively without the use of visible equipment, specifically in regards to using symptoms to gauge blood glucose levels (i.e. *"I haven't checked my sugar for a long time. I feel it's enough to sense my body....I'm not so stupid as to be unaware of my discomfort"*; Wang et al, 2013), although this omission was not necessarily always a result of anxiety. In Hains et al's (2007) anticipated adherence demands scale, the idea of being able to 'make up for' the omission of necessary self-management activities in social situations was captured within the statement *'I would wait until I was out of this situation before I did my self-care.'*

Avoidance of disclosing their diabetes to peers was another behaviour adopted by adolescents who were anxious about the potential fallout of this. Many adolescents expressed anxiety in regards to this dilemma -referred to as *'to tell or not to tell'* by Dickinson and O'Reilly (2004)- with most suggesting that they reserve the decision to tell others until they know them better, and feel more confident that they won't react negatively (Dickinson & O'Reilly, 2004; Peters et al, 2014; Wang et al, 2010; Wang et al, 2013). As one adolescent explained in Wang et al's study (2010): *"My parents and I decided to keep it a secret as I entered junior high... now, I wait to get to know people and then decide whom and how much I tell them. For those classmates I feel may tease others, I would not answer their questions"*. Wang et al (2013) likened this process to an experiment, with adolescents assessing and observing peers' responses, predicting whether they would be safe from uncomfortable reactions.

This difference between disclosure to close friends and more distant ‘peers’ was apparent in the study by Salamon, Hains, Fleischman, Hobart Davies and Kichler (2010), in which 100% of adolescents stated that they had told ‘*most of their friends*’, 50% stated that ‘*most of the kids in their grade knew*’, and 30% stated that they tell peers ‘*right away*’ about their diabetes status. However, all adolescents in Hussein and Abdel Sadek’s (2014) study expressed some degree of reservation in disclosing or discussing diabetes with their ‘friends’, with 90.4% ‘agreeing’ with the statement ‘*I don't want my friends to know anything about my illness*’, and the rest indicating that they felt this way ‘sometimes’ (though it was not discussed in the study whether friends had actually been told). Again, some adolescents appeared to omit this recommended care practice despite acknowledging the risks, with Dickinson and O’Reilly (2004) reporting that whilst all of the participating adolescents in their study understood the importance of informing others about their diabetes, they did not all do so consistently. Some adolescents, however, disclosed their diabetes to others irrespective of anxiety, with a female participant in Williams’ study commenting “*Everyone should know because then they can help if something happens. It’s not a question of minding or not*”. In a few cases, adolescents did not get a choice in disclosure, as teachers took to publicising this information themselves. This was not appreciated by the adolescents (Wang et al, 2013).

Beyond the point of disclosure, some were still hesitant to discuss their diabetes with others. Peters et al (2014) noted a distinction between individuals who tended to involve friends in their diabetes (including discussing it) and those who did not, with Williams (1999) suggested their male participants in particular were reluctant to discuss diabetes with friends at all (although the specific reasons for reservation in these cases were not elaborated on). In addition to discussion with friends, participants in one study discussed not wanting to discuss their active symptoms with teachers or classmates, with the given reason being that they might overreact, or consider them a ‘problem’.

The relation of such safety behaviours to social anxiety was suggested in several quantitative studies. Self-management was found to be hindered by (general) social anxiety in male adolescents in a study by Di Battista, Hart, Greco and Glozier (2009), whilst Berlin et al (2006) found a medium-sized relationship between adolescents' difficulty ratings of diabetes related problems –which most commonly occurred in social and peer contexts- and their metabolic control. Whilst these studies did not address the direction of these relationships (i.e. it could be that adolescents with poorer metabolic control or more difficulties with self-management are more likely to be reserved about their diabetes), this has been explored in research by Hains et al (2006) and Hains et al (2007). Here, indirect relationships were found between negative attributions made towards friends and peers and metabolic control, through the mechanisms of expected adherence difficulties and diabetes stress. This suggests that social anxiety can ultimately hinder both self-management and metabolic control. However, it is notable that some individuals, when faced with social anxiety, described simply carrying on with their management anyway (i.e. did not respond with avoidant safety behaviours; Wang et al, 2013, Lehmkuhl et al, 2009, Karlsson et al, 2006), with one adolescent in Wang et al's (2013) study explaining “*At first, my classmates were very curious. Gradually, they got used to it and I became more comfortable doing it in the classroom*”. Finally, it is worth emphasising that altered self-management in the presence of peers is not necessarily the norm, with 66.7% of adolescents in Lehmkuhl et al's (2009) study reporting that nothing changed in their self-care while with peers- although the proportion of these who may have experienced anxiety is not known.

Discussion

This review sought to explore whether (and how) adolescents with type 1 diabetes have previously reported social anxiety related to their diabetes. Experiences consistent with

five of the six components comprising Clark and Wells' (1995) model of social anxiety were reported and/or described within the eighteen studies reviewed. Such anxiety was predominantly associated with situations which involved managing, disclosing or revealing their diabetes within peer group settings, and avoidance of these situations was a typical response (safety behaviour).

Although diabetes related social anxiety has not knowingly been studied directly within the existing research literature, its identification within this review is not unexpected in the context of related research. For example, adolescents with diabetes (and indeed other chronic illnesses) have previously been found to demonstrate greater levels of social anxiety and experience of stigma than healthy peers (i.e. de Ornelas Maia et al, 2012; Storch et al, 2004; McCarroll et al, 2009; Vishwanath, 2014; Piquart & Shen, 2011; Fernandes et al, 2007), whilst adolescence in general is associated with a rise in social anxiety due at least in part to the increased importance of positive peer group relations (Holmbeck, 2002; Fuligni, et al, 2001; Bruce & Saeed, 1999; Velting & Albano, 2001). These phenomena maximise the likelihood (and thus potential identification) of both experiential social anxiety and specific anxiety provoking situations in adolescents with diabetes compared to non-diabetic peers.

Both anxiously anticipated and historically encountered negative social interactions related to diabetes were described by adolescents (and, in some cases, their parents). This is significant regarding the existing literature on the aetiology of social anxiety. On one hand, some authors and models suggest that some individuals are inherently more socially anxious, and as such may perceive or anticipate social threat in the absence of any actual danger (see Velting & Albano, 2001). However, others suggest that social anxiety develops as a *result* of previously encountered situations (i.e. negative past experiences), with negative and anxious cognitive styles developing as a consequence of this (Clark,

2001). This review did not clearly support evidence for one of these theories over the other, though in line with the first theory, some individuals described feeling anxious about situations despite never having encountered them.

However, in support of the second theory, other adolescents described developing fear of a specific situation due to previous negative reactions. Whilst it is theoretically possible that socially anxious individuals are more likely to hold negative attributions around ambiguous past social interactions, that such negative interactions were also described by adolescents who did not experience social anxiety in relation to their diabetes suggests that their reporting cannot be wholly attributed to a socially anxious disposition. Furthermore, the negative social encounters reported by adolescents in this study are significant, as they are situations over and above those experienced by adolescents who do not have diabetes. As such it is possible that one contributing factor to the greater levels of social anxiety in adolescents with diabetes is that they face a greater incidence of socially threatening situations.

None of the studies reviewed explicitly detailed experiences consistent with the 'processing of self as a social object' component described in Clark & Wells' (1995) model of social anxiety, which concerns the live-monitoring of how an individual appears to others during anxiety producing situations (i.e. 'I must look anxious because I feel anxious'). Whilst the general sense of 'feeling different' described in the underlying beliefs and assumptions theme might arguably be akin to a 'felt sense' of difference as described in the current theme by Clark and Wells (1995), this communicated felt sense was more pervasive and reflective rather than one arising acutely during feared situations. Three likely explanations for the absence of situation based self-monitoring are as follows. Firstly, as none of the reviewed studies directly aimed to explore diabetes related social anxiety, this particular acute stage of social anxiety would not have been probed in

detail (as opposed to more general questions about how adolescents ‘felt’ about their diabetes when in school). Secondly, as avoidance of feared situations was an available and frequently chosen option, it may be that these were rarely endured. As such, the live processing of the self as social object may not have been a familiar or accessible experience. Thirdly, it is notable that the adolescents in this study reported being anxious about revealing their diabetes to peers, rather than anxiety per se. Accordingly, symptoms of anxiety may not have been a particular concern for this group.

The inability to identify this pre-determined component of social anxiety within the literature also reflects the wider methodological limitations of using an existing model as the basis for data extraction and synthesis. Whilst the conceptualisation of social anxiety within Clark and Wells’ (1995) framework helped to organise this process, and maximised the connectedness of this review to existing and recognised understandings of social anxiety, there are some drawbacks to this approach. In particular, just as a phenomenon characteristic of general social anxiety was not identified in regards to diabetes related social anxiety, there may have been unique experiences of diabetes related social anxiety in the literature reviewed which were not captured as a result of this method. As such, this review should not be taken as a definitive and exhaustive description of the social anxiety experienced by adolescents in relation to their diabetes, but rather as a preliminary suggestion that social anxiety is experienced. Furthermore, although the Clark and Wells (1995) model can be interpreted from a continuum approach to ‘social anxiety’, employing a model which uses this term (as opposed to ‘social discomfort’) might invite interpretation of this review from a psychopathological stance, given historic conceptualisations. Although there may be cases where diabetes related social anxiety *is* clinically relevant (in terms of preventing functioning), it would likely be unhelpful to pathologise (i.e. seek intervention for) understandable responses to real

stigma. Consequently, it is important to emphasise that this review makes no categorical claims as to the clinical significance of the experiences described.

However, the findings of this review are nonetheless significant to the field of diabetes care. Existing research has suggested that the relatively poor self-management observed throughout adolescence occurs despite an understanding of its importance (Thomas, Peterson & Goldstein, 1997), with this review suggesting that social anxiety might be one barrier to optimal adherence. Researchers have previously found that negative cognitions are associated with poor adherence to self-management in adolescents with diabetes (Farrell, Hains, Davies, Smith & Parton, 2004), with the current review suggesting that negative cognitions around social outcomes of this may be a possible mechanism for this association. Similarly, the negative situations previously encountered by adolescents in this review may contribute in part to the finding that negative cognitions are generally higher in these adolescents compared with non-diabetic peers (Marini et al, 2013).

In addition to exploring these relationships within existing studies, further research issues are implicated from this review. It would be of particular interest to investigate the overlap between general and diabetes related social anxiety in this group- for example, determining whether the increased rate of social anxiety in adolescents with diabetes is related to their experience of diabetes specific situations. Additionally, it may be significant to explore the relationship between diabetes related social anxiety and peer support. Since researchers have previously found perceived rather than actual peer support to enhance self-management (Kyngäs, Hentinen & Barlow, 1998), the relative influence of social interactions and the cognitive processes involved would be one particular area of interest. Other areas of interest include the prevalence of perceived versus actual stigma experienced by those with diabetes, and the real familiarity of parents with their adolescents' experience of living with (and self-managing) the disease.

There were several major shortcomings in the current review. Firstly, it made no attempt to gauge the *extent* to which diabetes related social anxiety is experienced within this population. The lack of studies investigating this area, the varying methodological quality of the papers included and the small samples used within quantitative papers made it implausible to achieve this. Such limitations, in addition to the difficulty presented in identifying studies relevant to this topic (resulting in the majority of papers being identified through the ancestry method) emphasise the need for a coherent, high quality literature base for researchers considering this topic in the future. The present review made no attempt to look at variables which might mediate such anxiety (i.e. demographic or cultural differences, which may have been significant to idiosyncratic study findings given the geographical spread of the studies reviewed), and besides qualitative reports of forfeited self-management and generally negative emotional and cognitive states, there was no suggestion of the cumulative effects of such anxiety (i.e. its impact on individuals' overall functioning or wellbeing). Additionally, all findings were based on *reported* (rather than observed) social anxiety.

Nonetheless, this review has significant implications for those involved in the care of adolescents with diabetes. First and foremost, the potential for diabetes related social anxiety to become a barrier to self-management in peer group situations should not be underestimated. Clinicians involved in the care of adolescents with diabetes should endeavour to explore this area with their clients. Those who experience and are affected by such anxiety may benefit from psychosocial support, and interventions aimed at reducing this experience and its consequences could be developed. The review also raises implications regarding the importance of diabetes education for schoolteachers, as several adolescents in the reviewed studies mentioned insensitive or inappropriate treatment by school staff. Finally, all involved in the care of adolescents with diabetes should be mindful of the challenging and conflicting demands and pressures that this

group may face from different social groups in relation to their diabetes, and not undermine the potential impact of this on either their physical or psychosocial wellbeing.

