# THE UNIVERSITY OF HULL

Developing an understanding of the experiences of South Asian women with gestational diabetes mellitus living in the UK.

Being a dissertation submitted in partial fulfilment of the requirements for the

Degree of Doctor of Clinical Psychology

In the University of Hull

by

Amy Spratt

BSc (Hons)

June 2013

## Acknowledgements

Firstly, I would like to thank the Gestational Diabetes Mellitus (GDM) participants who gave up their time to be a part of this research and shared difficult experiences, thoughts and feelings of having a pregnancy with GDM. I am also extremely grateful to Dr. Donald Whitelaw, Sandra Dudding and Rachel Lawton for their help and support, particularly to Sandra and Rachel for their encouragement and help with recruitment.

I would also like to thank Dorothy Frizelle for her passion and support from the beginning to the end of the research process. Her expertise and guidance has been invaluable and put the project back on track a number of times. I'd also like to thank Dr. Diane Farrar for her advice and guidance with regards to ethics, R&D and all things 'research'.

I would like to thank my peers for being such a support throughout the project, particularly to the 'IPA' group, who have been an amazing sounding board and support for analysis and everything else. Thanks to my friends and family for supporting me, in particular my parents whose unwavering belief in me has enabled me to reach the end of this journey. Finally, thank you to Dave for making me smile even when things didn't seem worth smiling about, without your support none of this would have been possible.

#### Overview

This portfolio thesis includes 3 parts: a systematic literature review; an empirical paper and appendices.

Part one is a systematic literature review, considering the experiences of diagnosis and management of diabetes mellitus of South Asian people living in the UK. The review attempts to determine how culturally specific experiences may impact on illness perceptions for this population, links to theory and clinical implications are then discussed.

Part two is an empirical report of a qualitative study aimed at understanding the experiences and illness perceptions of South Asian women with first diagnosis of gestational diabetes mellitus (GDM). The results are discussed to propose an understanding of how these experiences effect pregnancy and perceptions of illness. These are then discussed with reference to theory and clinical implications.

Part three comprises appendices; a reflective statement which draws on personal experiences and reflects on the research process and an epistemological statement describing the epistemological position of the research.

# **Table of Contents**

Acknowledgements	2
Overview	3
List of Tables	6
List of Figures	6
Part 1. Systematic Literature Review	
Abstract	9
Introduction	10
Method	13
Results	16
Discussion	35
Conclusion	39
References	41
Part 2. Empirical Paper	
Abstract	50
Introduction	52
Method	57
Results	64
Discussion	74
Conclusion	79
References	80

# Part 3. Appendices

Appendix	
1.1 Diabetic Medicine Author Guidelines	88
2.1 Qualitative Research Quality Assessment Tool	99
2.2 Quality Assessment Table for Included Papers	101
3.1 British Journal of Obstetrics and Gynaecology	103
Instructions for Authors	
4.1 Shortened Introduction for Journal Submission	115
5.1 Epistemological Statement	119
6.1 Participant Information Sheet	122
6.2 Participant Consent Form	126
6.3 Interview Schedule	128
7.1 NHS Ethical Approval	131
7.2 Research Governance Approval for Bradford Teaching Hospitals	137
NHS Foundation Trust (BTHFT)	
7.3 Letter of Access for BTHFT	140
8.1 Worked Example of IPA	143
9.1 Reflective Statement	149

# **List of Tables**

Part 1. Systematic Literature Review	
Table 1. Search Strategy	14
Table 2. Overview of Included Studies	19
Part 2. Empirical Paper	
Table 1. Participant Demographics	59
Table 2. Superordinate and Corresponding Sub-ordinate Themes	64
Part 3. Appendices	
Appendix 2.1 Quality Research Quality Assessment Tool	99
Appendix 2.2 Quality Assessment Table for Included Papers	101
List of Figures	
Part 1. Systematic Literature Review	
Figure 1. The Self-Regulatory Model of Illness	11
Figure 2. Paper Selection Process	17
Figure 3. Hopson and Adams Model of Transition	37
Part 2. Empirical Paper	
Figure 1. The Self-Regulatory Model of Illness	55

# Part One:

**Systematic Literature Review** 

## Diabetic Medicine

## Vol. X, No. X Month 20XX, 000-000

# Experiences of diabetes mellitus of South Asian people living in the UK: A systematic review.

Amy Spratt\* Trainee Clinical Psychologist, Department of Clinical Psychology,

University of Hull – BSc (Hons)

Dr Diane Farrar, Research Programme Manager, Bradford Teaching Hospitals NHS

Foundation Trust (BTHFT) – PhD

Dr Dorothy Frizelle, Consultant Clinical Health Psychologist, Department of Clinical Psychology, University of Hull-BSc; BSc; ClinPsyD. AFBPsS

This paper is written in the format ready for submission to Diabetic Medicine.

Please see Appendix 1.1 for the Author Guidelines.

(Word count = 4982)

## **Abstract**

**Objective** To review literature exploring the experiences of South Asian people diagnosed with Diabetes Mellitus (DM).

**Methods** Key databases were systematically searched (MEDLINE, CINAHL, PsycINFO and Scopus), 872 papers were found. Papers were checked for relevance (removal of 841), then duplicates were removed (*n*=15), exclusion and inclusion criteria applied (*n*=7) leaving 9 papers. References of included papers were studied and a key author contacted, though no further papers were included. Papers were assessed for quality using the National Institute for Clinical Excellence (NICE) qualitative research quality assessment tool.

**Results** A synthesis of the results found that the discourses around causes of DM tend to be external (down to stress, move to the UK or Allah's will). Diagnosis of DM tended to cause fear, due to the perception of inevitable complications and death. The review also identified problems following recommendations due to cultural and social obligations, as well as holding culturally specific beliefs regarding food and exercise.

Conclusion The results of this review suggest that the approach of professionals to provide education and guidance regarding food and DM may not be entirely appropriate for this population. Culturally specific interventions that target perceptions of internal control and work within South Asian culture may be more successful in motivating good DM self-management.

**Keywords** South Asian; diabetes mellitus; experiences; illness perceptions; UK

# **Introduction**

DM is a chronic condition resulting in the body's inability to use glucose effectively. This results in glucose levels in the blood rising above normal levels [1]. Around 2.9 million people in the UK currently have a diagnosis of Type 1 (T1DM) or Type 2 diabetes<sup>a</sup> (T2DM), this is expected to rise to 5 million by 2025 due to rising obesity and an aging population [1]. Screening, diagnosis and treatment of DM cost the NHS £9.8 billion in 2010/2011 [2]. The most important intervention in DM care is self-management; good self-management helps to improve symptoms and reduce risk of diabetic complications<sup>b</sup> [3]. As the NHS is attempting to save £20 billion by 2014-15 [4], understanding the experiences and motivations of individuals to self-manage their DM (or not to self-manage) is becoming increasingly important. In order to achieve this, research into how people achieve good self-management and ultimately diabetic control<sup>c</sup> is needed.

Illness perceptions (IPs) are shown to influence illness outcomes and present an area ripe for clinical intervention in people with DM. The Self-Regulatory Model of Illness (SRM) suggests that IPs consist of individuals' cognitive and emotional representations of illness formed by experiences and other factors such as cultural and social influences [5]. Research suggests IPs predict interactions between illness cognitions, coping and

٠

<sup>&</sup>lt;sup>a</sup> T1DM is a result of the body being unable to produce any insulin (the hormone that helps glucose to leave the blood and enter the cells for fuel). T2DM develops when the body does make insulin, however the body either doesn't make enough, or the insulin that is produced is ineffective [1].

<sup>&</sup>lt;sup>b</sup> Complications from poorly controlled DM include retinopathy (eye disease caused by high blood glucose levels causing damage to the blood vessels in the retina), nephropathy (deterioration of functioning in the kidneys) or vascular problems such as cardiovascular disease. These are just a few of the many complications that may occur as a result of poor diabetic control [1].

<sup>&</sup>lt;sup>c</sup> Diabetic control meaning a blood glucose level of 4-7mmol/l before meals and less than 8.5mmol/l (T2DM) or 9mmol/l (T1DM) 2 hours after meals [6][7].

outcomes across a number of illnesses [8]. Patient's self-care and diabetic control may be driven by IPs [9].

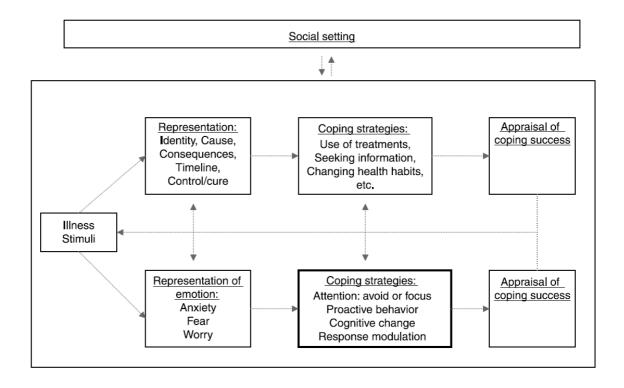


Fig. 1 - The SRM [5].

Additionally, there are differences in risk and prevalence of DM between minority ethnic groups and White British groups [10]. In South Asian populations, the prevalence of DM is around 20% compared with 3-4% in Caucasians [11]. NICE guidelines [10] recommend all patients with DM should be given the chance to attend structured educational programmes for managing DM [12]. With this in mind it follows that structured educational programmes targeted at enhancing self-management should capitalize on high prevalence populations, with culturally adapted interventions that address language differences [13]. If this is not the case and cultural impact on IPs is not considered it is possible that the benefit may be reduced.

Previous research suggests that education alone is insufficient to motivate adequate selfmanagement in DM as IPs are integral in health behaviour change [14]. Behavioural theories, like the Theory of Reasoned Action (ToRA), which state that intentions (determined by three main factors; subjective norms, attitudes and self-efficacy) best predict behaviour, can help explain this [15]. Structured education may target self-efficacy, however, intervention at the level of IPs would be needed to influence norms and attitudes: these are likely to be culturally specific [16].