References

- Berlin, K. S., Hobart Davies, W., Jastrowski, K. E., Hains, A. A., Parton, E. A., & Alemzadeh, R. (2006). Contextual assessment of problematic situations identified by insulin pump using adolescents and their parents. *Families, Systems & Health*, 24(1), 33-44.
- Bögels, S. M., Alden, L., Beidel, D. C., Clark, L. A., Pine, D. S., Stein, M. B., & Voncken, M. (2010). Social anxiety disorder: questions and answers for the DSM-V. *Depression and anxiety*, 27(2), 168-189.
- Bruce, T. J., & Saeed, S. Y. A. (1999). Social anxiety disorder: A common under-recognised mental disorder. *American Family Physician*, 60, 2311-2320
- Buchbinder, M. H., Detzer, M. J., Welsch, R. L., Christiano, A. S., Patashnick, B.S. & Rich, M. (2005). Assessing adolescents with insulin-dependent diabetes mellitus: a multiple perspective pilot study using visual illness narratives and interviews. *Journal of Adolescent Health*, 36, 9-13.
- Canadian Paediatric Society (2003). Age limits and adolescents. *Paediatrics & Child Health*, 8(9), 577.
- Clark, D. M. & Wells, A. (1995) A cognitive model of social phobia. In R. G. Heimberg, M. R. Liebowitz, D. Hope et al (Eds) *Social Phobia – Diagnosis, Assessment, and Treatment* (pp. 69–93). New York, NY: Guilford.
- Clark, D. M. (2001). A cognitive perspective of on social phobia. In W. R. Crozier and L.E. Alden (Eds.), *International Handbook of Social Anxiety: Concepts, Research and Interventions Relating to the Self and Shyness* (pp. 405-430). Hoboken, NJ: Wiley.

- Davidson, M., Penney, E. D., Muller, B. & Grey, M. (2004). Stressors and self-care challenges faced by adolescents with type 1 diabetes. *Applied Nursing Research*, 17(2), 72-80.
- De Boer, H. M., Mula, M., & Sander, J. W. (2008). The global burden and stigma of epilepsy. *Epilepsy & Behavior*, 12(4), 540-546.
- de Ornelas Maia, A. C. C., de Azevedo Braga, A., Brouwers, A., Nardi, A. E., & de Oliveira e Silva, A. C. (2012). Prevalence of psychiatric disorders in patients with diabetes types 1 and 2. *Comprehensive psychiatry*, 53(8), 1169-1173.
- Devine, K. A., Storch, E. A., Geffken, G. R., Freddo, M., Humphrey, J. L., & Silverstein, J. H. (2008). Prospective study of peer victimization and social-psychological adjustment in children with endocrine disorders. *Journal of Child Health Care*, 12(1), 76-86.
- Di Battista, A. M., Hart, T. A., Greco, L. & Glozier, J. (2009). Type 1 diabetes among adolescents: reduced diabetes self-care caused by social fear and fear of hypoglycemia. *The Diabetes Educator*, 35(3), 465-475.
- Diabetes UK (2008). *Minding the gap: The provision of psychological support and care for people with diabetes in the UK*. Retrieved from https://www.diabetes.org.uk/Documents/reports/Minding_the_gap_psychological_report.pdf
- Diabetes UK (2014, March). *Diabetes: Facts and stats*. Retrieved from <http://www.diabetes.org.uk/Documents/About%20Us/Statistics/Diabetes-key-stats-guidelines-April2014.pdf>

- Dickinson, J. K. & O'Reilly, M. M. (2004). The lived experience of adolescent females with type 1 diabetes. *The Diabetes Educator*, 30(1), 99-107.
- Farrell, S. P., Hains, A. A., Davies, W. H., Smith, P., & Parton, E. (2004). The impact of cognitive distortions, stress, and adherence on metabolic control in youths with type 1 diabetes. *Journal of Adolescent Health*, 34(6), 461-467.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5, 1–11.
- Fernandes, P. T., Salgado, P. C., Noronha, A. L. A., Barbosa, F. D., Souza, E. A., Sander, J. W., & Li, L. M. (2007). Prejudice towards chronic diseases: comparison among epilepsy, AIDS and diabetes. *Seizure*, 16(4), 320-323.
- Fulgini, A. J., Eccles, J. S., Barber, B. L., & Clements, P. (2001). Early adolescent peer orientation and adjustment during high school. *Developmental Psychology*, 37(1), 28.
- Hains, A. A., Berlin, K. S., Hobart Davies, W., Parton, E. A. & Alemzadeh, R. (2006). *Diabetes Care*, 29(4), 818-822.
- Hains, A. A., Berlin, K. S., Hobart Davies, W., Smothers, M. K., Sato, A. F. & Alemzadeh, R. (2007). Attributions of adolescents with type 1 diabetes related to performing diabetes care around friends and peers: the moderating role of peer support. *Journal of Pediatric Psychology*, 32(5), 561-570.
- Hanna, K. M., & Outhrle, D. W. (1999). Involvement in health behaviors among youth with diabetes. *The Diabetes Educator*, 25(2), 211-219.

- Helgeson, V. S., Reynolds, K. A., Siminerio, L., Escobar, O., & Becker, D. (2008). Parent and adolescent distribution of responsibility for diabetes self-care: Links to health outcomes. *Journal of Pediatric Psychology, 33*(5), 497–508.
- Holmbeck, G. N. (2002). A developmental perspective on adolescent health and illness: An introduction to the special issues. *Journal of Pediatric Psychology, 27*(5), 409-416.
- Hussein, H. A., & Abdel Sadek, B. R. (2014). Hindering factors of self-management in diabetes mellitus as perceived by adolescents versus mothers. *World Applied Sciences Journal, 29*(1), 9-19.
- Huus, K. & Enskär, K. (2007). Adolescents' experience of living with diabetes. *Paediatric Nursing, 19*(3), 29-31.
- Karlsson, A., Arman, M. & Wikblad, K. (2006). Teenagers with type 1 diabetes- a phenomenological study of the transition towards autonomy in self-management. *International Journal of Nursing Studies, 45*, 562-570.
- Kyngäs, H. Hentinen, M. & Barlow, J. H. (1998). Adolescents' perceptions of physicians, nurses, parents and friends: help or hindrance in compliance with diabetes self-care? *Journal of Advanced Nursing, 27*, 760-769.
- Lefebvre, C., Manheimer, E., & Glanville, J. (2011). Searching for studies. In J. P. T. Higgins and S. Green (Eds.), *Cochrane Handbook for Systematic Reviews of Interventions* (pp. 95-150). Available from www.cochrane-handbook.org.
- Lehmkuhl, H. D., Merlo, L. J., Devine, K., Gaines, J., Storch, E. A., Silverstein, J. H. & Geffken, G. R. (2009). Perceptions of type 1 diabetes among affected youth and their peers. *Journal of Clinical Psychology in Medical Settings, 16*, 209-215.

- Marini, E., Giannakopoulos, G., Charitaki, S., Belivanaki, M., Salavou, V., Liakopoulou, M., & Kolaitis, G. (2013). Mental health of adolescents with type I diabetes: A case report. *Health, 5*(8), 1268-1271.
- McCarroll, E. M., Lindsey, E. W., MacKinnon-Lewis, C., Chambers, J. C., & Frabutt, J. M. (2009). Health status and peer relationships in early adolescence: The role of peer contact, self-esteem, and social anxiety. *Journal of Child and Family Studies, 18*(4), 473-485.
- McConnell, E. M., Harper, R., Campbell, M., & Nelson, J. K. (2001). Achieving optimal diabetic control in adolescence: the continuing enigma. *Diabetes/metabolism research and reviews, 17*(1), 67-74.
- McNeil, D. W. (2001). Terminology and evolution of constructs related to social phobia. In S. G. Hofmann & P.M. DiBartolo (Eds.), *Social phobia and social anxiety: An integration* (pp. 8–19). Needham Heights, MA: Allyn & Bacon.
- Mulvaney, S. A., Rothman, R. L., Osborn, C. Y., Lybarger, C., Dietrich, M. S. & Wallston, K. A. (2011). Self-management problem solving for adolescents with type 1 diabetes: Intervention processes associated with an Internet program. *Patient Education and Counseling, 85*, 140-142.
- NHS (2007). *Making every young person with diabetes matter*. London, UK: Department of Health.
- Peters, L. W. H., Nawijn, L. & van Kesteren, N. M. C. (2014). How adolescents with diabetes experience social support from friends: two qualitative studies. *Scientifica, 2014*, 1-8.

- Pinquart, M., & Shen, Y. (2011). Depressive symptoms in children and adolescents with chronic physical illness: an updated meta-analysis. *Journal of pediatric psychology, 36*(4), 375-384.
- Pluye, P., Gagnon, M. P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies, 46*(4), 529-546.
- PRISMA (2015). *The PRISMA Statement*. Retrieved on 16/05/15 from <http://www.prisma-statement.org/statement.htm>
- Salamon, K. S., Hains, A. A., Fleischman, K. M., Davies, W. H., & Kichler, J. (2010). Improving adherence in social situations for adolescents with type 1 diabetes mellitus (T1DM): a pilot study. *Primary Care Diabetes, 4*(1), 47-55.
- Skinner, C., Petzing, J. & Johnston, C. (1999). Peers support and metabolic control in adolescence. *Journal of Diabetes Nursing, 3*(5), 140-144.
- Storch, E. A., Lewin, A., Silverstein, J. H., Heidgerken, A. D., Strawser, M. S., Baumeister, A., & Geffken, G. R. (2004). Peer victimization and psychosocial adjustment in children with type 1 diabetes. *Clinical Pediatrics, 43*(5), 467-471.
- Tfayli, H., & Arslanian, S. (2007). The challenge of adolescence: hormonal changes and sensitivity to insulin. *Diabetes Voice, 52*, 28-30.
- Thomas, A. M., Peterson, L., & Goldstein, D. (1997). Problem solving and diabetes regimen adherence by children and adolescents with IDDM in social pressure situations: a reflection of normal development. *Journal of Pediatric Psychology, 22*, 541-561.

- Veale, D. (2003). Treatment of social phobia. *Advances in psychiatric treatment*, 9(4), 258-264.
- Velting, O. N., & Albano, A. M. (2001). Current trends in the understanding and treatment of social phobia in youth. *Journal of Child Psychology and Psychiatry*, 42(01), 127-140.
- Vishwanath, A. (2014). Negative Public Perceptions of Juvenile Diabetics: Applying Attribution Theory to Understand the Public's Stigmatizing Views. *Health communication*, 29(5), 516-526.
- Wang, Y., Brown, S. A. & Horner, S. D. (2010). School-based lived experiences of adolescents with type 1 diabetes: A preliminary study. *Journal of Nursing Research*, 18(4), 258-265.
- Wang, Y., Brown, S. A., & Horner, S. D. (2013). The school-based lived experiences of adolescents with type 1 diabetes. *Journal of Nursing Research*, 21(4), 235-243.
- Williams, C. (1999). Gender, adolescence and the management of diabetes. *Journal of Advanced Nursing*, 30(5), 1160-1166.

Part Two: Empirical Paper

This paper is written in the format ready for submission to *Diabetes Care*. Please see Appendix F for submission guidelines.

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**When paper cuts lead to limb loss:
Experiences of amputation related to type 2 diabetes**

A qualitative, interview based study

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Abstract

Objective- Diabetic amputation occurs amidst a clinical, economical and sociocultural emphasis on preventability. This study explored individuals' experiences of amputation related to type 2 diabetes (with particular focus on perceptions of personal and external influences) in order to develop the minimal literature base on this form of amputation, and inform its clinical management.

Research Design and Methods- A phenomenological qualitative approach was used to elicit detailed accounts across the timeline of diabetic amputation. Eight adult males with amputations related to type 2 diabetes took part in semi-structured interviews. Interviews were transcribed, and themes identified in accordance with Interpretative Phenomenological Analysis.

Results- Five major themes were identified: Unawareness, doubt and dismissal; From shock to acceptance; Options and decisions; Knowing and realising; and Doing it differently.

Conclusions- Despite receiving education on related risks, interviewees did not link developing foot problems to diabetes, dismissing the significance of these. Good relationships with staff allowed individuals to feel supported in making the decision to amputate. The clinical and psychosocial importance of staff-patient relationships and individualised education are discussed, as well as the need for research exploring varied experiences of amputation.

Introduction

Complications related to diabetes account for around half of all lower limb amputations performed in the UK and Europe (1, 2, 3). Approximately 120 amputations are carried out on people with diabetes each week in England, with National Health Service expenditure on the procedure estimated at £119 million annually (4, 5). It is estimated that 5% of people with diabetes will undergo a related amputation (6). The majority of these amputations result from a foot ulcer or infection failing to heal, with toes, feet or legs (above or below knee) requiring removal (4).

However, not all foot problems result in amputation. Of the one in twenty people with diabetes who develop a foot ulcer each year, just over one in ten will require the amputation of a foot or leg (7). The National Institute for Health and Clinical Excellence stipulate that the management of ulcers should be overseen by a Multidisciplinary Footcare Team, who aim to prevent irreversible damage or the spread of infection through medical intervention and observation (8). The preventability of diabetic amputations has been emphasised by healthcare charities and organisations, and they have indeed been reduced by over 50% in hospitals with rapid access foot care teams (4). Nonetheless, for those who ultimately require amputation, around 1 in 5 will undergo further amputation(s) within a year, and up to 80% will die within 5 years of the procedure (9, 10).