A systematic review of the literature concerning culturally appropriate health education for South Asian migrants with T2DM found mixed results. Although blood glucose and knowledge about DM and healthy lifestyle improved at three and six months post intervention, there was no evidence to suggest this would be maintained [17]. In a UK study exploring reasons for poor glycaemic control, lack of knowledge was identified by only 14% of the 128 participants (46.9% South Asian), suggesting this is not the primary reason for lack of glycaemic control. Poor glycaemic control was attributed to lack of concordance with therapy and lifestyle change and infrequent attendance for review [18].

Each of these outcomes are behaviourally based, again highlighting the importance of addressing patient's IPs in the context of culture in order to influence intention and ultimately change behaviour. Additionally, self-efficacy, attitudes or subjective norms would need to be considered (necessary for behaviour change according to ToRA) [15] as well as emotional representations of illness (part of IPs according to the SRM [5]).

Therefore, it is important for health professionals to understand individuals' IPs and other subjective psychological processes likely to be involved in health behaviours [19]. Indeed, research has found differing IPs between patients with good T2DM control and those with poor control<sup>d</sup> [20]. Despite this, research into interventions based around IPs

<sup>&</sup>lt;sup>d</sup> Good control meaning that Hba1c (glycated haemoglobin) levels are between 6.5 and 7.5% for those with both Type 1 [7] and Type 2 [8] DM.

is still in its infancy [21] and specific knowledge and understanding of South Asian cultural influences is limited.

In summary, there is a clear rationale for better understanding of IPs about DM in South Asian people in the UK. This could better inform professionals' knowledge of cultural context, in turn informing practice with a view to maximising the potential of intervention(s) to bring about lifestyle change.

Though research has considered experiences of South Asian people with DM in the UK with a focus on healthcare provision [22], patient-centred research papers considering the unique perspective and IPs of South Asian people are few and mixed in measurement and outcome. Therefore, this review aimed to systematically assess available literature that has studied the experience of DM from the perspective of South Asian migrants in the UK. The review considered studies carried out in the UK only due to the unique interaction between UK culture and that of South Asian migrants. The disparity that this creates between this and one created in another country such as Australia may have an effect on the experience of DM and hence be less generalisable; making it more difficult to identify implications for the UK healthcare system [22].

#### Method

# **Data Sources**

A systematic search of the literature was carried out using the following databases;

Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline,

PsycINFO and Scopus, to allow a thorough search of psychological, medical and
sociological literature. References of relevant papers were searched to ensure inclusion
of any additional related papers. From this process, a prominent researcher in the field

was identified and contacted to ensure further research undergoing publication was included.

# **Search Strategy**

The electronic search was performed in November 2012 using the search terms in Table 1 which were chosen to optimise the chances of finding relevant literature. Search terms were identified via key papers and were discussed in a peer-group to ensure identification of all potential key words.

Table 1. Search Strategy

Search Construct	Search Terms
Experience	psych* OR emotion* OR adjust* OR
	anxi* OR depres* OR interv* OR
	mental*health OR "well#being" OR cop*
	OR perc* OR cogni* OR experi* OR
	"quality of life" OR "QoL" OR belie* OR
	predict* OR "life satisfaction" OR
	self*efficacy OR view
South Asia <sup>e</sup>	(South AND Asia*) OR Pakistan* OR
	India* OR Afghan* OR Bangladesh* OR
	Nepal* OR Bhutan* OR Maldive* OR
	"Sri Lanka*"
Diabetes	diabet*

<sup>&</sup>lt;sup>e</sup> Countries selected based on the countries involved with the South Asian Association for Regional Cooperation (SAARC)[23].

#### Northern Ireland

# **Selection Strategy and Inclusion Criteria**

Paper titles were reviewed, if considered to be potentially relevant, abstracts were studied to identify whether the paper would meet inclusion criteria. Papers were included for selection if participants were adults (18 years+) who had a diagnosis of DM. T1DM andT2DM were included as there were concerns that by reviewing only T2DM important experiences identified within the mixed type papers would be missed. Only peer reviewed papers were included to increase scientific rigour.

Papers that met these initial inclusion criteria were scrutinised further to identify whether they met additional inclusion criteria. Papers were included for review if they had quantitative outcomes or qualitative data relating to psychosocial experience of illness, diagnosis, health perceptions or lifestyle and if they stated outcomes/data specific to South Asian participants. Intervention and prevention papers were excluded in order to focus the review on experiences rather than effectiveness of interventions.

#### **Quality Assessment**

The NICE qualitative research quality assessment tool [24] (see Appendix 2.1) was used to assess the quality of each paper. The checklist is adapted from 4 other quality checklists to assess rigour and quality of qualitative research. Assignment of a numerical score was included to allow for assessment of inter-rater agreement. For each criterion a score of 3 (excellent) to 0 (not present/unsure) was given, with 2 meaning good and 1 equal to poor on that rating. The areas assessed included: aims, design,

participants, methodology, ethics, data analysis and report writing. Scores were summated to create a total score between 0 (poor) and 63 (excellent).

#### **Data Extraction**

A data extraction table was used to gather information from each included paper. This included participant demographics, study aims, method, outcomes and quality rating.

# **Data Synthesis**

Full manuscripts of all included papers were reviewed. A meta-synthesis was not undertaken due to heterogeneity of results. Qualitative synthesis of the results [25] was used due to all included papers utilising qualitative methodology [26].

# **Results**

## **Details of included papers**

Of the 872 papers initially identified from search terms, 841 did not meet inclusion criteria based on title and abstract. Removal of duplicates and application of exclusion criteria left 9 papers. No further papers were identified by contacting a prominent researcher in the field, searching through publications by authors of selected papers or by searching references of selected papers. Nine papers were reviewed in total. [Figure 2 shows the paper selection process.]

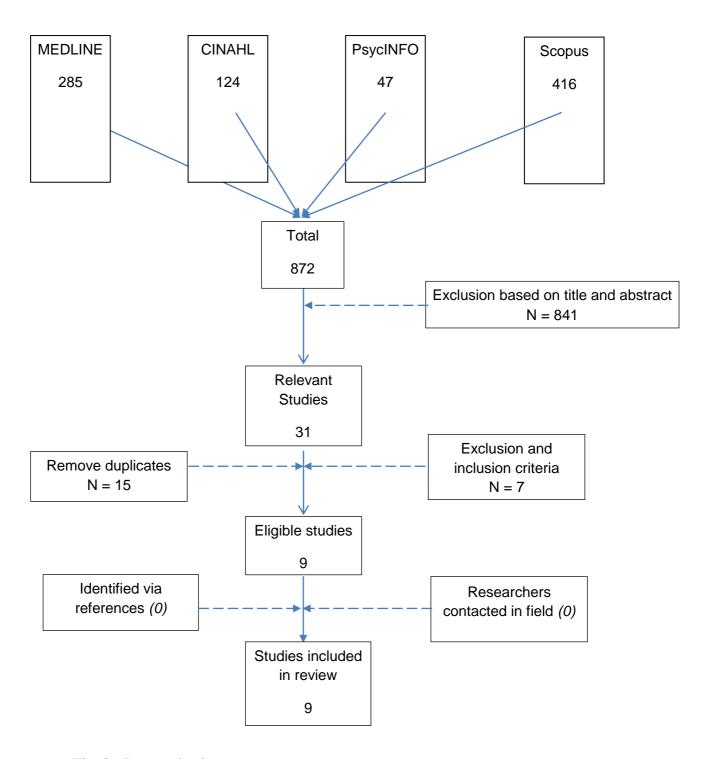


Fig. 2 - Paper selection process

# **Quality Assessment**

Included papers varied in quality from 23 to 56 out of a possible 63 points using the NICE qualitative research quality assessment tool [24] (see quality assessment table in Appendix 2.2). Although all papers were included in the review irrespective of quality

scoring, quality score was considered in formulating results. There were two items on the quality checklist that were particularly low; only two papers stated participant drop-out/take-up rate (how many potential participants were approached compared with how many participated) and only three papers reported the time course of the research. Interrater percentage agreement was 68.25%, which is quite low. However, when the reasons for such a low score were considered it was seen that because a 3-point scale was used, sometimes this disagreement may be of one point, with one rater deeming a point as sound and another as good. When there were differences of opinion such as this it was discussed between the raters. On all such occasions the difference in rating was 1 point, the rating given justified to the other rater, with the arrangement that a third rater would be asked to rate the papers if the ratings given were not seen as justifiable. With none of the ratings given being seen as invalid, the main researcher's ratings were used for the purpose of this review.

# **Results Table**

Below is the data extraction table for included studies including authors, stated aims, methodology, main outcomes and quality rating.

Table 2 – Overview of results

No	Study	Participants	Aim of Investigation	Methodology	Outcomes	QR
1 [27]	Choudhury, Brophy & Williams, 2009.	14 Bangladeshis  M = 4 (29%), F = 10  (71%)  Ages 26 - 67  T2DM  1st G = 14 (100%)  No Faith Info  (Can guess Muslim)	Understanding and beliefs about DM	Structured interviews – thematic analysis	No real understanding of cause or prevention, but understanding of healthy lifestyle for management; split reactions to diagnosis - some unexpected and paired with fear, for others it was expected, almost inevitable; participants had difficulty making the links between diet and DM – though most knew to reduce fat/sugars they did not understand why.  Difficulties following advice from healthcare professionals was identified and most participants had other health problems as well as DM;	35
<b>2</b> [28]	Chowdhury, Helman & Greenhalgh,	40 Sylheti  Bangladeshis  M = 23 (58%); F = 17	Food and eating beliefs	Narrative, semi-structured interviews,	Rigid adherence to halal foods; rice main part of every meal hence advice to alter the form/content is met with resistance; shallow frying in ghee or oil is main method of cooking and	34