A considerable amount of research has examined the psychosocial aspects of amputation in general. Reduced psychological wellbeing (i.e. increased levels of depression and anxiety) and altered self-image have repeatedly been reported post-amputation, with potential issues such as pain, prosthesis satisfaction and phantom limb syndrome⁴ presenting specific challenges (11). However, such research typically examines amputations of all aetiologies within one homogenous group, despite potentially distinct

⁴ The experience of sensation in a limb which has been removed

differences between aetiologies. For example, as opposed to those with traumatic amputations (i.e. resulting from accidents or injuries), individuals with diabetic amputations may have been aware of amputation as a risk attached to pre-existing diabetes, and/or may acknowledge that further amputations are possible.

In studies which distinguish between aetiologies, individuals with diabetic amputations have demonstrated lower psychological wellbeing than healthy and diabetic controls (12, 13), suggesting significant psychosocial consequences of diabetic amputation. Whilst there is conflicting evidence as to how psychosocial functioning following amputation differs from amputations of other aetiologies (14, 15), studies have revealed topics of significance for this population which may be unique. These include concern with the self-management of diabetes, the perception of the amputation as a ‘relief’ from pain and the attribution of responsibility for the amputation towards the self or clinician (16, 17, 18). Additionally, individuals with diabetes have been found to demonstrate poorer psychological wellbeing than those without at baseline, (19, 20, 21), suggesting that diabetic amputation may occur within an already challenging psychosocial landscape. This may impact upon individuals’ experiences of amputation.

This study sought to further explore individuals’ experiences of diabetic amputation, with a particular focus on the experience of perceived feelings of influence or responsibility over the amputation, conceptualised within psychological literature as Health Locus of Control (i.e. an individual’s perceived location of control over health events as being internal or external to themselves; 22). This focal experience was chosen given the theme’s recurrence in previous open ended qualitative interview studies with this population (17, 18), and in light of the current organisational and societal emphasis on the preventability of these amputations. The study specifically concerned people with

type 2 diabetes⁵, given the similar rhetoric on this form of the disease (23, 24), and suggestions from previous research that the psychosocial profile of the two types of diabetes may differ (including in regards to perceived influence over diabetes; 25). The primary aim of this study was to facilitate an understanding of the experience and meaning of diabetic amputation for those who have undergone it, with a secondary aim of eliciting experiences which may be unique to this aetiology. Such research may be valuable both in terms of expanding the body of literature, and in informing the clinical management of diabetic amputation.

Research design and methods

Design

This was a qualitative, semi-structured interview based study. Interviewees' transcribed responses comprised the data collected. Interpretative Phenomenological Analysis (IPA; 26) was used to inform the interview questions and analysis of the data.

Participants and recruitment

Opportunity sampling was used to recruit participants for a semi-structured interview based study. Individuals who were aged 18 or over, had type 2 diabetes, were native speakers of English and had undergone any level of diabetic amputation (from toe to above knee) were eligible for inclusion (since no consistent psychosocial differences have been found between different levels of amputation; see 11). Potential interviewees were recruited from a rapid access diabetic foot ulcer clinic in a hospital in the North of England, which oversaw the management of active foot ulcers and aftercare of related surgeries [see Appendices G – J for documentation of ethical approval and forms used].

⁵ Where the body produces insulin, but it is not *sufficient* to break down blood glucose. As opposed to type 1 diabetes, type 2 diabetes is linked to lifestyle factors, and is typically developed at an older age.

A final sample of eight eligible participants took part. All were male and white British, with a mean age of 65.00 years (SD = 14.33; range 41-89 years). The average time since diagnosis of diabetes was 10.50 years (SD =5.76; range 2-20 years). Further participant details can be found in table 1.

Table 1. Details of the interviewees

Pseudonym	Age	Age at diagnosis	Time since amputation*	Level
Darren	41	39	9 days	Below knee
Charlie	89	76	2 months	Below knee
Roger	73	53	3 years	Above knee
Mack	74	63	6 months	Multiple toes (Bilateral)
Brian	54	50	7 months	Below knee
Owen	66	58	4 years	Partial foot
Vic	71	57	1 month	Foot
Pat	64	52	15 months	Toe

*In the case of progressive amputations, time since most recent procedure

Procedure

A semi-structured interview concerning the perceived influence of self, others and chance (based on the construct of Health Locus of Control) at various stages of amputation was developed⁶ [see Appendix K]. Ethical approval was obtained from the National Health Service ethics committee. Eligible participants were invited to take part in the study by clinic staff. Informed consent was obtained for all participants prior to the interview with the researcher. Interviews lasted 30-60 minutes, and were audio-recorded and transcribed. Due to the semi-structured nature of the interview, amputation related experiences raised

⁶ The clarity and appropriateness of the interview was reviewed and approved by members of an internet forum for people with diabetes. Consequently, no changes were made following this review.

by the individual that had not specifically been probed by the interviewer (i.e. that were not specifically related to perceptions of influence) were also explored.

The IPA approach was used to analyse the resulting data. The process of analysis followed that described by Smith, Jarman and Osborn (27). Individual transcripts were examined in detail [see Appendix L], with emergent themes identified within each. These were then sorted into a smaller number of super-ordinate themes. Relationships between these themes were explored, facilitating the re-organisation of themes. To enhance credibility, the decision making process was tracked, and a second researcher independently coded a sample of transcripts to add to and compare with emergent themes. Clusters of themes from each transcript were then brought together, and groupings of themes across the accounts established. Quotations relating to each concept were extracted, aided by tabular representations [see Appendix M]. The process involved ongoing interaction with, and reflection upon, the original data and themes.

Results

The following themes were synthesised from the interviewees' accounts. A summary of these themes (and subthemes) is presented in table 2

Unawareness, doubt and dismissal

Each interviewee described being unaware, doubtful or dismissive of the potential severity of damage to their feet, and/or of the connection of such damage to type 2 diabetes. For most, such perspectives were restricted to the initial development of the foot problem, although for some these remained present at the time of interview. Typically, the initial problem had stemmed from a clear chance event (including wearing new footwear, stepping on a nail, insect bites or gout), although one individual, Roger, could identify no clear origin for the swelling of his leg:

Table 2. Themes and subthemes synthesised from interviewees' accounts.

Theme	Subtheme
Unawareness, doubt and dismissal	<p>The origin of the damage as separate from diabetes</p> <p>The damage as seemingly inconsequential</p> <p>Dismissing the need for professional help</p> <p>Deterioration and eventual professional involvement</p> <p>Struggling to grasp (having) diabetes</p>
From shock to acceptance	<p>Initial reaction to prospect of amputation</p> <p>The value of staff support</p> <p>Time to adjust</p> <p>Acceptance of amputation</p>
Options and decisions	<p>Uncertainty</p> <p>The turning point</p> <p>Weighing up the pros and cons</p> <p>It's <i>your</i> decision</p> <p>Valuing others' support</p> <p>Valuing others' advice</p>
Knowing and realising	<p>Acknowledging previous knowledge</p> <p>Realising through experience</p> <p>Looking for more information</p>
Doing it differently	<p>Amputation as less negative than expected</p> <p>Wanting to avoid further amputations</p> <p>Perceptions of personal influence</p> <p>Optimism vs. pessimism about self-management</p> <p>The importance of listening to others</p> <p>Everyone makes mistakes</p>

“I started worrying a bit then. Because... well, you don't know what's wrong with it. But you have doctors, so. So you just leave it, well, come and get it in their hands and that's it. You can't do nowt about it.”

Whilst this unprecedented swelling worried Roger, most dismissed their early foot problems, which presented only as small, acute damage- variously described as ‘nowt/nothing’, a ‘silly bloody thing’, a ‘blister’ and a ‘paper-cut. They expected these would eventually heal, and were not worth attending to. As Mack explained:

“Instead of like, coming straight away and doing something about it and seeing the doctor, I didn't. Because I thought “Oh, it's nowt”. You know, like I'd cut meself and stuff and stupid stuff and I've just let it get on and it's mended on its own... I didn't realise that diabetes did as much damage, you know?”

At the time it was felt that such damage would resolve on its own, or with basic management at home. Two individuals, Brian and Darren, considered this self-efficacy and reluctance to seek help a ‘typical man thing’. However, when the damage began to seriously impact functioning or had failed to resolve after considerable time, professional support was eventually sought- in Darren's case, on the persuasion of his family. Most were quickly seen by the specialist diabetes service, although one was initially treated (unsuccessfully) by a GP.

When the connection between ulcers and diabetes was explained by staff, interviewees had different responses. Most accepted the relation to diabetes as valid, mentioning being told of these risks before, but not consciously acknowledging them (although Pat denied having been informed). Some admitted not previously feeling that they really ‘had’ diabetes before, having not felt any different since diagnosis. Darren, who was not

diagnosed until he sought treatment for his ulcer, accepted both his diagnosis and its connection to the ulcer. Owen, however, outwardly refuted the suggestion:

“They put on the record that it was caused with diabetes. I said bollocks.”

From shock to acceptance

Upon contact with the specialist team, all were quickly confronted with the possibility of amputation- although the timescale of this varied. In the case of Owen, whose foot had developed gangrene, this was discussed with urgent effect:

“He says well, you’ve got gangrene. It’s either them two toes come off or, if I wait a couple of days, your foot comes off.”

However, for most this was first discussed as an eventual ‘last resort’. Whilst in all cases the suggestion came as unwelcome, it was more surprising for those who had long dismissed the problem as insignificant. For Vic, the news was a ‘shock’:

“It were a bit of a shock when he first told me. You know what I mean, I said ‘come off?’ and he said yeah it’ll be your toe has to come off.”

Others, however, had not found it particularly surprising. As Pat explained:

“I had been coming [to the clinic] for so long and I’d seen everybody round, talking to people, and I had a good idea... what would happen. I mean, but they don’t... cut corners what they’re telling you.”

Each interviewee described this ‘directness’ from staff, and regarded it as a positive thing. Though all but one (Owen) had initially undergone several courses of treatment in order to ‘save’ their limbs or extremities, early awareness of the possibility of amputation had

made then able to come to terms with this over time- making the eventual amputation easier to accept. Vic described this transition:

“It isn’t like a surprise... You know what’s going to happen. I mean they told me. There were always a saying at the back of me mind, they used to say, keep it in your mind that we may have to amputate your leg... You’ve just got to bear that in mind, that that could be the worst scenario”

Besides the passage of time, this internal transition was sometimes aided by gradual normalisation of amputation within the clinic. Interacting with patients and staff for whom amputation was an everyday reality –as in Pat’s example above- provided reassurance that life after amputation was manageable.

Options and decisions

For all interviewed, amputation was fundamentally a decision. Although the urgency with which the decision had to be made varied, all explicitly indicated that they felt that it was ultimately theirs to make, as explained by Mack:

I: Do you think that if you had said no [to the amputation] they would have listened?

M: Oh yeah, yeah, well they’ve got to haven’t they really? You know I mean, it’s your decision, isn’t it?

Where possible, the interviewees first had opted to try to salvage the extremity or limb, which involved ongoing treatment. Throughout this period, they described feeling supported by the staff, as Charlie illustrated:

C: Other people were trying to save it, but they’re more used to it than me, and I think they knew it couldn’t be saved. But I were adamant, I were gonna save it.

I: And did they listen to you... did they let you make that decision?

C: They let me make it, and they backed me all the way through.

However, this pursuit of treatment came with the acknowledgement that alternate interventions were not always effective, nor predictable. This was conferred to them by staff, as Darren explained:

“He said we’ll see how that [dressing] goes, but he said obviously if that doesn’t, you know, work, it might, it will require like further surgery. Which will mean... losing your foot or your whole leg.”

The decision to amputate typically came over time, after a series of ultimately unsuccessful interventions. Many described a distinct point at which they felt amputation was ‘inevitable’; occasionally connected to a development with the complication. This, combined with the increasing functional difficulty of living with ulcers and compared with the risk of further limb loss or death, meant that amputation was eventually considered the best option. As Darren described:

“When we first started talking about it... it seemed you know like a big massive decision... I was sat there thinking, you know, I don’t want to... cut part of me leg off. But then... down the line and with it not healing... it were... quite a simple decision”

Throughout this process, support and advice from staff were greatly appreciated by all. Evident investment in patient care, a long relationship and a ‘personal’ style meant that the interviewees particularly trusted and respected professional opinions, which were assimilated into their own decisions. A smaller number additionally highlighted the support of family during this time.

Knowing and realising

Whilst some denied having previously been informed about the specific risks of diabetes, others described the experience of amputation as bridging the gap between ‘knowing’ and ‘realising’ such consequences. For some, this had signified the first tangible problem they

had experienced due to diabetes. Brian described his initial despondent relationship with his diabetic status thusly:

“When they come along and say you’ve got diabetes, well, ‘I haven’t got diabetes, I’m walking 2 and a half marathons a week’, you know, so, you know, 4 to 500 calories a pint felt, you know, fine.”

Without any immediate problems evident, the significance of diabetes and associated self-management was lost on those receiving relevant information and advice. Brian went on to emphasise that it was not a lack of knowing that prevented him from initially seeking help for his foot, but rather a lack of implementing this knowledge, due to the perceived harmlessness of it:

“The problem had been I knew what I had to do- if I had a cut on my toe, I had to get it looked at. And I didn’t. That’s why I say it was my stupidity, rather than lack of knowledge.”

Whilst Brian later speculated whether he may have taken the message on board more readily if he had discussed complications with a likeminded patient rather than a professional, others maintained that personal experience was the only effective way of learning. For example, though Vic now considered diabetes serious and worth ‘taking on board’, he was unsure that anybody else’s messages would ever have been heard:

“It’s a shame, you have to... it takes all this to make you learn, and you didn’t listen properly to begin with... It’s like somebody saying to you, watch out, careful, you’ll get run over. That don’t alter your way of crossing road. You won’t feel conscious every day, I’d better stand on this causeway and remember what they told me...you don’t.”

Many discussed having since made an effort to find out more about diabetes and its link to complications, which involved actively questioning staff. Understanding the

mechanisms by which diabetes contributes to foot problems and amputation⁷ was considered helpful, as this tied together the advice given around self-management and such risks.

Doing it differently

The experience of amputation was universally described as less negative than expected, with some functional loss and associated effects on social and occupational life being the only problems highlighted by this group, and several enjoyable experiences arising from it. However, in discussing future possible complications, all indicated that they would prefer not to lose anything further; although each also acknowledged this as a possibility. The perceived personal influence over this outcome varied between interviewees. A minority, including Roger, felt that nothing they could do could influence such a recurrence:

“R: I don’t want to lose nowt, but if there’s anything that has to come off it will come off, you know.

I: Do you feel that there’s any way that you can prevent things from needing to come off?

R: No. No I’m alright now. Touch wood.”

Others described feeling that although amputation may not be entirely avoidable, there were things they could do to make it less likely. These included self-management through diet and exercise, checking their feet regularly, and contacting the foot clinic immediately if problems were detected. Some were enthusiastic and optimistic about these changes, motivated by positive results such as weight loss and staff acknowledgement. Pat,

⁷ These include sensory neuropathy (a lack of feeling; especially in the extremities), poor circulation, increased susceptibility to infections and poor wound healing, all of which can result from excessive blood glucose levels.

however, who felt he had tried to self-manage as well as possible since he was first diagnosed, described how tiring this could become:

“It’s a bind. You know, to do it, because you’re supposed to check it before your breakfast, after your breakfast, before your dinner... If you’re out and you’re doing something you can’t”

Whilst Vic factored spousal support into his self-management, most considered future efforts to manage complications to be between themselves and the team. Although the majority were happy to accept the advice of the team, Pat in particular found that their recommendations could sometimes conflict:

“The first thing they say to you [when you have an ulcer]- rest it. Elevate your foot. And then you go to your diabetic nurse and they say you’ve put weight on.”

However, Vic and Charlie, who experienced progressive amputations, described eventually losing sight of the importance of self-management after previous amputations- suggesting that this initial motivation might not be sustainable. Charlie, who explained that his diabetes had previously been managed by his late wife, suggested that he would likely prioritise his self-management once a complication became imminent:

“If owt starts going wrong, then I’ll stop [eating sweets]”

Finally, although many felt in hindsight that they had been primarily responsible for their amputations, none held lasting negative feelings about this. Instead, it was acknowledged that they, like everybody, sometimes made poor choices. Furthermore, all were adamant that they in no way attributed any blame to staff.

Conclusions

In light of previous literature and a societal rhetoric on preventability, this study enquired about individuals' experience of perceived influence (personal and other) over the course of amputation. Whilst by the time of interview most interviewees believed that they could reduce the likelihood (if not prevent) further amputations, perceived influence had not felt relevant prior to historic amputations, as none interviewed had related emerging foot problems to diabetes. Instead, the asymptomatic nature of the disease had led to doubt or dismissal over its significance- or even existence. This is interesting with regards to the popular 'health belief' model (see 28), which includes the role of disease severity in regards to disease related behaviours, but which assumes that the individual 'realises' that they have the given condition.

For those who accepted the diagnosis, the perceived seriousness was low. This sentiment echoes that in previous research such as that by the International Diabetes Federation (29), in which 64% of British participants with type 2 diabetes stated that they had a 'mild' form of the disease, and Holmström and Rosenqvist (30), where participants indicated that Type 2 diabetes was not 'real diabetes'. Hence, diabetes (and its self-management) was not prioritised, and emerging foot problems were not attributed or related to the disease. Instead, these were only attended to once they became problematic in their own right, with sensory neuropathy and masculine ideas about care seeking (31) further delaying this reaction.

Whilst prospective amputation initially came as a shock, agency in treatment decisions and emotional support from family and/or (more commonly) staff allowed those interviewed to adjust to the idea. Such factors have been referred to as 'coping' strategies (32), with previous researchers similarly suggesting that problem-focussed coping (i.e. trying to salvage the limb) is helpful when problems may be practically overcome, after which point emotion-focussed coping (i.e. talking through feelings with staff) is more

beneficial (i.e. 33). Additionally, the passage of time allowed for the normalisation of amputation by staff and other patients, and potentially the emotional remediation of transition as suggested by Hopson and Adams (34).

Two major clinical implications arise from this study. Firstly, it is apparent that the organisational importance placed upon type 2 diabetes (evident, for example, in the increased resources invested; 35) is not translating universally to patients. In this study, formal education unsuccessfully contended with an asymptomatic presentation and a concept of type 2 diabetes as harmless and/or a 'fad'. Since individual preferences for information varied between interviewees (i.e. written vs. spoken, peer delivered), individually tailored education approaches are advisable, in addition to an acknowledgement of the intangibility of the disease and a basic explanation of the mechanisms involved in foot damage.

Secondly, this study highlighted the importance of the staff relationship in the face of prospective amputations. Amputation was not described as a wholly negative experience by those interviewed, who cited a transparent, personal and supportive approach by staff as the predominant reason for this. Additionally, they exhibited a less blaming stance to themselves or others than those in similar studies (17, 18), which may be related to the emotional support facilitated by staff. Consequently, staff relationships of these qualities may foster better psychosocial outcomes of diabetic amputation; possibly in addition to the enhanced clinical outcomes of diabetes and related complications associated with clinician empathy (36, 37).

However, since this study concerned a purposefully homogenous sample, these conclusions and implications cannot be assumed to be generalisable to all in this situation. Conversely, the demographics of the sample may have had particular relevance to the experiences described. The sociocultural idea of being a 'big strong man' and thus

dismissing the need for help (rather than admitting weakness) was made explicit in two accounts, and thus male gender (and associated masculine ideas) may have proved a specific barrier to timely intervention for those in this study. Indeed, negative attitudes to care seeking have previously been speculated to contribute to the greater rate of complications and amputation related to type 2 diabetes in men (38). Similarly, that most interviewees were retired, lived alone and had ongoing foot problems likely influenced the experiences described. For example, living alone meant that others were not present to encourage them to seek timely support, and may have influenced the strong relational bonds that formed with staff.

Accordingly, further research should aim to explore the topic with samples with varied demographics, from different teams, and also in those with type 1 diabetes, whose beliefs around their condition may be different (i.e. in terms of believing the illness to be real). Nonetheless, the present study carries real implications for research and care in this underexplored but increasingly significant area- particularly in terms of efforts to understand and close the gap between 'knowing' and 'realising' of risks in patients with type 2 diabetes.

References

1. Vamos, E. P., Bottle, A., Majeed, A., & Millett, C. (2010). Trends in lower extremity amputations in people with and without diabetes in England, 1996–2005. *Diabetes Research and Clinical Practice*, 87(2), 275-282.
2. López-de-Andrés, A., Martínez-Huedo, M. A., Carrasco-Garrido, P., Hernández-Barrera, V., Gil-de-Miguel, Á., & Jiménez-García, R. (2011). Trends in lower-extremity amputations in people with and without diabetes in Spain, 2001–2008. *Diabetes Care*, 34(7), 1570-1576.
3. Moxey, P. W., Gogalniceanu, P., Hinchliffe, R. J., Loftus, I. M., Jones, K. J., Thompson, M. M., & Holt, P. J. (2011). Lower extremity amputations—a review of global variability in incidence. *Diabetic Medicine*, 28(10), 1144-1153.
4. Diabetes UK (2013, February). *Fast track for a foot attack: Reducing diabetic amputations*. Retrieved from <https://www.diabetes.org.uk/Documents/Reports/putting-feet-first-foot-attack-report022013.pdf>
5. National Health Service (2012, March). *Foot care for people with diabetes in the NHS in England: The economic case for change*. Retrieved from <https://www.diabetes.org.uk/documents/nhs-diabetes/footcare/footcare-for-people-with-diabetes.pdf>
6. Colagiuri, S., Colagiuri, R., Conway, B., Graiger, D., & Davey, P. (2003). *DiabCo\$ Australia: Assessing the burden of Type 2 diabetes in Australia*. Canberra: Diabetes Australia.
7. Diabetes UK (2010, March). *Diabetes in the UK 2010: Key statistics on diabetes*. Retrieved from https://www.diabetes.org.uk/documents/reports/diabetes_in_the_uk_2010.pdf

8. National Institute for Health and Clinical Excellence (2011, March). *Diabetic foot problems: Inpatient management of diabetic foot problems*. Retrieved from <http://www.nice.org.uk/guidance/CG119>
9. Schofield, C. J., Libby, G., Brennan, G. M., MacAlpine, R. R., Morris, A. D., & Leese, G. P. (2006). Mortality and Hospitalization in Patients After Amputation A comparison between patients with and without diabetes. *Diabetes Care*, 29(10), 2252-2256.
10. Singh, N., Armstrong, D. G., & Lipsky, B. A. (2005). Preventing foot ulcers in patients with diabetes. *Journal of the American Medical Association*, 293(2), 217-228.
11. Horgan, O., & MacLachlan, M. (2004). Psychosocial adjustment to lower-limb amputation: a review. *Disability & Rehabilitation*, 26(14-15), 837-850.
12. Coffey, L., Gallagher, P., Horgan, O., Desmond, D., & MacLachlan, M. (2009). Psychosocial adjustment to diabetes-related lower limb amputation. *Diabetic Medicine*, 26(10), 1063-1067.
13. Peters, E. J., Childs, M. R., Wunderlich, R. P., Harkless, L. B., Armstrong, D. G., & Lavery, L. A. (2001). Functional status of persons with diabetes-related lower-extremity amputations. *Diabetes Care*, 24(10), 1799-1804.
14. Greive, A. C., & Lankhorst, G. J. (1996). Functional outcome of lower-limb amputees: a prospective descriptive study in a general hospital. *Prosthetics and Orthotics International*, 20(2), 79-87.
15. Singh, R., Ripley, D. & Hunter, J. (2008). Does diabetes increase levels of depression and anxiety after lower limb amputation? *Diabetes Research and Clinical Practice*, 80, 14-15.

16. Carrington, A. L., Mawdsley, S. K. V., Morley, M., Kinsey, J., & Boulton, A. J. M. (1996). Psychological status of diabetic people with or without lower limb disability. *Diabetes Research and Clinical Practice*, 32(1), 19-25.
17. Livingstone, W., van de Mortel, T. F. & Taylor, B. (2011). A path of perpetual resilience: Exploring the experience of a diabetes-related amputation through grounded theory. *Contemporary Nurse*, 39(1), 20-30.
18. Meatherall, B. L., Garrett, M. R., Kaufert, J., Martin, B. D., Fricke, M. W., Arneja, A. S., & Embil, J. M. (2005). Disability and quality of life in Canadian aboriginal and non-aboriginal diabetic lower-extremity amputees. *Archives of Physical Medicine and Rehabilitation*, 86(8), 1594-1602.
19. Bosić-Živanović, D., Medić-Stojanoska, M., & Kovačev-Zavišić, B. (2012). The quality of life in patients with diabetes mellitus type 2. *Vojnosanitetski Pregled*, 69(10), 858-863.
20. Anderson, R. J., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). The prevalence of comorbid depression in adults with diabetes a meta-analysis. *Diabetes care*, 24(6), 1069-1078.
21. Lustman, P. J., & Gavard, J. A. (1995). Psychosocial aspects of diabetes in adult populations. In R. Aubert (Ed.), *Diabetes in America* (pp. 507-518). Darby, Pennsylvania: Diane.
22. Wallston, K. A. (2001). Conceptualization and operationalization of perceived control. In A. Baum, T. A. Revenson, & J. E. Singer (Eds.), *The handbook of health psychology* (pp. 49–58). Mahwah, NJ: Erlbaum

23. National Institute for Health and Clinical Excellence (2011, May). Preventing type 2 diabetes: population and community-level interventions. Retrieved from <https://www.nice.org.uk/guidance/ph35>
24. National Institute for Health and Clinical Excellence (2012, July). Preventing type 2 diabetes: risk identification and interventions for individuals at high risk. Retrieved from <https://www.nice.org.uk/guidance/ph38>
25. Trento, M., Tomelini, M., Basile, M., Borgo, E., Passera, P., Miselli, V., ... & Porta, M. (2008). The locus of control in patients with Type 1 and Type 2 diabetes managed by individual and group care. *Diabetic medicine*, 25(1), 86-90.
26. Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261–271.
27. Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology* (pp. 218–240). London: Sage.
28. Walker, R. (1999). Models in health psychology: An introduction. *Journal of Diabetes Nursing*, 3(6), 188-191.
29. International Diabetes Federation (2007). *Choosing to take control in type 2 diabetes*. Retrieved from <http://www.idf.org/webdata/docs/ChooseControlReport.pdf>
30. Holmström, I. M., & Rosenqvist, U. (2005). Misunderstandings about illness and treatment among patients with type 2 diabetes. *Journal of Advanced Nursing*, 49(2), 146-154.
31. Charles, N., & Walters, V. (2008). Men are leavers alone and women are worriers: Gender differences in discourses of health. *Health, Risk and Society*, 10, 117–132.

32. Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
33. DeGraff, A., & Schaffer, J. (2008). Emotion-focused coping: a primary defense against stress for people living with spinal cord injury. *Journal Of Rehabilitation*, 74(1), 19-24.
34. Hopson, B. & Adams, J. D. (1976). Towards an understanding of transition: Defining some boundaries of transition. In J. Adams, J. Hayes & B. Hopson (Eds.), *Transitions: Understanding and managing personal change* (pp.3-25). London, UK: Martin Robertson.
35. Diabetes UK (2015, January). State of the nation: Challenges for 2015 and beyond. Retrieved from <https://www.diabetes.org.uk/Documents/About%20Us/What%20we%20say/State%20of%20the%20nation%202014.pdf>
36. Hojat, M., Louis, D. Z., Markham, F. W., Wender, R., Rabinowitz, C., & Gonnella, J. S. (2011). Physicians' empathy and clinical outcomes for diabetic patients. *Academic Medicine*, 86(3), 359-364.
37. Del Canale, S., Louis, D. Z., Maio, V., Wang, X., Rossi, G., Hojat, M., & Gonnella, J. S. (2012). The relationship between physician empathy and disease complications: an empirical study of primary care physicians and their diabetic patients in Parma, Italy. *Academic Medicine*, 87(9), 1243-1249.
38. Bruun, C., Siersma, V., Guassora, A. D., Holstein, P., & Fine Olivarius, N. (2013). Amputations and foot ulcers in patients newly diagnosed with Type 2 diabetes mellitus and observed for 19 years. The role of age, gender and co-morbidity. *Diabetic Medicine*, 30(8), 964-972.

Part Three: Appendices

Appendix A - Submission guidelines for *Qualitative Health Research*

Qualitative Health Research (QHR) is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

QHR is a member of the Committee on Publication Ethics.

This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE)

1. Article types

Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/qhr> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned. Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas:

Description and analysis of the illness experience
Experiences of caregivers
Health and health-seeking behaviors
Health care policy
Sociocultural organization of health care

A Variety of Perspectives

QHR addresses qualitative research from variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

In-Depth Timely Coverage

Articles in QHR provide an array of timely topics such as: experiencing illness, giving care,

institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTeX templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our Manuscript Submission Guidelines page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association ["APA"], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for "APA format."

4.5 Reference style

QHR adheres to the APA reference style. Click [here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting the SAGE Journal Author Gateway for guidelines on How to Help Readers Find Your Article Online

5.3 Corresponding author contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission

process should be sent to the QHR editorial office as follows:

Vanessa Shannon, Managing Editor, vshannonqhr@gmail.com.

Appendix B - Quality assessment tool (Mixed Methods Appraisal Tool; Pluye et al, 2011)

Responses: Yes (score 1), No (score 0), Can't tell, comments

Methodological quality criteria

Screening questions (for all types)

- Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?
- Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).

Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.

1. Qualitative

- 1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question(objective)?
- 1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?
- 1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?
- 1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?

2. Quantitative randomized controlled (trials)

- 2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?
- 2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?
- 2.3. Are there complete outcome data (80% or above)?
- 2.4. Is there low withdrawal/drop-out (below 20%)?

3. Quantitative nonrandomized

- 3.1. Are participants (organizations) recruited in a way that minimizes selection bias?
- 3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?
- 3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?
- 3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?

4. Quantitative descriptive

- 4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?

- 4.2. Is the sample representative of the population under study?
- 4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?
- 4.4. Is there an acceptable response rate (60% or above)?

5. Mixed methods

- 5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?
- 5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?
- 5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?

Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

References

- Pluye, P., Robert, E., Cargo, M., Bartlett, G., O’Cathain, A., Griffiths, F., Boardman, F., Gagnon, M.P., & Rousseau, M.C. (2011). *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews*. Retrieved on 16/05/15 from <http://mixedmethodsappraisaltoolpublic.pbworks.com>.

Appendix C – Methodological quality assessment scores

Study	Qualitative				Quantitative RCT				Quantitative Non-randomised				Quantitative Descriptive				Mixed Methods			Score
	1.1	1.2	1.3	1.4	2.1	2.2	2.3	2.4	3.1	3.2	3.3	3.4	4.1	4.2	4.3	4.4	5.1	5.2	5.3	
Berlin et al, 2006	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	75%
Buchbinder et al, 2005	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%
Davidson, Penney, Muller & Grey, 2004	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%
Di Battista, Hart, Greco & Glozier, 2009	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	1	-	-	-	100%
Dickinson & O'Reilly, 2004	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%
Hains et al, 2007	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	75%
Hains, Berlin, Davies, Parton & Alenzadeh, 2006	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	75%
Hussein & Sadek, 2014	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0	1	-	-	-	25%
Huus & Enskar, 2007	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%
Karlsson, Arman & Wikblad, 2008	1	1	0	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Lehmkuhl, Gaines & Silverstein, 2009	1	0	1	0	-	-	-	-	-	-	-	-	1	1	1	1	1	1	0	50%*
Mulvaney et al, 2011	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	75%
Peters, Nawjin & van Kesteren, 2014	1	1	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Salamon, Hains, Fleischman, Davies & Kichler, 2009	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	75%
Skinner, Petzing & Johnson, 1999	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	0	-	-	-	50%
Wang, Brown & Horner, 2010	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	100%
Wang, Brown & Horner, 2013	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	100%
Williams, 1999	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%

* As per the MMAT scoring guidelines, the overall score for a mixed methods study is the lowest of the applicable method scores included

Appendix D –Inter-rater agreement of MMAT scores

Raw scores

The MMAT scores awarded to each paper by rater can be seen in table x.

Table x. MMAT scores awarded to each paper by rater

Rater	Study	Qualitative					Quantitative RCT					Quantitative randomised					Non-Quantitative					Mixed Methods					Score						
		1.1	1.2	1.3	1.4	1.5	2.1	2.2	2.3	2.4	2.5	3.1	3.2	3.3	3.4	3.5	3.6	3.7	3.8	3.9	4.1	4.2	4.3	4.4	4.5	4.6		4.7	4.8	4.9	5.1	5.2	5.3
Rater 1 (Author)	Berlin et al, 2006	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	0	-	-	-	-	-	-	-	-	50%
	Di Battista, Hart, Greco & Glozier, 2009	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	-	-	-	-	-	75%
	Hussein & Sadek, 2014	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0	1	-	-	-	-	-	-	-	-	25%
	Huus & Enskar, 2007	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%
	Karlsson, Arman & Wikblad, 2008	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%
	Lehmkuhl, Gaines & Silverstein, 2009	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0	0	1	1	1	1	0	-	-	-	-	50%
Rater 2 (Independent)	Wang, Brown & Horner, 2013	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	100%
	Berlin et al, 2006	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	0	1	1	-	-	-	-	-	-	-	-	75%
	Di Battista, Hart, Greco & Glozier, 2009	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	1	-	-	-	-	-	-	-	-	100%
	Hussein & Sadek, 2014	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0	0	0	1	-	-	-	-	-	-	-	-	25%
	Huus & Enskar, 2007	1	1	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	50%
	Karlsson, Arman & Wikblad, 2008	1	1	0	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	75%
Rater 2 (Independent)	Lehmkuhl, Gaines & Silverstein, 2009	1	0	1	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	1	1	1	1	1	1	1	0	-	-	-	-	50%
	Wang, Brown & Horner, 2013	1	1	1	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	100%

Score agreement

Cohen's Kappa was used to evaluate the level of inter-rater agreement between the two raters across the sample of seven papers (see SPSS output below). The ordinal scores (0 or 1) assigned to every appropriate criterion for each paper (i.e. MMAT questions 1.1, 1.2, 1.3 and 1.4 for qualitative papers) were compared. The resulting value ($\kappa = .574$) is suggested by Altman (1999) to indicate moderate agreement ($\kappa = 0.41 - 0.60$).

SPSS Output:

Case Processing Summary						
	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Rater 1 * Rater 2	35	100.0%	0	0.0%	35	100.0%

Rater 1 * Rater 2 Crosstabulation

Count		Rater 2		Total
		0	1	
Rater 1	0	9	1	10
	1	6	19	25
Total		15	20	35

Symmetric Measures

		Value	Asymp. Std. Error ^a	Approx. T ^b	Approx. Sig.
Measure of Agreement	Kappa	.574	.137*	3.564	.000
N of Valid Cases		35			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

*The 95% confidence interval for κ is $\kappa - 1.96 \times SE(\kappa)$ to $\kappa + 1.96 \times SE(\kappa)$

References

Altman, D. G. (1999). *Practical statistics for medical research*. New York, NY: CRC Press.

Appendix E – Data extraction form

Author(s)/Year:

Type: (*Quantitative, qualitative, mixed methods*)

Objective/Aims/Focus:

Participants

- **Group(s):** (i.e. adolescents, parents)
- **n(s):**
- **Demographics:** (i.e. gender, age; each group)

Context: (*Clinic, summer camp etc*)

Methods

- **Measures:**
- **Methodology:** (i.e. questionnaire, interview)
- **Analysis:**

Summary of findings:

Excerpts relevant to diabetes related social anxiety:

Comments:

Appendix F - Submission guidelines for *Diabetes Care*

***Diabetes Care* Instructions for Authors**

Last updated on November 19, 2013.

1. ABOUT THE JOURNAL

Diabetes Care is a journal for the health care practitioner that is intended to increase knowledge, stimulate research, and promote better management of people with diabetes. To achieve these goals, the journal publishes Original Articles on human studies in the following categories:

- 1) Clinical Care/Education/Nutrition/Psychosocial Research
- 2) Epidemiology/Health Services Research
- 3) Pathophysiology/Complications
- 4) Cardiovascular and Metabolic Risk

The journal also publishes clinically relevant review articles, letters to the editor, and commentaries. Topics covered are of interest to clinically oriented physicians, researchers, epidemiologists, psychologists, diabetes educators, and other health professionals. The journal does not publish descriptions of study designs without data, papers on in vitro studies, or studies involving animals.

The editor-in-chief of *Diabetes Care*, William T. Cefalu, MD, began his term with the January 2012 issue. Dr. Cefalu's editorial team began reviewing first submissions on July 1, 2011.

2. POLICIES

The American Diabetes Association's Publications Policy Committee follows the recommendations of the International Committee of Medical Journal Editors (ICMJE), the World Association of Medical Editors (WAME), and the Committee on Publication Ethics (COPE) for guidance on policies and procedures related to publication ethics. The policies for *Diabetes Care* have been adopted from those three advisory bodies and, where necessary, modified and tailored to meet the specific content, audiences, and aims of *Diabetes Care*. Comprehensive information related to the editorial and ethical policies of *Diabetes Care* can be found in **Publication Policies and Procedures for *Diabetes Care***. The Association's Publications Policy Committee or Subcommittee on Ethical Scientific Publications will consider on a case-by-case basis policies that are not addressed in the policies document, which contains information related to the following topics:

- Study Design
- Originality and Prior Publication
- Authorship and Contributions
- Acknowledgments
- Conflict of Interest
- Data Access and Responsibility
- Clinical Trials, Systematic Reviews, and Meta-Analyses
- Plagiarism

- Digital Image Manipulation
- Responses to Possible Scientific Misconduct
- Peer Review
- Editorial Decisions
- Prepublication of Accepted Articles
- Reuse, Post-Prints, and Public Access
- Errata
- Media Embargos
- Advertising
- Supplements

Frequently referenced segments of the document appear below.

2.1. *Diabetes Care* publishes only material that has not been published previously (either in print or electronically) and is not under consideration for publication elsewhere, with the exception of an abstract that is less than 400 words in length. Prior presentation of data (e.g., at a scientific meeting or via webcast) does not preclude publication in *Diabetes Care*, but should be disclosed in the Acknowledgments of the paper and in the author's comments to the editor upon manuscript submission. All submissions to the journal will be scanned for possible duplicate or prior publication using the CrossCheck/iThenticate plagiarism detection system (www.ithenticate.com). Any article that eclipses a certain similarity threshold with another article will be closely reviewed by ADA. Authors who submit previously published work to the journal will be banned from submitting future manuscripts to the journal, and their funding body and/or institution will be notified.

All contributions, including solicited articles and symposia, are critically reviewed by the editors and/or invited referees. Reviewers' comments are usually provided to the authors. The decision of the editors is final.