	2000.	(42%)		focus groups,	generous use is seen as affluent; generally traditional eating	
		Ages 24 -78		sorting	practices have been retained with a few exceptions such as	
				exercises and	peas, baked beans and pizza, normally where young children	
		No DM data		structured	have been exposed to these at school; 'special' foods were more	
		$1^{\text{st}} G = 39 (98\%)$		vignette	generally available in the UK were used more (e.g. bread, meat,	
		$2^{\text{nd}} G = 1 (2\%)$		exercise –	sweets, fruit and fruit juice) than in Bangladesh but cooking	
		2 0 = 1 (270)		thematic	methods remained the same; foods classified on 2 dimensions	
				analysis using	(digestibility and strong-weak); cooking also feeds into these	
				NUDIST	classifications and can change classification; in keeping with	
					the view of the human body as a machine illness is seen to	
					come from outside, as a germ or a result of imbalance rather	
					than a failing of the organs which is seen to be a result of age	
					but not malfunction; food choices made on the perceived needs	
3	Duthie-Nurse,	20 Guajarat Indians	Diet and	Survey and	Religious considerations prevail, commensality appears to be	23
[29]	1998.	M = 0, F = 20 (100%)	disease	semi-structured	most difficult for Hindu women trying adhere to a particular	

		No ages		interviews	diet – this was particularly difficult due to perceived isolation if they followed an alternative diet; none of the participants took	
		T2DM			part in exercise, a major barrier to this was fear of racial	
		$1^{\text{st}} G = 19 (95\%)$			harassment (due to time of study); discourse of being 'cured' on	
		Unknown G = 1			return to India – major change in lifestyle, eating traditional	
		Faith = Hindu			food, walking everywhere, and lower stress levels	
		40 Sylheti		Narrative,	View that youth and health went together and that illness was	
		Bangladeshis		semi-structured	an expected part of ageing; merging of traditional and western	
	Greenhalgh,	M = 23 (58%); F = 17	II a alkla la ali - £-	interviews,	views – most healthy figure large but not too large –	
4	Helman &	(42%)	Health beliefs	focus groups,	understanding that this is unhealthy particularly with DM;	
[30]	Chowdhury,		and models of	sorting	external attribution of cause of illness; fear and devastation at	46
[50]	1998.	Ages 24 -78	illness	exercises and	diagnosis; control of DM felt to be in restoring balance; food	
		No DM data		structured	perceptions different to western views of nutrition with fattier	
		$1^{\text{st}} G = 39 (98\%)$		vignette	foods thought to be strength giving, and weak foods being	
		1 0 = 39 (98%)		exercise –	foods such as boiled rice and cereals, raw, grilled and baked	

$2^{\text{nd}} \text{ G} = 1 (2\%)$	thematic	foods seen as indigestible – was however understanding that
No faith info (can	analysis using	'strength-giving' foods could worsen illness in the old/infirm;
guess at Muslim)	NUDIST	beliefs that balance, i.e. balance of food entering the body to
		excretions through sweat, semen, urine, etc, is equated with
		health – led to a general belief that immigration and lack of
		sweating is part of cause of DM; exercise viewed as potentially
		exacerbating illness, no translation of the word 'exercise' into
		Sylheti and that which was closest had negative connotations;
		powerful views of medical professionals as having all the
		answers; monitoring thought to be important when
		experiencing symptoms, little understanding of preventative
		care

<b>5</b> [31]	Keval, 2009.	18 Gujarat Indians  M = 10 (56%); F = 8  (44%)  Ages 40 - 88  T1DM & T2DM  No G info  Faith = Hindu	Health and illness	Semi- structured interviews – grounded theory	Pre-existing familiarity of DM due to others' experiences;  Aware of a need to exercise and its link with DM, but majority were not involved in formalised exercise; difficulties between managing diet and fulfilling social obligations and faith practices (e.g. offerings at temple/Divali) – also meant that there tended to be a lack of disclosure; use of bitter melon/bitter gourd as a complementary medicine.	39
	Lawton,	32 - 9 Indian (28%);	Beliefs around	Semi-	Varying advice given by professionals; continued consumption	
6	Ahmad,	23 Pakistani (72%)	food and	structured	of South Asian foods despite perception that they were	
[32]	Hanna,	M = 15 (47%); F = 17	eating	interviews -	'dangerous', but some integration of western food in	56
[ <b></b> ]	Douglas,	(53%)	practices	thematic	morning/lunchtime meals; classify food as 'strength-giving';	
	Bains &	(3370)	_	analysis using	cultural expectation to participate in eating together hence a	

	Hallowell,	Ages 33 – 71		NUDIST	weighing up of eating being 'dangerous' vs. alienation –	
	2008.	T2DM  2 <sup>nd</sup> G=6 (19%)  1 <sup>st</sup> G=26 (81%)			balance tended to be to eat small amounts leading to a lack of satiation; men have further difficulties with managing diet as they have little input into food preparation.	
		Faith = Muslim, Sikh, Hindu & Christian				
<b>7</b> [33]	Lawton, Ahmad, Hanna, Douglas & Hallowell, 2005.	32 - 9 Indian (28%); 23 Pakistani (72%) M = 15 (47%); F = 17 (53%) Ages 33 - 71 T2DM	Beliefs around exercise and facilitating/ prohibiting factors	Semi- structured interviews - thematic analysis using NUDIST	Understand that they should be undertaking physical activity; however few made a conscious effort to increase physical activity; lack of time identified as a problem, for women cultural norms also seen as a problem as they are expected to remain home and attend to the home; feelings of vulnerability when going out alone, especially when they do not speak English, and worries that they may be judged if they had a problem whilst out (e.g. leg seized up);	46

		2 <sup>nd</sup> G=6 (19%)  1 <sup>st</sup> G=26 (81%)  Faith = Muslim, Sikh,  Hindu & Christian				
		32 - 9 Indian (28%); 23 Pakistani (72%) M = 15 (47%); F = 17		Semi-		
<b>8</b> [34]	Lawton, Ahmad, Peel & Hallowell,	(53%) Ages 33 – 71	Perceptions of  DM and  understanding	structured interviews - thematic	Accounts of responsibility and blame in South Asian more likely to be external and include stress, familial responsibility, immigration, genetics (somewhat) and more fatalist accounts –	40
	2007.	T2DM  2 <sup>nd</sup> G=6 (19%)  1 <sup>st</sup> G=26 (81%)	of causation	analysis using  NUDIST	it is Allah's will.	
		Faith = Muslim, Sikh,				

<b>9</b> [35]	Meetoo & Meetoo, 2005.	Hindu & Christian  25 Pakistanis  M = 8 (32%), F = 17 (68%)  Ages 20-80  T1DM & T2DM  No G Info  No Faith Info	Explanatory models	Semi- structured interview – domain/themati c analysis	Actiological factors most cited were stress then heredity, though a mechanism for heredity was not provided, just a general family history stated; vivid recollections of onset, recollection of symptoms; participants had difficulty explaining the pathophysiology of DM, but instead talked about the potential complications; views of the consequences of DM were particularly negative, with beliefs of a 'hard future' and a loss of independence with no thoughts of any way of preventing this other than putting their faith in God or awaiting a 'magical cure'; Asian participants (not Caucasian ones) were found to use unconventional medicines including karella/grapefruit/okra as well as prescribed medicines; 16 participants (64%) admitted to not following the recommended diet, particularly at social events; also suggested by contrast of Caucasian participants,	40
---------------	------------------------	--	--------------------	--	---	----

		possibility that participants were less familiar with how to
		regulate their blood glucose as their Caucasian counterparts;
		dietary modifications a major source of problems and only 9
		(36%) Asian participants participated in exercise.

Participants - M = Male; F = Female;  $T1DM = Type\ 1$  Diabetes Mellitus;  $T2DM = Type\ 2$  Diabetes Mellitus; DM = Diabetes Mellitus;  $I^{st}\ G = I^{st}$  Generation immigrant;  $2^{nd}\ G = 2^{nd}$  Generation immigrant;  $No\ G$  info = no information about which generation immigrant participants are.

*Method* – *NUDIST* = *Non-numerical Unstructured Data Indexing, Searching and Indexing software* 

QR = Quality Rating

**Throughout -** DM= Diabetes Mellitus

#### **Overview**

The age range of participants was 20-80 years, although age data was not available for all papers. The proportion of males to females ranged from 42% to 100% female, average 58.44% female and 41.56% male.

T2DM was studied independently in five papers (Papers 3, 6, 7, 8 and 9), and T1DM and T2DM were studied in two papers (Papers 5 and 9). No papers studied only participants diagnosed with T1DM. Two papers did not identify which type their sample recruited (Papers 2 and 4). Both papers used the same data set and were written by the same authors.

The participants of all papers were from one or a combination of three countries of origin; Bangladesh (Papers 1, 2 and 4), India (Papers 3, 5, 6, 7 and 8) and Pakistan (Papers 6, 7, 8 and 9).

All papers used interviews as their main data collection method; however 3 papers (Papers 2, 3 and 4) also used surveys, focus groups, sorting exercises, structured vignette and narrative production. Data analysis included grounded theory and thematic analysis, with the support of the Non-numerical Unstructured Data Indexing, Searching and Indexing (NUDIST) software for documenting, indexing and analysing in Papers 2, 4, 6, 7 and 8 [36].

Papers assessed a variety of areas related to South Asian peoples' experiences of DM. These included diet and food beliefs (n=3, papers 2, 3 and 6), exercise beliefs (n=1, paper 7), experience of the disease (n=3, papers 1, 4 and 5) and explanatory models (n=5, papers 1, 3, 4, 8 and 9), though there were overlaps in aim.

## Understanding of causation and explanatory models

Studies 1, 4, 8 and 9 explicitly considered understanding of causation and/or explanatory models of DM. Paper 8 suggests that South Asian participants are likely to attribute DM to external causes, responsibility within this group is placed with stress caused by familial responsibility and immigration, genetics, fate and that this is 'Allah's will'. The authors noted the concept of individual responsibility was absent, and ideas of DM 'happening' to a person were characteristic. Paper 4 found health was equated with balance, particularly in substances entering and leaving the body. This belief was typical of this sample (Sylhet Bangladeshis) and led to the assumption that DM was caused by an imbalance of ingoing and outgoing substances, caused by reduced sweating following the move to Britain. However, paper 4 also found some acceptance of individual responsibility resulting from the belief that eating too much sugar causes DM.

The findings of paper 9 provide further support for external causes of DM with stress being the most common cause given, followed by heredity. Though causes of stress were not discussed, these findings agree with those of paper 8, whose participants shared a similar background (Pakistani). However, in paper 1 only one participant identified genetics as being a cause, the majority (8 of the 12 who understood the question) stated they did not know what caused DM.