5.1 Original Articles. Original Articles should be arranged in the following order: title page, structured abstract, introduction (no heading), “Research Design and Methods,” “Results,” “Conclusions,” “Acknowledgments,” “References,” tables, and figure legends.

A **structured abstract** is required for all Original Articles. Abstracts for an Original Article should not exceed 250 words. (This is not to be confused with abstracts submitted to the Annual Scientific Meeting, for which the word limit is higher.) The abstract must be self-contained and clear without reference to the text and should be written for a general journal readership. The abstract format should include four sections: “Objective” (the purpose or hypothesis of study), “Research Design and Methods” (the basic design, setting, number of participants and selection criteria, treatment or intervention, and methods of assessment), “Results” (significant data found), and “Conclusions” (the validity, limitations, and clinical applicability of the study and its results).

The **Conclusions** section should discuss the findings of the study in the context of past research concerning the topic of the article, in particular highlighting how these findings add new information. Also, this section should, where possible, assess the possible clinical relevance of the findings avoiding any claim or terminology of superiority, especially when statistically significant but quantitatively modest differences are found.

The **word count limit** for Original Articles is 4,000 words, excluding words in tables, table legends, figure legends, title page, acknowledgments, and references. In addition, an original article is limited to a combination of 4 tables and figures. **References** are limited to 40 citations.

A conflict-of-interest statement for all authors must be included in the Acknowledgments section of the main document, which should follow the main text and precede the references. If there are no relevant conflicts of interest to disclose, authors should indicate as such in the Acknowledgments section.

In the case of **multicenter studies**, authors should provide a list of participating investigators in an appendix to the paper. Papers will not be reviewed if this information is not included.

Where appropriate, **clinical and epidemiological studies** should be analyzed to see if there is an effect of sex or ethnicity. If there is no effect, it should be stated as such in the “Results” section.

6. MANUSCRIPT FORMAT AND STYLE

Articles must be in clear and understandable English. Non-native English authors are encouraged to seek the assistance of an English-proficient colleague, or a communications agency, such as American Journal Experts, to help improve the clarity and readability of a paper before it is submitted to the journal.

For specific information on the parameters and limits for various manuscript categories (e.g., section headings, word limits, etc.), see section 5, Manuscript Categories.

6.1. Title Page. Every manuscript, regardless of article type, must have an accompanying title page. In addition to the title, the title page should include a short running title (less than 47 characters and spaces combined); the first name, middle initial, last name, and highest academic degree of each author; affiliation (in English) of each author during the time the study was conducted; name, current address, telephone number, fax number, and e-mail address of the corresponding author; and the word count and number of tables and figures.

6.2. Main Document. The main document file includes the title page, abstract, main text, acknowledgements, figure legends, references, and tables. Please do not use headers, footers, or endnotes in your paper.

The Main Document should be in Word document format (not as a PDF). This will allow our Editorial Office to verify the word count and our production staff to turn your paper (if accepted) into an article.

6.3. Text Composition. Articles should be written in clear, concise English following the recommendations for scientific writing found in *Scientific Style and Format*, the Council of Science Editors (CSE) style manual (7th ed., 2006, Reston, VA, Council of Science Editors). All accepted manuscripts will be edited according to the CSE style manual and *The Chicago Manual of Style* (16th ed., 2010, Chicago, IL, The University of Chicago Press) by ADA professional publications staff. The authors are responsible for all statements made in their articles or editorials, including any editing changes made by staff. Proof pages will be sent to the corresponding author and should be read carefully.

The designations *type 1 diabetes* and *type 2 diabetes* should be used when referring to the two major forms of diabetes. Abbreviations for diabetes, such as T2D for *type 2 diabetes*, should not be used. The term *diabetic* should not be used as a noun.

All manuscripts should be double-spaced, in Arial or Times New Roman 12-point font, and saved as a .doc, .txt, or .rtf file. In addition, please do not "lock" or "page protect" your document, and avoid using footnote and endnote functions.

6.4. Abbreviations and Units. Abbreviations should be used only when necessary, e.g., for long chemical names (HEPES), procedures (ELISA), or terms used throughout the article. See the list of abbreviations that need not be defined; all others must be defined at first use. Abbreviate units of measure only when used with numbers. Abbreviations may be used in tables and figures. The CSE style manual contains lists of standard scientific abbreviations.

Clinical laboratory values and units should be in Système International (SI) form. Kilocalories should be used rather than kilojoules.

HbA1c values should be dually reported as “% (mmol/mol).” Please use the NGSP’s HbA1c converter at <http://www.ngsp.org/convert1.asp> to calculate HbA1c values as both % and mmol/mol.

6.5. Font. Text, including title and author names, should be in 12-point Arial or Times New Roman. Please avoid using boldface font. Text in tables should be no smaller than 10-point font.

6.6. Margins. Margins should be 1" at the top and bottom and 1" on the left and right sides.

6.7. Acknowledgments. The acknowledgments are located after the main text and before the reference list. Acknowledgments should contain the author contributions paragraph, brief statements of assistance, the guarantor's name (person[s] taking responsibility for the contents of the article), funding/financial support, and reference to prior publication of the study in abstract form, where applicable.

6.8. References. The reference list should go at the end of the document, after the main text and acknowledgments (if applicable) and before the tables. Original Articles are limited to 40 references. Letters are allowed 5 references. Review Articles are allowed 60 references, and meta-analyses should have no more than 40 references.

Reference numbers in the text should appear in chronological order in normal type and in parentheses [e.g., “In the study by Norton et al. (23)...”]. Please do not use the footnote or endnote function to cite studies or create a reference list. A reference manager must have the ability to customize the display of references. For example, the reference application should have the option to list the references at the end of the paper, as opposed to listing the references as endnotes or footnotes at the bottom of each page, and should not embed the list in the text as a series of endnotes/footnotes. When using a reference manager (e.g., Thomson's EndNote Reference Program), don't forget to generate the list as a bibliography in a style suitable to *Diabetes Care*, and then save and submit as the final step to creating the references. Otherwise, references should be manually inserted.

All authors must be listed by first initials and last name in each reference, and please provide inclusive page numbers. Journal titles should be abbreviated according to the National Library of Medicine's List of Journals Indexed for Medline; for unlisted journals, please provide complete journal titles. Material in press may be cited, but copies of such material may be requested. Authors are responsible for the accuracy of the references. Click here for examples of how references should be formatted.

6.9. Supplemental Data. Non-essential tables, figures, and/or videos may accompany articles as online-only supplemental files, but authors are asked to include a comment to the editor at the time of manuscript submission that explains the rationale and justification for submitting and possibly posting the supplemental materials.

All online-only supplementary files should be combined in one document file whenever possible and uploaded during the submission process. The file must be clearly labeled as "Online-Only Supplemental Material" (tables, figures, etc.) or "Online Supplemental Video." In addition, supplemental online-only files must be referenced in the main text of the manuscript at least once (e.g., "Supplemental Table S1").

All online-only supplemental files are subject to review, but such files will not be copyedited or proofread by ADA production staff. As such, authors are encouraged to review their supplemental files carefully before submitting them.

Lists that include names of **principal investigators or writing groups** may also be submitted as online-only supplements if they exceed 150 words. Otherwise, the names of principal investigators or writing groups should be listed in an appendix at the end of the main document, before the references.

6.10. Tables. Each table should be inserted on a separate page at the end of the document with the table number, title, and legend indicated. Table legends should be inserted below the table and should not be included inside the table. Tables should be created using Word and the "Insert Table" command. Please use Arial or Times New Roman font, no smaller than 10-point. Tables with internal divisions are not allowed (Tables 1A and B) and should be submitted as individual tables (Tables 1 and 2). Please avoid using shading within a table. If a table includes data that require explanation in the legend, apply the following sequence of symbols, from top to bottom, left to right: *, †, ‡, §, ||, ¶, #, **, ††, ‡‡.

6.11. Figures. *Diabetes Care* uses digital publishing methods throughout the journal production process. If your article is accepted, it will be published in both the print and online journal. The following sections provide information on how to format your figures to ensure the best possible reproduction of your images.

Size. Figures should be produced at the size they are to appear in the printed journal. Please make sure your figures will fit in one, two, or three columns in width. Multi-paneled figures should be assembled in a layout that leaves the least amount of blank space.

1 column = 13 picas wide, 2.2 in, 5.6 cm

2 columns = 28 picas wide, 4.6 in, 11.7 cm

3 columns = 41 picas, 6.8 in, 17.3 cm

Font. At 100% size, fonts should be 8-10 points and used consistently throughout all figures.

Text. Information on the axes should be succinct, using abbreviations where possible, and the label on the y-axis should read vertically, not horizontally. Key information should be placed in any available white space **within** the figure; if space is not available, the information should be placed in the legend. In general, figures with multiple parts should be marked A, B, C, etc., with a description of each panel included in the legend rather than on the figure.

Line and bar graphs. Lines in graphs should be bold enough to be easily read after reduction, as should all symbols used in the figure. Data points are best marked with the following symbols, again assuring that they will be readily distinguishable after reduction: ○ ● □ ■ △ ▲. In the figure legend, please use words rather than the symbols; e.g., "black circles = group 1; white squares = group 2; black bars = blood glucose; white bars = C-peptide." Bars should be black or white only, unless more than two datasets are being presented; additional bars should be drawn with clear bold hatch marks or stripes, **not** shades of gray. Line or bar graphs or flow charts with text should be created in black and white, **not** shades of gray, which are difficult to reproduce in even tones.

Formatting digital figures files for print and online reproduction. To meet ADA's quality standards for publication, it is important to submit digital art that conforms to the appropriate resolution, size, color mode, and file format. Doing so will help to avoid delays in publication and maximize the quality of images, both online and in print. Please refer to ADA's Digital Art Guidelines when preparing your files. If you are unable to provide files that meet the specifications outlined in the Guidelines, you may submit your original source files (files from the program in which they were originally created).

Reproductions. If materials (e.g., figures and/or tables) are taken from other sources, the author must provide written permission for reproduction from the original publisher and author at the time of submission. In addition, the source should be cited at the end of the figure legend. For more information, refer to Permissions: Help for Authors.

Appendix G - Ethical approval documentation

(This appendix has been removed from the final version of the thesis)

Appendix H – Participant information sheet

Title of the study: Experiences of diabetic amputation: Exploring the perceived influence of self, others and chance

What is the purpose of the study?

Research suggests that individuals vary in terms of how much they perceive control of situations and events -including those related to health- as being influenced by themselves, others, or chance/fate. This study aims to explore how such influences are perceived by individuals with type 2 diabetes who have undergone diabetic amputation. This research study is being undertaken as part of an educational qualification

Why have I been invited?

The research requires six to ten adult (18 – 65 years old) participants who have undergone an amputation following ulceration arising from type 2 diabetes, and who are native speakers of British English.

What will happen if I decide to take part?

For the main part for this research you will be asked to take part in an interview which will last approximately one hour. During this time you will be asked about how much influence you feel different people/factors have had at different times during the course of your amputation (i.e. the development of ulceration, the decision to amputate) and your feelings about who/what might influence possible complications in the future. It will only be you and the main researcher at the interview. The interview will be audio-recorded. Although this might be a difficult subject, it is important that you be as open and honest as you can be. The interview will take place at a time that is convenient for both you and the researcher, in rooms at the department of Diabetes & Endocrinology at Bradford Royal Infirmary during regular clinic days. It may be possible for you to arrange an interview around an existing clinic appointment.

Do I have to take part?

You do not have to take part. If you decide at any stage that you do not want to take part anymore you can withdraw at any point up to the time that the research is submitted for publication.

What are the possible benefits of taking part?

It is hoped that this research will help inform professionals of ways in which they can help individuals who have/are at risk of diabetes related ulceration and amputations. For example, if interviewees indicate feeling they had too much/too little influence during the course of their amputations, publications could suggest that professionals consider this in their approaches to treatment.

What are the possible disadvantages and risks of taking part?

There are no direct costs involved in you taking part although given the nature of the topic, it may be that you become upset talking about your experiences. The main

researcher will be able to suggest possible support available to you if you have concerns in this respect.

What is there is a problem?

If your experience is not satisfactory or you have concerns about any aspect of this study you can contact Dr Dorothy Frizelle (email: d.frizelle@hull.ac.uk; phone: 01482 464087) at the University of Hull, or contact the NHS Patient Advice and Liaison Service (PALS) of the sponsoring trust (email: pals@humber.nhs.uk; phone: 01482 303966). Complaints will not affect treatment at your NHS service.

Will my taking part in this study be kept confidential?

All information will be kept confidential except in the event that information suggesting that yourself or others may be in danger. The information will be transcribed after the interview during which all identifiable information will be removed. Direct quotes from the interview may be used in the write-up of the research and subsequent publication but you will never be personally identified. In normal circumstances only the researcher and their supervisor will be allowed to see the information. No information will be disclosed to your GP or other health professional.

After all information has been used for research purposes it will be kept at the University of Hull for 10 years after which time it will be destroyed.

What will happen to the results of the study?