It seems the majority of South Asian respondents attribute the cause of DM to external factors, with few notions of personal responsibility, though an acceptance of responsibility was present within one sample (paper 4). Although other explanations regarding balance within the body were also given, it is important to note this potential for acceptance of responsibility within the Bangladeshi population was not seen in participants from India and Pakistan. When considering the quality of paper 4, it has

one of the highest quality scores (46), hence there is some confidence that this is a valid finding despite its contradiction of papers 1, 8 and 9 (which scored lower at 40, 40 and 35).

# Experiences of living with diabetes

Fear

Papers 1 and 4 considered reactions to diagnosis. Respondents in paper 4 (Sylhet Bangladeshis) spoke of fear and devastation at diagnosis due to the perception that DM is chronic, incurable and will lead to complications and a loss of life. Though DM is chronic and incurable, if well managed complications and mortality can be avoided [1]. However, another very different reaction to diagnosis was posited; a distinct lack of surprise as symptoms had been recognised from other family members with DM (Paper 1).

Difficulties following professional guidance

Paper 1 explicitly addressed advice given by professionals; advice received was felt to be good but some participants felt they had to be satisfied with the information given as there were no alternatives. Paper 1 also found that advice was not always adhered to. The view of 'advice being good' is supported by findings in paper 4, where respondents placed medical professionals in a powerful role, perceiving them to have the answers. Again this conflicted with a lack of adherence to advice; respondents tended only to monitor and perceive monitoring as important when experiencing symptoms rather than incorporating this as part of regular self-management. Participants also had little understanding of the need for preventative care, suggesting that, despite great importance being placed on the guidance of professionals, understanding or interpretation(s) is limited.

Difficulties due to social obligations, commensality and cultural norms

This theme was present in all but 2 papers (papers 8 and 9) reviewed, with the most important factors being commensality (the practice of eating at a table together), social and cultural obligations (such as Ramadan<sup>f</sup> in Islam) and cultural norms (for example that women remain in the home and that men do not partake in food preparation practices).

Papers 3, 5 and 6 discussed difficulties for participants to maintain a healthy diet alongside the practice of commensality. Paper 1 identified that the result tends to be a weighing up of the consequences of both options; isolation and alienation through rejecting normal cultural practices vs. difficulties with DM management. This led to a reduced amount of food being consumed and a lack of satiation. Papers 3 and 5 found similar discourses and both recruited Gujarat Indian participants of the Hindu faith. The main difficulties identified were social obligations and faith practices, with social isolation being the perceived consequence of avoiding these obligations, which also led to a lack of disclosure about their diagnosis to others. These discourses were seen across faiths, particularly at special occasions such as weddings, and the majority (64%) of participants in paper 9 admitted non-adherence.

Difficulties with DM self-management due to cultural norms were identified by papers 6 and 7. Paper 6 identified men having little input into food preparation as a barrier to healthier diet. Paper 7 identified the cultural norm for women to remain within and care for the home and family as a major barrier to exercise.

It is important to consider that these findings are due to cultural norms, not beliefs about food, the act of eating or the act of exercise.

<sup>&</sup>lt;sup>f</sup> Ramadan is the ninth month of the Islamic calendar in which Muslims are required fast from dawn until sunset [37].

## Beliefs about diet and food and its relation to diabetes management

Papers 2, 3, 4, 5 and 6 addressed food and eating practices within South Asian populations in the UK.

Consumption of 'South Asian' foods

Paper 6 identified that Indian and Pakistani participants received varying advice from healthcare professionals regarding diet and nutritional intake. They noted informants continued to eat traditional South Asian foods despite the perception they were 'dangerous' for DM management, however there was some integration of western food into diets, particularly at breakfast and lunchtime, but the evening meal remained more traditional.

Paper 2 found, in its Bangladeshi sample, a rigid adherence to halal<sup>g</sup> meat, and maintenance of rice as the main part of every meal and advice to change this was met with strong resistance. Generally traditional ingredients were used, however there were food additions such as pizza and baked beans, particularly where children came into contact with these at school. There was also a positive change identified in this paper as foods more difficult to obtain in Bangladesh, that tended to be more 'special event' foods (such as meat and fruit) were cheaper and more freely available in Britain, hence found its way into daily diet.

Finally, a number of papers highlighted the use of bitter gourd or bitter melon as a complementary medicine thought to lower blood sugar and help control DM. This was reported by informants in papers 1, 5 and 9, suggesting respondents wished to control

<sup>g</sup> Halal meat is that which Muslims are allowed to eat by Islamic law. According to the Qur'an humans should not eat meat from pigs or carnivorous animals. In addition animals should be treated with respect and killed as quickly and kindly as possible, and as blood is considered harmful to consume the animals' body should be completely drained of blood as part of the preparation process [38].

their blood sugar, however are more likely to use culturally specific methods that fit with cultural norms than medical advice regarding diet and exercise that do not fit.

Use of traditional cooking methods

Traditional cooking methods remained intact according to paper 6, which found the main method was to shallow fry in oil or ghee (a type of butter) with spices and flavourings. This was understandable alongside the conclusions drawn by papers 4 and 6, that raw, baked or grilled food was indigestible (paper 4) and unpalatable (paper 6), and those of paper 2 which suggested that generous use of ghee/oil and spices is seen to be a sign of affluence.

#### Food classifications

The authors in paper 6 highlighted the tendency of Pakistani and Indian informants to classify food as 'strength giving' or 'weak foods' rather than by nutritional content as would be by western societies (such as carbohydrate content, protein content, etc.). This was commented on within paper 4, where authors identified that fattier foods were seen as 'strength-giving' whereas 'weak foods' were foods like boiled rice and cereals. There was, however, an understanding that strength giving foods could worsen illness in the ill/old/infirm. This was considered further by the authors of paper 2, where categorising of 'strength-giving' and 'weak foods' was further analysed. It was found that generally food was categorised across 2 domains; that of strength and digestibility. These findings suggest these systems for classification mirror underlying South Asian beliefs that all beings have two 'aspects of being'- a physical and the power or 'strength' within a food. The idea of digestibility then reflects the ease with which strength may be extracted.

Paper 2 also reflected that cooking feeds into the classification system, with foods becoming more digestible and stronger with cooking methods such as spicing and frying, whereas steamed or boiled foods that are only mildly spiced are seen as weaker.

Commensality and eating as a social event

Paper 6 observed that balancing social and faith requirements and trying to manage DM led to participants eating smaller amounts, and a lack of satiation. Indeed this seemed to be the main method of managing DM. Seemingly the translation of diet to participants led to a reduction in the amount that they are rather than a change in content. This was supported by papers 3 and 5, where religious practices of commensality at the temple were the most prevalent barrier to adhering to a healthy diet. However, paper 6 identified other methods of adherence to a healthy diet and social and faith practices, where sugar and other 'unhealthy' ingredients were removed or substituted at preparation stage. This, however, is more of a difficulty for men as they have little input into food preparation processes.

# Beliefs about exercise and its relation to diabetes management

Five of the selected papers considered use of, beliefs about, and barriers to exercise (papers 3, 4, 5, 7 and 9).

All papers (except paper 4) suggested informants had a general understanding of the need to exercise, however few undertook regular exercise. There were mixed findings as to understanding of the importance of exercise. Some (Papers 5 and 7) suggested understanding, but no action was taken, and some (Papers 3 and 9) did not explore this. Paper 4 suggested participants did not understand the rationale, and feared exercise may in fact exacerbate symptoms.

There were multiple barriers reported for lack of exercise. Paper 7 reported lack of time as a major barrier and this pertained to different cultural responsibilities; for women, the responsibility of caring for the home and for the men the responsibility of earning for their families. A further barrier was fear of vulnerability. Respondents explained that they felt vulnerable due to an inability to speak English and feared they may be judged if they were to have any difficulties. These findings were supported by paper 3, though at the time this paper was carried out there had been recent acts of racial harassment in the area. Papers 5 and 9 did not provide barriers or belief systems that may have contributed to a lack of exercise.

Paper 4 investigated this more fully. The authors of this paper considered the implication of the word exercise to the Sylhet Bangladeshi population. They found no direct translation of the word 'exercise' into Sylheti, and the closest possible translations had particularly negative connotations. This lack of familiarity with formal exercise may also be the cause of some difficulties for South Asian people in carrying out exercise for DM management.

## **Discussion**

#### Overview

This study aimed to systematically review the experience of DM in South Asian populations in the UK. There were consistent findings across studies highlighting that South Asian individuals with DM have a significantly different understanding of causation and DM management to that of western culture. Findings consistently suggest that South Asian individuals attribute cause of DM externally, with the most common causes being stated as stress, immigration to the UK, heredity, and fatalistic views about

DM being 'God's will'. These causes are due to attributions made by individuals around events at the time of onset of DM such as immigration or familial stress, suggestions that they are 'cured' on return to country of origin, and familiarity with DM due to family history. The latter experience also adds towards the fatalistic view point, as it can mean that DM is seen as something that 'just happens' and is unavoidable.

Additionally, evidence of differing views of this population from westernised ideas regarding food and exercise was found. In western culture the prevalent discourses around nutritional content of food and importance of exercise are strong and are significantly reinforced if a diagnosis of DM is given [31]. However, South Asian ideas about nutritional value are based on a different classification system, viewing foods as 'strength giving' or 'weak' and exercise has particularly negative associations when translated.

Themes will be discussed with regards to interpretation and implications.

## **Causes and Explanatory Models**

The stark contrast of ideas of causation in South Asian culture and western culture could mean that as professionals attempt to prevent DM and ensure good self-management through education, they often miss the difficulties and direct contradiction of this education to some perceptions of people of South Asian origin. In addition, low levels of perceived responsibility (as held by this population) is likely to result in inaction as it is beliefs and evaluations that influence our attitudes which in turn predicts intention to carry out a behaviour (ToRA [15]). Attribution Theory [39] suggests that when individuals attribute responsibility for events externally they perceive themselves as unable to alter outcomes. When individuals make external attributions for their health and/or diagnosis, a fatalistic and overly accepting coping style may result due to the evaluation that changing behaviour won't alter outcomes. Research that considers

attribution of control in DM provides further evidence of this, and suggests that group interventions for individuals with DM is associated with higher levels of perceived internal control [40]. These ideas of increasing perceived control should be at the core of developing targeted interventions for this population.