When the research is completed it will be written up as a thesis to be submitted to the department of Psychological Health and Wellbeing at the University of Hull. It will also be submitted to an academic publication with the aim that it will be published and available to help other professionals. A written summary will also be sent to participants who would like to be informed of the results.

Who has reviewed the study?

The study has been favourably reviewed by the University of Hull Faculty of Health and Social Care ethics committee.

Further information and contact details

If you are interested in taking part in the study, and/or would like any further information, please contact Jess Hare, Trainee Clinical Psychologist (email: j.a.hare@2012.hull.ac.uk; postal: Department of Psychological Health and Wellbeing, University of Hull, Cottingham Road, Hull HU6 7RX).

Thank you for your time.

Appendix I – Participant consent form

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 02/04/2014 (Version 1.0) for the above study. I have had the opportunity to consider the information. If I had any questions, they 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 up to the point of data analysis and transcription, without my medical care being affected.

3. I agree to take part in the interview part of the study and understand that my interview will be audio taped.

4. I understand that my demographic and interview data will be transcribed and stored anonymously and confidentially.

5. I understand that data collected during the study may be discussed in consultation with the named researchers' supervisor, and may be accessed by regulatory bodies associated with the research.

6. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.

7. I understand that confidentiality may be broken in the event that information suggesting that myself or others may be in danger.

Name of participant

Date

Signature

Participant pseudonym

Appendix J – Participant demographic questionnaire

Age: **Age diagnosed with type 2 diabetes:**

Gender:

- Male
- Female
- Other

What is your current level of amputation?

How long ago did your amputation(s) take place?

Please choose one option that best describes your ethnic group or background:

White

- English / Welsh / Scottish / Northern Irish / British
- Irish
- Gypsy or Irish Traveller
- Any other White background, please describe

Mixed / Multiple ethnic groups

- 5. White and Black Caribbean
- 6. White and Black African
- 7. White and Asian
- 8. Any other Mixed / Multiple ethnic background, please describe

Asian / Asian British

- 9. Indian
- 10. Pakistani
- 11. Bangladeshi
- 12. Chinese
- 13. Any other Asian background, please describe

Black / African / Caribbean / Black British

- 14. African
- 15. Caribbean
- 16. Any other Black / African / Caribbean background, please describe

Other ethnic group

- 17. Arab
- 18. Any other ethnic group, please describe

Appendix K - Semi-structured interview schedule

NB: Standard prompts applying to each question (if not already covered by participant answer)

- *In what way(s)?*

- *Can you think of any positive/negative influences?*

Development of ulcer: Personal understanding of factors which lead to the development of the ulcer

1. At the time, how much did you feel that you yourself influenced its development?
2. At the time, how much did you feel others (i.e. staff, friends/family) influenced its development?
3. At the time, how much did you feel chance/fate influenced its development?

Decision to amputate: Personal understanding of factors which lead to the decision to amputate

4. How much did you feel that you yourself influenced the decision to amputate?
5. How much did you feel others (i.e. staff, friends/family) influenced the decision to amputate?
6. How much did you feel fate/chance was in control of the decision to amputate?

Post-amputation: Personal understanding of factors which might lead to further ulcers/amputations

7. How much do you feel that you yourself can influence the possible development of further ulcers?
8. How much do you feel that others (i.e. staff, friends/family) can influence the possible development of further ulcers?
9. How much do you feel that fate/chance can influence the possible development of further ulcers?

Any further comments?

Appendix L - Example of data analysis

Emergent Themes	Brian (lines 1-60)	Exploratory Comments
	I: Okay, so I'm going to start off asking you about the initial problem that lead to the amputation. Did you say that you had an ulcer?	
Seeming inconsequentiality	B: Err no, <u>I only had a tiny little cut. On my toe, a tiny little cut on my second toe of my right</u>	→ Started small, inconsequential?
Tangible explanations	<u>foot.</u> Um, it was <u>caused by, um, wearing new boots,</u> and not breaking them in. I then did a	→ Tangible, practical cause
Minimising need for care	<u>typical man thing. I put some germaline on it and stuck a plaster on it.</u> By the time I'd got	→ 'Masculine', minimal self-care
Taking it seriously	round to <u>actually thinking I should do something about it,</u> it had become a quarter inch size blister. And I subsequently found out it had infected the top joint of that toe.	→ Eventually taken seriously
	I: So it started as tiny little cut.	
Seeming inconsequentiality	B: <u>Yep, it was nothing. Paper-cut type thing.</u>	→ Seemingly inconsequential
	I: So things developed from that one small cut?	
Inevitability	B: Mm well, <u>such is life.</u> But it were me own	→ 'Shit happens'
Assuming responsibility	<u>fault. It were nobody else's fault, it were my stupidity.</u>	→ Assuming responsibility; self-critical (of minimising, ignorance?)

	I: What do you think of it was... what was stupid that you did?	→ Active decision not to
Making choices		
	B: Well, <u>I decided not to take professional help</u>	→ Seeking care = weakness?
Minimising need for care	and do it myself. You know, <u>be a big strong man</u> . And just stick a plaster and a bit of germaline in it. I changed it on a regular basis.	
	And I didn't actually notice until the last time when I went to Horton Park for my podiatry appointment that it had got to a quarter of an inch. And <u>then I got sent straight here</u> . And, um,	→ Taken seriously by staff → Staff investment
Taking it seriously		
Staff investment	<u>they did everything they could</u> . They had me in for about five weeks, twice a week. Er, but	→ Point of no return?
Turning point	<u>unfortunately it had infected the joint</u> . So fairly early on I'd realised <u>that I needed to have to take the toe taken off</u> . And that were gonna be <u>the solution</u> . Er we went erm, I came in, um, on a Wednesday afternoon and they said "Look, we'd better have the doctor to have a look at it tomorrow". I came in on the Thursday morning, and erm, the profe- uh- the Professor XXXX came in and <u>said "No, we'll get you in and get your toe off"</u> . Now <u>obviously with that, the consequences of that</u> is that you producing a new wound. And um, three days after they'd took me toe off, <u>it became quite clear that it</u>	→ Acceptance of amputation; necessary 'solution'
Acceptance of amputation		
Amputation as necessary		
Staff decisiveness		→ Decisive stance from staff
Tangible explanations		→ Logical, tangible cause
Amputation as necessary		→ Decision 'clear', necessary

were gonna have to be done further, further on
because it had gone black. And it wasn't
Staff transparency healing, it were pussing and it were oh, all → Staff were transparent, open
things that go with it. And as I said it was made
Weighing up the options you know- Professor XXXX and his team → Weighing up options
Amputation as a decision discussed it with me- told me the consequences
Partnership of not having it done, and told me the → Joint decision, partnership
consequences of having it done. And the
decision was made jointly that we should take
it off below the knee.
I: So did you feel that you had a say in that as
well- they gave you the information...
B: Oh yes. They were- they could not have been
Initial shock any- in my position I'm quite an optimistic → Initial 'shock'
Making choices person so- the initial sort of five six hours came
Amputation not as a very, came as a major sort of shock. But → Cost/benefit
worst outcome analysis;
life/death
Amputation as a then you've two choices, you know- do you decision
challenge want to live, or do you want to live with one → Amputation as
leg? Well, I'm prepared to live with one leg. can be overcome
And it's not going to beat me, and I'm now in
the process where I've got, I've got a prosthesis.
So I'm not quite up on it yet, but I'm getting
there. And um, you know, it's not gonna beat
Individual differences me. I'm not, I'm not one to be thrown down, → Optimistic
I'm quite optimistic about it. disposition/
personality helps
to overcome

I: And do you think that- do you think that helps?

B: Oh, yes. Oh you've got to be- you can't let...

Amputation as a challenge

it get you down because you get- if you let it get you down then it starts to slow you down, and you become, you come to a point... I meet- I've met other people because I- the way I am about

→ Can let it get you down; don't

Looking forwards

it, you meet other people and you say- I, I'm always optimistic, there's always something

→ Looking to future (positive)

Amputation as ongoing process

forward. When it comes to this, there's always something... you're not, you're not finished with. I've had three and a half, four months in a wheelchair. And, and I've lost a load of weight... I've, um, and it's probably not what you want to hear but I've lost me man- me man

→ Diabetic amputation as ongoing process, not single event

Positive outcomes

boobs have gone, me shoulders have, have formed, the tops of me arms so... so that's the benefit.

→ Positive outcomes from amputation

Appendix M – Example of supporting quotes

Superordinate theme	Subordinate theme	Examples of supporting quotes
Unawareness, doubt and dismissal	“I’d just put it down to...”	<p>“It was caused by, um, wearing new boots, and not breaking them in.” (Brian)</p> <p>“Where the wound on me foot were, it was on the bottom of me foot. So obviously as I was walking, erm it were just... I think it was just a combination of pressure and friction” (Darren)</p> <p>“I put it down to... something definitely bit me, when I were on holiday. I definitely got bit” (Mack)</p> <p>“ I stood on a nail... A roofing nail. For cladding.” (Owen)</p> <p>“At first I just thought they’re strange boots, how I put these boots on, they’ve rubbed it.... And I thought have I, have I rubbed it and caused a blister or something. And that’s all I thought it were.”</p> <p>“I can’t say why [the ulcer developed]. I’d just put it down to, well, with it swelling up and that, you know.” (Roger)</p> <p>“It were an ulcer on a toe. Which was caused by, er, a screw inside me boot that had come through.” (Vic)</p>
	“I thought oh, it’s nowt this”	<p>“It was nothing. A paper-cut type thing.” (Brian)</p> <p>“I thought oh, it’s nowt this. I weren’t pleased at [previously] losing me toes like but, you know, I thought, well it’s nowt” (Charlie)</p> <p>“When it occurred I thought oh, that’s nowt. I thought it’s nowt” (Mack)</p> <p>“You know, like I’d cut meself and stuff and stupid stuff [before] and I’ve just let it get on and it’s mended on its own.” (Mack)</p> <p>“And I thought have I, have I rubbed it and caused a blister or something. And that’s all I thought it were.” (Pat)</p> <p>“It can be a cut, you can bang your toe, you can do all sorts which you don’t even feel. But yet, if you were normal, it would be really bad. And you’d take it, you’d take action straight away.” (Vic)</p>
	“I decided not to take professional help”	<p>“I mean me dad and me brothers they said you know, you need to go to the doctors and I would say oh, you know, I’m fine.” (Darren)</p>

	(cont.)	<p>“Instead of like, coming straight away and doing something about it and seeing the doctor, I didn’t. Because I thought “Oh, it’s nowt”(Mack)</p> <p>(Interviewer): “And how long after... you stepping on the nail, how long after [did you seek help]?” (Owen): “Er... we were into third week.”</p> <p>“The morning after it was like a big pink ring. And uh, I left it and... I mean for rest of the week” (Vic)</p> <p>“Well, I decided not to take professional help and do it myself. You know, be a big strong man. And just stick a plaster and a bit of germaline in it. I changed it on a regular basis. (Brian)”</p>
	“I got it tended to, but...”	<p>“Well to be honest I didn’t really take much notice of it. I got it tended to, but I thought it were going to be nothing.” (Charlie) “</p> <p>We tried to... my wife’s very good at doing owt. She like, kept it clean, and we put iodine on it and everything.” (Mack)</p> <p>“And er, so, we found some dressings and made some pads and went [to the GP]... and the nurse didn’t know nothing about it. And she dressed it like it were a blister, you know. Not sort of like padded up, like they do here.” (Pat)</p> <p>“The local doctors... they were dressing ‘em but... they didn’t quite understand what they were doing.” (Vic)</p>
	“And then I got sent straight here”	<p>“I didn’t actually notice until the last time when I went to Horton Park for my podiatry appointment that it had got to a quarter of an inch. And then I got sent straight here [to the foot clinic].” (Brian)</p> <p>“The second and third toe on me left foot turned black. So obviously, I went up to hospital” (Darren)</p> <p>“It just got worse and worse. Now I hadn’t obviously I didn’t know that it had gone through to me bone. So the day I come here, like I’d rung up. And I said... I could do with... coming to A&E. And then somebody said no go, come here first. So I come here... they had me in hospital straight away, same day.” (Mack)</p> <p>“I was tired and I couldn’t dress and I couldn’t cook... I were just, you know, just couldn’t do anything. I just fell asleep in here and there were nurses here who were like what’s wrong with me, you know. And she said well I said, I’m coming about me toe. And they took me straight in.” (Mack)</p>

	(cont.)	<p>“The first time I see me own doctor... as I rung him, he says I’m coming up. I says when? He says I’m on me way, I’m running up.” (Owen)</p> <p>“One day the diabetic nurse... popped in [to the GP service]. And she said ring here. And I were up here and then I were up in hospital. I didn’t... they don’t let you go here... there’s no oh, I’ll go and get a bag, it’s you’re here (laughs)” (Pat)</p> <p>“I was in shop one Saturday and I had to go to... A&E because it were that painful” (Vic)</p> <p>“When I came here as soon as the doctor saw it he said you need it to come off, and that were me first experience” (Vic)</p>
	<p>“I’d been told I had diabetes, but...”</p>	<p>“I was one of those, I hadn’t ‘got’ diabetes... I had none of the other symptoms. I had a bit of lack of sensitivity in my toes but, you know, I’ve worked outside for 30 years, if you know what I mean.” (Brian)</p> <p>“I’d been told I had diabetes, but I didn’t believe I’d got diabetes... I had a very physical job and it didn’t affect the way I was. Um, and, well...I used to say “oh you know, it’s just another fad”. (Brian)</p> <p>“It weren’t doing me any harm at time so... and they kept saying don’t eat any sweets, don’t but no, no no” (Charlie)</p> <p>“I mean, I had the symptoms. Like obviously, like tired, thirsty. But you see I’m a typical male you know. I just passed it of as... due to working. Which it often is. Bit silly but you know, typical.” (Darren)</p> <p>“I didn’t realise that diabetes did as much damage, you know?” (Mack)</p> <p>“I didn’t link it to diabetes. They put on the record that it was caused with diabetes, I said bollocks.” (Owen)</p> <p>“It seems a bit hard to get hold of it, that you are a diabetic. Because there’s nothing... I didn’t feel no different.” (Pat)</p>

Appendix N - Epistemological Statement

When I began reviewing the literature around the psychosocial aspects of diabetic amputation, I initially had in mind that I would be doing a quantitative study, as this was the only methodology that I had been told to consider as ‘research’ before. However, when I discovered that only a small number of studies considered diabetic amputation in its own right- most of which were quantitative studies measuring generic indicators of ‘adjustment’ as given to those with amputations in general- I speculated that this measurement of pre-defined and *presumably* salient constructs might lead researchers to miss experiences and concepts of interest which might be unique to this group.