## **Living with Diabetes**

The predominant reaction of participants to diagnosis of DM was shock and fear, a reaction which can be predicted by models of transition [41] which suggests we are often immobilised by our emotions at crisis points. In western culture we would then (mostly) expect an individual to experience low mood, followed by acceptance and motivation to action (see Fig. 3), however this does not appear to be the case in the South Asian population. Instead there's an accepting inevitability of negative consequences. Though this may be positive in that people are accepting of diagnosis, it could result in people following a different trajectory; one of inaction.

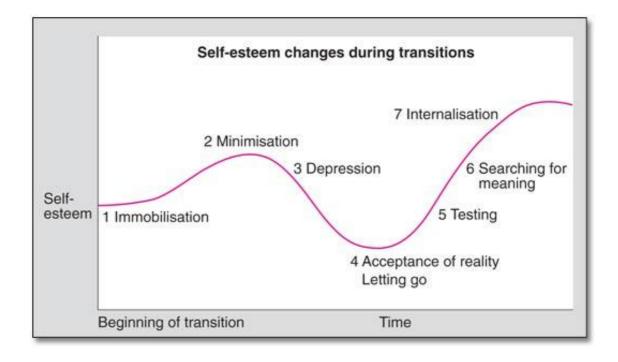


Fig. 3 - Hopson and Adams' Model of Transition [41]

Participants tendency to attribute diagnosis of DM to 'God's will' and their belief there is little hope of avoiding negative consequences of DM, but faith in God must prevail, suggests this population have a propensity to use fatalistic coping. Fatalistic coping styles have been extensively researched with regards to cancer patients [42]. The result of fatalistic coping is acceptance, resulting in high psychosocial well-being [43], but also a belief that outcome is not in the individual's hands; hence a healthy lifestyle, screening or treatment will not change one's fate [44]. This has clinical implications for targeted intervention that increases perception of own control in South Asian DM patients as with appropriate self-management and good diabetic control there are reduced risks of complications [1].

There are also elements of avoidant coping in this group, highlighted by participants' difficulties following professional advice, despite reporting that it had been good.

Research into avoidant coping in medical populations has identified avoidant coping as having a short-term function in reducing anxiety and aiding recovery [45], however prolonged avoidance can lead to treatment non-adherence, increased hospital admissions and reduced decision-making [46]. Again this style of coping is likely to be problematic for participants with DM as avoidant coping styles work to minimise distress by denying the existence of a problem, hence leading to poor self-management.

#### **Beliefs about Diet and Exercise**

One of the most important areas is that of food classification and perception of nutritional value, due to the fact that advice and guidance of professionals directly conflicts with this perception. For example in South Asian culture, frying foods is seen as the most palatable and 'strength giving' way of preparing food, however from the professional point of view, frying foods increases fat content, potentially leading to an increased BMI and risk of DM complications. In addition the lack of formal exercise in

the country of origin means that the cultural norm is not to engage in exercise, however lifestyle would also be different, with more activity, different food and no access to transportation [29]. Therefore, professional advice and support needs to be given in this context, taking into account cultural differences and culinary traditions. This has been shown to be effective in Holland when intensive guidance is given initially then reduced [47]. There is limited research in the UK, and generally considers culturally specific education programmes, whereas the review suggests that education alone is insufficient, and interventions should aim to support individuals to make changes within their current cultural context.

#### **Conclusions**

The review highlighted some specific issues for this population that are compounded by cultural and religious norms. A perception of lack of control has a major impact on coping, as South Asian individuals experience fear and develop avoidant coping styles to manage this and form fatalistic views of the inevitability of difficulties. It is important that these issues are addressed in order to motivate self-management of DM. Interventions aimed at increasing perceptions of control, management of anxiety and developing more adaptive coping styles should be utilised in order to engage individuals in self-management of DM.

Overall the literature review suggests that professionals may be missing important barriers to DM management within their education/intervention programmes; that what is being asked of patients does not fit with cultural and religious norms. It is clear that South Asian people have some understanding of DM causation, and that changes in lifestyle are important. However, there are significant cultural and religious barriers to making significant lifestyle changes and maintaining such changes. A change of

approach to advise and support South Asian participants to make changes that work within their own cultural norm framework may be more successful in motivating DM self-management. Existing research on this is very limited, and in the UK non-existent. Further research may be needed to consider how this might be achieved.

### **References**

- [1] Diabetes UK. (2011) Diabetes in the UK 2011/12: Key Statistics on Diabetes.

  London: Diabetes UK, 2011. Available at

  http://www.diabetes.org.uk/documents/reports/diabetes-in-the-uk-201112.pdf. Last accessed 21st January 2013.
- [2] Hex, N., Bartlett, C., Wright, D., Taylor, M. & Varley, D. (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs.

  Diabetic Medicine, 29(7), 855-862.
- [3] Diabetes UK. (2009) Improving supported self-management for people with diabetes. London: Diabetes UK. Available at http://www.diabetes.org.uk/Documents/Reports/Supported\_self-management.pdf Last accessed 9<sup>th</sup> March 2013.
- [4] Department of Health [DOH] (2011) Quality, Innovation, Productivity and

  Prevention (QIPP). Retrieved from

  http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPP/index.h

  tm on 21st January 2013.
- [5] Cameron, L. D. & Jago, L. (2008). Emotion regulation interventions: A common-sense model approach. *British Journal of Health Psychology*, 13(2), 215-221.
- [6] National Institute for Health and Clinical Excellence. (2004). *Type 1 diabetes:*diagnosis and management of type 1 diabetes in children, young people

  and adults. London; UK, National Institute for Clinical Excellence.

- [7] National Institute for Health and Clinical Excellence. (2008) Type 2 Diabetes,

  National clinical guideline for management in primary and secondary

  care (update). London; UK, National Institute for Clinical Excellence.
- [8] Hagger MS, Orbell S. (2003) A meta-analytic review of the common-sense model of illness representations. *Psychology & Health*, *18*(1), 141–184.
- [9] Harvey, J.N. & Lawson, V.L. (2009) The importance of health belief models in determining self-care behaviour in diabetes. *Diabetic Medicine* 26(1), 5–13.
- [10] National Institute for Health and Clinical Excellence. (2012). NICE Public

  Health Guidance 38: Preventing type 2 diabetes: risk identification and

  interventions for individuals at higher risk. London; UK, National Institute

  for Clinical Excellence.
- [11] Barnett, A. H., Dixon, A. N., Bellary, S., Hanif, M. W., O'Hare, J. P., Raymond, N. T. & Kumar, S. (2006). Type 2 diabetes and cardiovascular risk in the UK south Asian community. *Diabetologia*, 49,(10), 2234-2247.
- [12] Department of Health (2005) Structured Patient Education in Diabetes: Report from the Patient Education Working Group. The Stationery Office,

  London.
- [13] Hill, J. (2006). Management of diabetes in South Asian communities in the UK.

  Nursing Standard (Royal College Of Nursing (Great Britain): 1987),

  20(25), 57-64.
- [14] Mazzuca, S.A.(1982) Does patient education in chronic disease have therapeutic value? *Journal of Chronic Disease*, *35*(7), 521–529.

- [15] Ajzen, I. (1991). The Theory of Planned Behaviour. *Organizational Behaviour* and Human Decision Processes, 50,(2), 179-211.
- [16] Redding, C. A., Rossi, J. S., Rossi, S. R., Velicer, W. F. & Prochaska, J. O.,
  (2000). Health Behavior Models, *The International Electronic Journal of Health Education*, 3(Special Issue), 180-193.
- [17] Hawthorne, K., Robles, Y., Cannings-John, R. & Edwards, A. G. K., (2008). Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups. *Cochrane Database of Systematic Reviews*, 3.
- [18] Khan, H., Lasker, S. S. & Chowdhury, T. A. (2011). Exploring reasons for very poor glycaemic control in patients with Type 2 diabetes. *Primary Care Diabetes*, *5*(4), 251-255.
- [19] Leventhal, H. & Cameron, L. (1987). Behavioural theories and the problem of compliance. *Patient Education and Counselling*, *10*(2), 117-138.
- [20] White P Smith, S, & O'Dowd, T (2001) Psychosocial determinants of glycaemic control in type 2 diabetes. *Dept. Public Health and Primary Care*, Trinity College Dublin.
- [21] Keogh, K. M., White, P., Smith, S. M., McGilloway, S., O'Dowd, T. & Gibney, (2007). Changing illness perceptions in patients with poorly controlled type 2 diabetes, a randomised controlled trial of a family-based intervention: protocol and pilot study. *BMC Family Practice*, 8, 36.
- [22] Alam, R., Speed, S. & Beaver, K. (2012). A scoping review on the experiences and preferences in accessing diabetes-related healthcare information and

- services by British Bangladeshis. *Health and Social Care in the Community*, 20(2), 155-171.
- [23] South Asian Association for Regional Cooperation (SAARC) (2009). Available at http://www.saarc-sec.org/ Last accessed 17th May 2013
- [24] National Institute for Health and Clinical Excellence (2009). Appendix I:

  Methodology checklist: qualitative studies. *The guidelines manual*.

  London; UK, National Institute for Clinical Excellence.
- [25] Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M.,
  Britten, N., Roen, K. & Duffy, S. (2006) Guidance on the conduct of
  narrative synthesis in systematic reviews. Results of an ESRC funded
  research project. (Unpublished report, 2006, University of Lancaster, UK).
- [26] Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., Yardley, L., Pope, C. & Donovan, J. (2011). Evaluating metaethnography: a systematic analysis and synthesis of qualitative research.

  Health Technology Assessment, 15(43).
- [27] Choudhury, S. M., Brophy, S. & Williams, R., (2009). Understanding and beliefs of diabetes in the UK Bangladeshi population. *Diabetic Medicine*, 26,(6), 636-640.
- [28] Chowdhury, A. M., Helman, C. & Greenhalgh, T., (2000). Food beliefs and practices among British Bangladeshis with diabetes: implications for health education. *Anthropology & Medicine*, 7,(2), 209-226.

- [29] Duthie-Nurse, G., (1998). An anthropological study into the views on diet and disease of a sample of Hindu Gujarati-speaking women with Type 2 diabetes. *Practical Diabetes International*, 15,(4), 109-111.
- [30] Greenhalgh, T., Helman, C. & Chowdhury, A. M., (1998). Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *British Medical Journal*, *316*,(7136), 978-983.
- [31] Keval, H., (2009). Cultural negotiations in health and illness: the experience of type 2 diabetes among Gujarati-speaking South Asians in England.

  \*Diversity in Health and Care, 16,(4), 255-265.
- [32] Lawton, J., Ahmad, N., Hanna, L., Douglas, M., Bains, H. & Hallowell, N., (2008). 'We should change ourselves, but we can't': accounts of food and eating practices amongst British Pakistanis and Indians with type 2 diabetes. *Ethnicity and Health*, *13*,(4), 305-319.
- [33] Lawton, J., Ahmad, N., Hanna, L., Douglas, M. & Hallowell, N., (2005). 'I can't do any serious exercise': barriers to physical activity amongst people of Pakistani and Indian origin with Type 2 diabetes. *Health Education Research: Theory and Practice*, 21,(1), 43-54.
- [34] Lawton, J., Ahmad, N., Peel, E. & Hallowell, N., (2007). Contextualising accounts of illness: notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociology of Health & Illness*, 29,(6), 891-906.
- [35] Meetoo, D. & Meetoo, L., (2005). Explanatory models of diabetes among Asian and Caucasian participants. *British Journal of Nursing*, *14*,(3), 154-159.

- [36] Richards, T. & Richards, L., (1991). The NUDIST Qualitative Data Analysis System. *Qualitative Sociology*, 14,(4), 307-324.
- [37] Haq Islam (2013). About Ramadan. Available at http://www.haqislam.org/articles/ramadan/ Last accessed 29<sup>th</sup> May 2013.
- [38] Halal Food Authority (2001). Definition of Halal. Available at http://www.halalfoodauthority.co.uk/definition-of-halal/ Last accessed 16<sup>th</sup> May 2013.
- [39] Miller, I. W. & Norman, W. H. (1979) Learned Hopelessness in Humans: A

  Review and Attribution-Theory Model. *Psychological Bulletin*, 86(1), 93118.
- [40] Trento, M., Tomelini, M., Basile, M., Borgo, E., Passera, P., Miselli, V., Tomalino, M., Cavallo, F. & 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.
- [41] Hopson, B. & Adams, J. (1976) "Towards an Understanding: defining some boundaries of transition dynamics" in Adams, J., Hayes, J. & Hopson, B., Eds (1976) Transition: Understanding and managing personal change London: Martin Robertson.
- [42] Hinton, J. (1999). The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliative Medicine*, 13(1), 19-35.

- [43] Lampic, C., Wennberg, A., Schill, J-E., Glimelius, B., Brodin, O. & Sjödén, P-O. (1994). Coping, Psychosocial Well-Being and Anxiety in Cancer
   Patients at Follow-Up Visits. *Acta Oncologica*, 33(8), 887-894.
- [44] Niederdeppe, J. & Levy, A. G. (2007) Fatalistic Beliefs about Cancer Prevention and Three Prevention Behaviours. *Cancer Epidemiology, Biomarkers & Prevention*, 16(5), 998-1003.
- [45] Buetow, S., Goodyear-Smith, F. & Coster, G. (2000). Coping strategies in the self-management of chronic heart failure. *Family Practice*, 18(2), 117-122.
- [46] Levine, J., Warrenburg, S., Kerns, R., Schwartz, G., Delaney, R., Fontana, A., Gradman, A., Smith, S., Allen, S. & Gasgoine, R. (1987). The Role of Denial in Recovery from Coronary Heart Disease. *Psychosomatic Medicine*, 49(2), 109-117.
- [47] Middlekoop BJC, Geelhoed-Duijvestijn PHLM, van der Wal G. (2001)

  Effectiveness of culture-specific diabetes care for Surinam South Asian patients in the Hague. *Diabetes Care*, 24(11), 1997–1998.

Part Two:

**Empirical Paper** 

British Journal of Obstetrics and Gynaecology

Vol. X, No. X Month 20XX, 000-000

The experiences of South Asian women with a first diagnosis of gestational diabetes mellitus

Amy Spratt\* Trainee Clinical Psychologist, Department of Clinical Psychology,

University of Hull – BSc (Hons)

Dr Diane Farrar, Research Programme Manager, Bradford Teaching Hospitals NHS

Foundation Trust (BTHFT) - PhD

Dr Dorothy Frizelle, Consultant Clinical Health Psychologist, Department of Clinical

Psychology, University of Hull-BSc; BSc; ClinPsyD. AFBPsS

\* Corresponding Author: Tel: 07538788506

Email Address: a.spratt@2007.hull.ac.uk

This paper is written in the format ready for submission to the British Journal of

Obstetrics and Gynaecology. Please see Appendix 3.1 for the Author Guidelines.

(Word count = 5766)

49

### **Abstract**

**Objective:** This research aims to explore South Asian women's experiences of Gestational Diabetes Mellitus (GDM), with a focus on emotional experience and cognitive representations of illness.

**Design:** Qualitative methodology (IPA) was utilized.

**Setting and Sample:** Seven South Asian women with a first diagnosis of GDM were recruited from a hospital-based clinic in the North of England

**Methods:** Semi-structured interviews were carried out with participants about their experiences GDM. Interviews were transcribed and analysed using interpretive phenomenological analysis (IPA).

**Results:** Themes emerged around duty to protect the baby, making sense of diabetes mellitus (DM) by using the experiences of others and beliefs about causes, constraint over the pregnancy and emotional responses.

Conclusions: All participants described a change in attitude from feeling as though they had a 'normal' pregnancy to feeling anxious or fearful about pregnancy. Women also described feeling as though they had lost the anticipated pregnancy role (I.e. eating for 2, taking it easy). Participants made sense of GDM using their understanding of family member's experiences and cultural beliefs about causes of DM. These formed a perception of some inevitability of developing Type 2 diabetes mellitus (T2DM) in future. Emotional responses included anxiety and fear followed by getting 'used to' having GDM, as well as guilt and blame. It is recommended that emotional support should be available during pregnancy, and postpartum follow-ups focused on supporting continued changes rather than the current strategy of monitoring for development of T2DM.

**Keywords:** gestational diabetes mellitus; GDM; South Asian; experiences; illness perceptions

# **Introduction**<sup>h</sup>

DM is a condition in which the glucose levels in the blood are too high because the body is unable to use it effectively<sup>1</sup>. Currently around 2.9 million people in the UK have a diagnosis of either Type 1 diabetes mellitus (T1DM) or T2DM<sup>1</sup> and it is estimated that by 2025 this figure will have risen to 5 million<sup>1</sup>. As the NHS is aiming to make £20 billion in savings by 2014/15<sup>2</sup> the prevention of T2DM is becoming an important economic as well as public health issue when considering expense to the NHS as it is estimated that in 2010/11 T2DM cost the NHS £8.8 billion<sup>3</sup>.

As part of a strategy to address this the National Institute for Health and Clinical Excellence (NICE) have developed a pathway with recommendations of how to prevent T2DM at a community, group and individual level<sup>4</sup>. This pathway includes national and local interventions to encourage healthier lifestyles and reduce body mass index (BMI)<sup>j</sup>, as well as guidelines for professionals when working with individuals, specifically encouraging risk assessments and identifying those at risk of developing T2DM.

These NICE guidelines suggest that assessments should be offered to individuals that are at higher risk of developing T2DM, including those from high risk ethnic-minority backgrounds, adults over the age of 40 and adults with conditions that increase their risk

h For the purpose of thesis and viva an extended introduction has been included, however a shortened

version has been created for the purpose of submission (Appendix 4.1) as required for the British Journal of Obstetrics and Gynaecology (BJOG) (see Appendix 3.1 for BJOG author guidelines).

<sup>&</sup>lt;sup>i</sup> T1DM is a result of the body being unable to produce any insulin (the hormone that helps glucose to leave the blood and enter the cells for fuel). T2DM develops when the body does make insulin, however the body either doesn't make enough, or the insulin that is produced is ineffective<sup>1</sup>.

<sup>&</sup>lt;sup>j</sup> As increased BMI increases risk of developing T2DM<sup>5</sup>.

of T2DM (including obesity, hypertension<sup>k</sup>, cardiovascular disease<sup>l</sup> and a history of GDM)<sup>4</sup>. The guidelines suggest that those at risk of developing T2DM should be given guidance on reducing risk or delaying the onset of T2DM by undertaking health behaviour change such as increasing levels of physical activity, achieving a healthy BMI, and making healthy changes to their diet<sup>6</sup>.

One of the risk factors for T2DM is history of GDM. GDM is defined as impaired glucose tolerance first diagnosed in pregnancy<sup>7</sup>. This is different to pregnant women with pre-existing diabetes, but is similarly associated with higher rates of maternal and perinatal problems compared to non-diabetic women<sup>8</sup>. NICE guidance<sup>9, 10</sup> recommends screening of at-risk women at 24-28 weeks gestation. Risk factors include BMI over 30, previous macrosomic (large for gestational age) baby, previous GDM, family history of DM or family origin with a high prevalence of DM (South Asian, black Caribbean or Middle Eastern).

In addition to problems experienced by mothers with GDM in pregnancy and birth there are also complications that are more likely post-pregnancy. A woman who has experienced GDM acquires an increased risk of developing T2DM after pregnancy. This risk continues long-term<sup>11</sup> and continues to increase with further pregnancies<sup>12</sup> after pregnancy with GDM, with recurrence rates reported between 30 and 84% after an index pregnancy with GDM<sup>13</sup>. There is also evidence of increased long term risk of T2DM and consequent cardiovascular disease in such mothers<sup>14</sup>.

<sup>&</sup>lt;sup>k</sup> Hypertension is also known as high blood pressure and is defined as having a blood pressure reading over 140/90mmHg<sup>15</sup>.

<sup>&</sup>lt;sup>1</sup> Cardiovascular disease includes all the diseases of the heart and cardiovascular system, including angina and heart attack (coronary heart disease) and stroke<sup>16</sup>.