I thus decided that the literature called for exploratory studies, where the experiences of this population could be enquired about more openly. This is a function better served by qualitative research (Willig, 2001). Having found two qualitative papers which presented two conflicting accounts from individuals on perceived responsibility for diabetic amputation (one concerning self-blame and guilt, and the other holding care staff responsible), I wanted to explore this particular idea of accountability in further detail. I felt this discussion may be unique to this aetiology- especially given the discourses of preventability around diabetic amputations, and type 2 (as opposed to type 1) diabetes.

The qualitative approach I ultimately chose to explore this area was Interpretative Phenomenological Analysis (IPA). Central to IPA is a focus on phenomenology, the study of first-person experiences of an ‘object’ or event (Smith & Osborn, 2003). In IPA, it is assumed that these subjective experiences can be accessed through reflection, which can be facilitated (alongside other means) by the discussion of such events and associated ‘phenomena’ in semi-structured interviews (Larkin, Watts & Clifton, 2006). The ‘interpretative’ element refers to the hermeneutic (meaning-related) stance that experiences and events will be made sense of through the subjective interpretations of

those viewing them (Smith, Flowers & Larkin; 2009). These interpretations will themselves be informed and shaped by the idiographic experiences of the interpreters- for example, by their cultural context. In IPA, a 'double' hermeneutic is operating- the researcher ascribes interpretative meaning to the participant's account, which already inherently includes the participant's subjective meaning of the experience. In all, the functions of IPA can be summarised as firstly giving a voice to the experiences of individuals, and then attempting to making sense of these (Larkin, Watts & Clifton, 2006).

I opted to use IPA over other qualitative approaches for a number of reasons. In the first instance, I was attracted to it for its prevalence in health psychology, and its specific focus on experiences and perceptions (Smith, 1996; Brocki and Wearden, 2006). Furthermore, given the focus on people with amputations as a homogenous group in the majority of existing research, I was keen to use an approach that gave a clear focus to the voices and experiences of individuals. I thus found the stated idiographic emphasis in IPA preferable to the more macroscopic focus of grounded theory, and the ambiguous (though more frequently less idiographic) method of thematic analysis. Whilst it would have been (and is) possible to employ thematic analysis within a wide range of epistemological stances, I found that I so closely identified with many aspects of the stated positioning of IPA that using this method over the primary alternative was a clear choice.

In particular, I appreciated the element of reflexivity in IPA, in which the researcher is explicitly identified as having a personal and influential relationship with the 'data', having previously been frustrated at the claim that this is not the case in quantitative studies (where biases can most certainly exist!). I similarly appreciate the explicit acknowledgment that interpretations are tentative and subjective, and identify with the ontological stance of critical realism (Larkin, Watts & Clifton, 2006), which posits that although there is a 'reality', the sense that humans make of this is of primary importance. Perhaps most of all, I appreciated the contextualised nature of IPA, as I have a particular

interest in how the sociocultural context related to individuals experiences of events- with such considerations sparking my interest in visible difference to begin with.

Reflexive statement

In line with the acknowledgement of researcher influence on the course of research and interpretations made in IPA studies, below are presented some of the primary assumptions which I brought to this research. These were influenced by various sources and experiences- personal, social, cultural, and research based- and, whilst they are by no means exhaustive, will have had considerable influence on my contribution to the research. These assumptions include:

- That there would be some form of interaction between diabetes and amputation- leading to experiences unique from those in non-diabetic amputations.
- That amputation is an undesirable and traumatic event (though my perspective on major bodily changes may be unusually optimistic given my personal experiences).
- That the risk of amputation in type 2 diabetes would be acknowledged, and that individuals will have been informed of this (as distinct from traumatic amputations).
- That individuals would be aware of the potential preventability of such amputations.
- That there is a link between poor diabetes self-management and amputation.

These assumptions were not all initially apparent to me, but emerged slowly through reflection. Overall, I came to realise that *I* assumed that individuals with type 2 diabetes were somewhat responsible for their amputations. Before interviews, I thus held a more negative stance of my study population compared to where my initial interests had begun (chance subjects of unforeseen trauma- see Appendix O). This was a gradual and uncomfortable acknowledgment. However, many of these assumptions were starkly challenged when I began interviewing- for example, my first interviewee had not been

aware of his diabetic status until he required amputation. Accordingly, my assumptions and interpretations continued to change considerably over the course of the research.

References

- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and health, 21*(1), 87-108.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology, 3*(2), 102-120.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*, 261-271.
- Willig, C. (2001). *Qualitative research in psychology: Adventures in theory and method*. Buckingham, UK: Open University Press.
- Smith, J. A. & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 53-80). London, UK: Sage.
- Smith, J. A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, research and method*. London, UK: Sage.

Appendix O- Reflective statement

My initial response to undertaking this sizeable research project was one of enthusiasm. Being an insatiably curious person and having worked as a research assistant for a number of years, the research component of the course was something I was particularly looking forward to. I had started the doctorate with a keen interest in the psychology of spinal injuries, an area in which I'd undertaken a literature review in my undergraduate degree. This interest itself arose from people's responses- including, initially, my own- to my partner, who has such an injury. I noticed that people automatically assumed or questioned about his personality in light of this. I began to question what it was *really* like for people whose bodies were markedly and visibly different to others to live in a world where bodies and identity are often taken to be synonymous.

Consequently, I was excited when diabetic amputation was proposed as a possible research topic by my eventual research supervisor, as amputation fitted this remit of interests. The diabetes aspect- which would eventually take centre stage- was entirely incidental to me at this point. I was interested in *visible* differences, and considered chronic health problems a separate area. Whilst I initially hoped to span across different aetiologies of amputations in my research, I became very surprised that different aetiologies of amputation weren't often considered separately. After reading a lot of medical literature about the preventability of diabetic amputations, I realised this contrasted with the primarily accidental injuries I had reviewed in the literature on spinal cord injuries. I was interested in how this background idea that the amputation could have been avoided might shape people's experiences.

The decision to undertake qualitative research was not an easy one for me. My undergraduate course had instilled a dismissal of qualitative approaches as not 'real' research, and whilst I now personally value these approaches I still feel as though others

retain this view when I explain my research to them. I have felt at times as though qualitative research is taken as shorthand for lazy work, or that requiring less intelligence than quantitative work. This has been frustrating, but also an enlightening insight into the discourses that exist within the research world. However, I chose to opt for this research in light of the lack of literature addressing the unique experiences of those with diabetic amputations. It seemed it would be missing the mark to throw a lot of quantitative measures at a given population without first scoping out which issues they themselves felt poignant to their experiences. I have since come to consider qualitative work to fit better in some respects with the ethos of clinical psychology, given its emphasis on individuality, and the known presence of the other. In my previous education of quantitative research, it had been hard to picture the numbers as people. In qualitative work this is inescapable, and I feel this has made for a more sensitive approach in my research.

The same appreciation of the people behind the papers applies to my systematic literature review. This topic was directly inspired by the adolescents I worked with in a paediatric diabetes service. Keeping diabetes secret out of fear of friends' reactions was a frequent clinical issue, and it surprised me when I discovered no coherent literature on this. Whilst my empirical study was initially driven more by curiosity, my literature review was driven by a desire to draw attention to the struggles plaguing my clients (and, as it transpired, other adolescents in the literature). However, I developed the same sense of responsibility about my empirical study once I began talking to 'real' people about this; firstly on the online forums in the development stages, and then in the case of my eventual interviewees. I was struck by the desire to talk about experiences by every available patient in the clinic where I recruited- I often hadn't had the chance to go through the paperwork and turn on the recorder before the men started energetically recounting their experiences!

It was only in speaking with people behind my chosen topic that I realised I myself had previously held the idea that they were somehow 'responsible' for their complications. I came to suspect that my original ambivalence about diabetic as opposed to traumatic amputations was in my considering the latter to be blameless subjects of adversity- a 'group' I have always felt strongly compelled to empower and advocate. In realising that those with type 2 diabetes were, in fact, recipients of considerable and unjust stigma from others (including myself), and in hearing stories that challenged the idea of the willingly irresponsible stereotype, there was a switch in my position from pure interest to a compulsion to tell the other side of the story. It was only in conducting my interviews that I became aware what my preconceptions had been, as they were repeatedly challenged by the experiences my interviewees recalled. This was a difficult experience- one that involved some guilt, and a considerable amount of humility.

Aside from this, however, my predominant issues with research were largely practical. Conducting a study out of area with limited allotted time in which to do this was frustrating, although the hospitality of the team and patients awaiting me made this journeying feel worthwhile. Similarly frustrating was a stalling of my R&D application due to staff absences and resignations on the receiving end, meaning this took far longer than could have been foreseen. The momentum of the study felt broken by such issues- I would feel inspired to progress with the research, but find myself physically unable to move it along. I have also come to reflect that this capacity for ideas and inspiration often overrides my ability to decide on and stick to a course of action. Narrowing down and confining my ideas was something I found research supervision to be very useful for, as it required me to make them concise and coherent, and I would definitely benefit from using others in this capacity in the future.

A final issue of significance was the journal of choice for each of the papers. It surprised me how much pre-emptively choosing the scope and audience of the journal changed in

some way the form of the research itself. Deciding where each study would be best placed was helpful in some ways (i.e. in clarifying the overall aim/tone of paper), but felt restrictive in others. Whilst I knew I wanted a diabetes-specific readership for my empirical study given the acute topical relevance of the issue at hand (thus opting for a large interdisciplinary journal in *Diabetes Care*), placing my systematic literature review was more difficult. This was a paper which felt relevant to readers outside of diabetes professionals, as it concerned the recognised construct of ‘social anxiety’ and the broader consideration of adolescence. Initially, the journal I chose for this review was the *Journal of Pediatric Psychology*, where the issues covered felt relevant. However, as I began to synthesise the data, it felt difficult to properly explore the themes encountered within the allotted word count (30 pages including references). Knowing that my empirical paper would ultimately be restricted to 4,000 words, I began to search for an alternative journal which would allow more scope for freedom for my review. I ultimately elected for the word-limitless *Qualitative Health Research*, which was relevant to the area covered in my study, and where I felt free to fully appreciate the method I had chosen. I retained a vague benchmark of around 30 pages (*excluding* references) in order to hone some focus (which was very necessary!). Whilst I found it enjoyable writing more freely, I have overall come to acknowledge that the journals which will accept longer articles are few and far between, thus limiting the choice for potential audiences. As such, I think that for future research I will try to write papers in keeping with more typical word counts for the sake of optimum choice.

My passion for research has not been wavered over the course of this work, but rather expanded. I feel a great part of this is in finally connecting research to real issues faced by real people, which is inherent to the study of clinical psychology in a way that I never found the fields studied in undergraduate psychology to be (i.e. people reduced to reaction speed times). I feel that connecting my research to issues I am working with clinically

will be a continued source of motivation for me- though I am now mindful that my experiences with clients will likely shape the assumptions I bring to research, and will have to strive to be aware of this. I feel that both papers in this portfolio captured the essence of my principle interests- the meanings and perceptions of a physical change to an individual (especially in terms of identity- such as the children who felt fundamentally ‘different’ on account of their diabetes), and how this relates to the context of an often judgmental social world. Whilst I can foresee future frustrations with limited time in which to carry out future research, hopefully within this area, I feel that ultimately my drive to do justice for the people involved will be sufficient to overcome such obstacles. Ultimately, I believe that research is an ethical responsibility of clinical psychologists, and that it should be conducted with the sense of importance and humanity that is afforded to clinical work.