Several studies have investigated the perception the mother has of her likelihood of developing T2DM following GDM. These studies have aimed to understand mother's perceptions of risk as it is an important factor that has been shown to determine whether they will participate in preventative behaviours such as exercise, healthy eating and weight loss after pregnancy<sup>17</sup>. For instance, one study found that although 90% of women were aware that GDM was a risk factor for the development of T2DM, only 16% believed themselves to be at high risk<sup>18</sup>. This study seems to show incongruence between understanding of and perception of risk for developing T2DM. This incongruence can be seen in other studies, which have reported no association between the amount of advice remembered and the extent to which preventative strategies are employed<sup>19</sup>. These studies clearly show that some of the strategies used by health professionals to promote preventative behaviours could be enhanced by further understanding of women's experiences, as a straightforward explanation of the risk of not using such strategies does not appear to be effective. This may ultimately serve to promote better and more effective T2DM prevention strategies in these women.

One way of understanding the incongruence between understanding and perception of risk is to consider models of illness perceptions. The self-regulatory model of illness behaviour (SRM) suggests an interaction between cognitive and emotional illness representations leading to coping and outcome appraisal<sup>20</sup>. In a GDM context the coping behaviours may include obtaining information and reassurance seeking, monitoring and changes to lifestyle; appraisal would depend on outcome, for example complications in pregnancy, disappearance of GDM, etc. It is fair to suggest that cognitive representations of the illness would not alone be responsible for coping behaviours, as there is an interaction between cognitive and emotional representations. This model may help to explain why, although the majority of women with GDM have cognitive

understanding of their illness and perception of the risks involved are accurate, few believe themselves to be at high risk, as emotional representations are not accounted for.

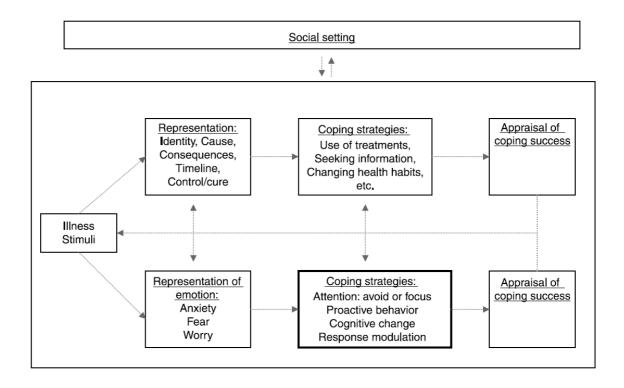


Fig. 1 - The SRM<sup>20</sup>.

Research exploring the experiences of women with GDM have used quantitative methods, however, studies that use qualitative methods are less prevalent, meaning that we currently do not have a thorough understanding of women's experiences in order to guide further research (for example, should a measure of quality of life, illness perceptions or depression be used?). Another weakness of quantitative research in this context is the temporal changes of women's experiences as their pregnancy develops. Therefore the lack of longitudinal research identifying differences in experiences at different points within pregnancy, highlights a current weakness of the quantitative research in this area. A grounded theory study<sup>21</sup> further highlights the importance of changes over time. They interviewed ten white British women with a diagnosis of GDM in current pregnancy, and determined the main themes of "From stun to gradual balance" describing their initial reaction and the steady progress that the women took to

adapt to their illness. The study suggests that the diagnosis of GDM initiates a number of challenges for the woman to overcome, but that for the women involved in this study there was a decision to overcome these challenges in order to ensure their health and that of the unborn child.

Bandyopadhyay, Small, Davey, Oats, Forster & Aylward<sup>22</sup> carried out a qualitative study using thematic analysis and looked at the experience and understanding about GDM of 17 South Asian women with GDM living in Australia, identifying reactions to diagnosis and barriers to following professional guidance. Two face to face interviews were carried out with each participant, one after diagnosis of GDM and one 6 weeks postpartum. This study found that, similarly to women from other cultural backgrounds, women experience fear, shock and distress in immediate reaction to their diagnosis. The study also considered the rationale for not carrying out preventative measures such as diet and exercise and found that this contradicted with Asian women's cultural beliefs about food consumption and pregnancy. In their home countries socioeconomically deprived women would experience adverse pregnancy outcomes due to under nutrition or malnutrition and strenuous labour, hence women in a more middle socioeconomic class in Australia would believe that rest and more food is the best way to avoid these adverse outcomes<sup>22</sup>. These beliefs are in direct contrast to the recommended behaviours for self-management of GDM.

In summary, the incidence of T2DM is rising within the UK, and the costs of screening, diagnosis and management are increasing along with it. NICE<sup>4</sup> suggests that health professionals should be providing guidance for individuals with higher risk of developing T2DM on how to reduce risk and delay onset of the disease. One of the groups at risk are women who have had a diagnosis of GDM, however research considering a woman's perception of risk of developing T2DM following GDM

suggests that understanding of risk may not be sufficient to motivate these individuals to carry out behaviours that reduce their risk. One explanation for this is by considering the self-regulatory model of illness behaviour<sup>20</sup>, which suggests an interaction between cognitive and emotional illness representations leading to behaviours. This model would suggest that by understanding both cognitive and emotional illness representations, professionals may be able to develop more effective interventions to motivate behaviour change.

There is currently a dearth of knowledge related to GDM in ethnic minority groups. Their experience and needs may be different from Caucasian women so should be explored. Although Bandyopadhyay and colleagues<sup>22</sup> have explored experiences of South Asian women with GDM living in Australia, research identifying that up to 65% of the GDM population in the UK as being South Asian<sup>23</sup> highlights the need for similar research in the UK. With South Asian women significantly more likely to go on to develop T2DM following a pregnancy with GDM than their Caucasian counterparts this research has clear potential clinical and cost implications. Therefore, this research aims to explore South Asian women's experiences of GDM, with a focus on emotional experience as well as cognitive representations (via illness perceptions) and how these may impact on expectations of future health.

#### **Method**

### Design

Qualitative IPA methodology was utilised, with data collected from 7 semi-structured interviews. The research reflects a relativist epistemology which has a greater emphasis

on the acquisition of knowledge and approaches reality as being subjective and based in individual experience [Please see epistemological statement (Appendix 5.1).].

### **Participants**

The study used a convenience sample of participants from Maternal Diabetes clinics. Clinics were attended by the researcher, and all patients present at these clinics that met the inclusion criteria. The Diabetes Specialist Nurses (DSN) approached eligible patients whilst in clinic to provide a brief introduction to the study and gain verbal consent for the researcher to provide further information in verbal and written format [See Patient Information Sheet and Consent Forms in Appendix 6]. In total 20 patients were approached and 7 agreed to take part in the study. The main reasons for women to decline participation were: being too busy preparing for the arrival of their baby (7), or that they did not wish to arrange yet further appointments alongside those they were already attending(6).

Table 1. Demographic Data for Participants.

	Age	Country of	Country of	Occupation	Number of	Religion	Method of	Weeks of Gestation
Participant	Range	Origin	Birth	Classification (ONS) <sup>24</sup>	Children		Control	at Interview
1	30-39	Pakistan	Pakistan	Elementary Occupation	1	Islam	Diet and Exercise	33
2	40-49	Pakistan	Pakistan	Elementary Occupation	0	Islam	Medication	31
3	20-29	India	India	Professional Occupation	1	Hindu	Insulin	35
4	20-29	Pakistan	Pakistan	Housewife	0	Islam	Medication	29
5	30-39	Pakistan	Pakistan	Housewife	0	Islam	Medication	37

6	20-29	Pakistan	Pakistan	Housewife	0	Islam	Insulin	37
7	20-29	Pakistan	UK	Professional Occupation	0	Islam	Insulin	33

#### **Inclusion Criteria**

Participants were approached to take part if they fitted with the following inclusion criteria;

- South Asian origin; to focus on the experiences of South Asian women due to the high (and increasing) prevalence of GDM within this group.
- Over the age of 18; this research was focused on the experiences of adult women, in order to eliminate any additional difficulties that may arise due to normal development in adolescence.
- First diagnosis of GDM; women in their first pregnancy with GDM were included as it was felt that experiences of women with recurrent GDM may be influenced by previous pregnancies with GDM.

#### **Measures**

Semi-structured interviews were undertaken with seven participants. The interview schedule contained open-ended questions designed to draw out information pertinent to the research questions; the experience of diagnosis and GDM management and their illness perceptions. The interview was developed by the researcher with the input of an Urdu translator based in the hospital clinics to ensure that the interview schedule was clear and appropriate [Please see Interview schedule (Appendix 6.3)]. Feedback showed that the interview schedule was suitable, although one change was suggested to the wording of a question to improve clarity. Feedback was given by the first participant after the first interview to identify whether any further questions may have been appropriate or if any existing ones made clearer. [As the interview schedule was felt to be appropriate, this interview was transcribed and included in the final data set.] All

interviews were carried out, audio-recorded and transcribed by the researcher. One interview used a family member (Husband) as translator as the participant was unable to speak enough English to carry out the interview in English, however was still keen to take part in the research. Another participant wished her husband to be present in the interview, and though he commented on questions within the interview, these were then followed up and confirmed by the participant herself. As the study aimed to understand the woman's experience, the participant's husband's comments were then removed from the transcript and the transcript analysed without them.

#### Procedure

Ethical approval was obtained from West of Scotland Research Ethics Service via proportionate review (Appendix 7.1). Research and Development (R&D) approval was obtained from the NHS Foundation Trust in which the research was carried out (Appendix 7.2) and a letter of access obtained following confirmation of preengagement checks (Appendix 7.3). Between September 2012 and April 2013 DSN enquired whether patients diagnosed with first occurrence GDM would be interested in participating in the study. If the patient showed interest they were provided with an information sheet (Appendix 6.1) and asked for the consent of the patient for the researcher to provide more information. If the patient consented to this then the researcher introduced the study in more detail and was available to answer any questions. If the patient was still interested in participating, the researcher took contact details to contact them within 7 days. After time for consideration of participation, if the participant was still interested in partaking in the study a meeting was arranged at a time and place convenient for the participant to be interviewed. At the point of meeting the participant was given the opportunity to discuss the study further before completing the

written consent form (Appendix 6.2). At this stage all participants agreed to continue with the study. At the end of the interview all participants were given the option of being contacted by post with feedback about the main findings and implications of the research.

### **Analysis Procedure**

Each participant was allocated a pseudonym and all 7 audiotaped interviews were transcribed verbatim by the researcher. Transcripts were then printed with line numbers and read several times by the researcher to further familiarise themselves with the content. The data were then analysed according to the guidelines for interpretative phenomenological analysis by Smith, Flowers and Larkin<sup>25</sup> [see Appendix 8.1 for worked example].

Stage One: The researcher immersed themselves in the data by reading and re-reading the transcripts, noting anything of significance and/or interest in the left hand margin on the second reading. Comments were then separated into descriptive (focused on the content of the transcript) linguistic (concerned with the use of specific language) and conceptual (which were interested in the comments of participant's at a more interrogative level). At this stage three independent researchers read extracts of interview transcripts, making initial comments in the domains described above.

Discussion between researchers then helped to identify and form a consensus around emerging themes.

Stage Two: Transcripts were re-read again by the researcher and any emerging themes were documented on the transcripts. These were also discussed with three independent researchers in order to ensure that themes emerging formed valid interpretations of the transcripts.

Stage Three: The researcher then looked for patterns and similarities across themes emerging from within and across the seven transcripts. Participant's quotes were used to support identified themes.

*Stage Four:* The most pertinent themes from across all 7 participants were then combined and re-organised to form super-ordinate and subordinate themes. Throughout analysis the researcher discussed the process with a peer group in order to ensure a valid interpretation.

Within IPA the researcher is required to suspend their own critical judgement while initially reading through the data to allow focus on the data itself. Following this however, there is an anticipation that a researcher's own experiences and assumptions will begin to shape the interpretation of the data, as their way of making sense of the data will depend on these assumptions. In order to identify how personal assumptions may interact with the data, the lead researcher kept a reflective diary, and also had discussions with both the peer group and supervisor to identify particular interpretations that may be more available to the lead researcher than to other individuals with different experiences.

### **Results**

<u>Table 2. Super-ordinate and sub-ordinate themes</u>

Super-ordinate Themes	Sub-ordinate Themes
Duty	Duty to protect

	'I need to be careful'			
	'he went through so much, so I can			
Making sense of Diabetes	go through so much'			
	Causes of Diabetes			
	Not a 'normal' pregnancy			
Constraint over the Pregnancy	Can't enjoy the pregnancy			
	Battle for control			
Emotional Dagranges	'I got used to it now'			
Emotional Responses	Guilt and Blame			

## **Duty**

# Duty to protect

The majority of women interviewed identified their anxiety and fear about the possibility that harm to the baby may be the outcome of their diagnosis. As a result most of the women explained that they saw it as their duty to strictly adhere to their treatment and kept as tight a control of their GDM as possible in order to protect their unborn child from harm.

'y'know like in the morning if I'm asleep I have to wake up, you know on the time to check it (laughs) it's like your duty you have to do (laughs)' Participant 2, 527-528

Further to this, some of the participants also admitted that they were keeping a tighter control over their GDM than they may have done had there only been their own health to consider.

'I always think well it's protective for the baby really because, I find if I wasn't pregnant, maybe I'd be a bit more naughty but because I'm pregnant, I, err, that's the sorta motive' (Participant 7,426-429)

Some participants had also given thought to the potential consequences of a lapse of control. One participant attempted to explain the thought processes that this had started.

'if I don't look after myself, if I don't control my diet, then obviously my child can get affected by it, which I don't really want cos if a child, new born child is in the world and has already got so many problems with it, you can't live with that can you?'

(Participant 1, 705-707)

#### 'I need to be careful'

There was a general feeling amongst all the participants that the experience of having GDM should be taken as a lesson, almost a snapshot of what life could be like if they didn't change their habits.

'it opened my eyes to, I need to be careful' (Participant 6, 275)

Participants described looking forward to getting back to normal, and one even commented on wanting to eat some of the foods that they were missing, but there was a commonality amongst all that these ideas and cravings were held alongside new ideas about risk and behaviour change, and a feeling that they owed it to themselves to make changes to avoid T2DM.

'I said to my husband, oh, when, when I've had this baby that's it I'm going onto my pizzas and burgers' (Participant 7, 532-534)

'but then the other half's thinking, no if I, if I change my diet now then it might it will work in my favour later' (Participant 7, 800-801)

Despite this wish to change in order to delay or stop the development of T2DM, there was also a certain amount of resignation to a future with T2DM.

'in terms of my health, I really think that I will be type 2 diabetes when I'm older' (Participant 7, 789)

# Making sense of Diabetes

# 'he went through so much, so I can go through so much'

The experiences of others, both good and bad, formed a large part of the beliefs about DM held by the participants. This reinforces that, despite growing access to information (via the media and the internet), the majority of participants still used the experiences of others to make sense of their own experiences.

'he went through so much, so I can go through so much and you know I'd be a burden on other people' (Participant 1, 230-232)

The experiences of others with GDM also played its part in managing anxiety. The majority of participants knew, or knew of, other women who had experienced GDM, and this perception that you weren't alone or the only one had a positive effect on the participant's perception of GDM.

'and it's much more widespread than you think and er, that made me feel better.'
(Participant 7, 462-463)

From the point of view of the participants it seemed that the more common GDM, the less anxiety provoking the experience.

'another friend of mine, erm, she also had in her second pregnancy so, I just find it common.' (Participant 3, 733-735)

There was, however, an understanding that, despite its prevalence, not all stories about GDM would necessarily have the desired (from the point of view of participants) outcome. It seemed that some participants were likely to avoid identifying those experiences with negative outcomes.

'if you go on the internet you see it will be their own experiences, might be good, might be bad, if it's good, then it's good for you, if they put some bad experience, even though you're not in that state you tend to feel in that state so....' (Participant 3, 292-288)

### Causes of diabetes

In interviews participants mentioned different ideas about the cause of DM. It seemed that there were various levels of understanding about causes, some coming from the guidance of professionals, but many coming from cultural ideas about DM.

Firstly it seemed that lifestyle (i.e. eating sugary foods and a lack of exercise) was seen to be a causing factor, and this was seen with the majority of participants.

'So I can be diabetic as well and because of the foods I've been eating and been doing less exercise, that's when it starts' (Participant 1, 178-179)

'you think maybe I've done something wrong, maybe you have too many, erm,

sort of starchy, sugary foods and I shouldn't, but then part of it was hard to cope with

because I always associate gestational diabetes with sugar' (Participant 7, 629-631)

Many of the participants again talked about GDM being a result of pregnancy, a part of

the hormone levels changing throughout the term of the pregnancy. This relates well

with those ideas brought up previously about using the experiences of others,

particularly those with positive outcomes, to understand one's own experiences. If you

are to assume that DM will not be present post pregnancy, then pregnancy, or a part of,

is the cause, hence changing hormones in pregnancy is an appropriate explanation of

GDM.

'it's just in pregnancy, its hormones' (Participant 1, 613)

'it's a part of pregnancy' (Participant 3, 462)

'It's not a long term thing just due to her pregnancy''' (Participant 4, 30)

Another factor that was suggested by one of the participants was that of stress. Again

this could be seen to fit in with hormones and pregnancy, however there is evidence to

suggest that this is a more general belief within South Asian culture.

'you do get diabetes lot, because of stress as well' (Participant 3, 498)

Constraint over the Pregnancy

Not a 'normal' pregnancy

\_

<sup>m</sup> Reference to 'her pregnancy' as husband is translating for participant 4 and referred to his wife throughout in the third person rather than translating directly into the first.

69

When asked about their attitude towards their pregnancy most of the women acknowledged a change in attitude, from feeling positive to now feeling anxious and feeling as though the pregnancy has changed from being 'normal'.

'I wasn't worried about my pregnancy, I was like okay everything's normal, no worries whatsoever, but since I've been diagnosed I've got so many worries'

(Participant 1, 354-355)

'Erm, I've taken maternity early because I had a lot of... trouble in this pregnancy (laughs)' (Participant 3, 41)

Despite this acknowledgement of the difficulty of pregnancy, many of the issues discussed did not raise the level of emotion that may have been expected within their context. Often worries and anxieties would be minimised or avoided, with participants preferring to focus on the practicalities of managing GDM rather than the emotional reactions to diagnosis.

'yeah, because of the still birth thing I thought, right I'm gonna struggle with this and I'm absolutely useless at operating some sort of, you know, just using that (gestures towards blood monitor)' (Participant 7, 301-302)

### Can't enjoy the pregnancy

Within pregnancy there are multiple discourses around women 'eating for two' and 'taking it easy' and it seems that management of GDM creates some loss of this 'pregnancy role'.

'I think the last two, three months you think, right seven month has gone, last two months left, you wanna, I was always thinking I want to enjoy this phase, I wanna

eat what I want I want to sleep when I want to sleep, but then, they're not as enjoyable with diabetes as they should be' (Participant 6, 593-595)

In addition to the loss of the role they envisaged themselves taking up, there are also issues for some of the women (particularly those on insulin) regarding managing monitoring and treatment within their daily lives.

'I feel its err, erm, a messy job (laughs)' (Participant 3, 315)

This 'messy job' also has implications for convenience and embarrassment, as well as some issues about where participants felt comfortable injecting on their bodies.

'when they said the place to inject it is in your tummy I, I found that really hard to adjust to' (Participant 7, 237-238)

Finally, another area that caused concern (particularly for participants on insulin) was the concern about childbirth itself. Some participants were having an induction or were considering a caesarean to minimise the risk in childbirth.

'I want to go full term, I want to take my time, enjoy the last month.... so now I feel like... I'm rushing to get induced' (Participant 6, 333-334)

'y'know at first I wouldn't have dreamt of thinking caesarean, but now it's just like, wow, it's sort of, thought change' (Participant 7, 863-864)

## Battle for Control

Within the pregnancy there also appear to be some battles that women have to go through in order to retain some of the ownership of the pregnancy, rather than requiring outside influences to manage. The first battle is to avoid treatment, particularly insulin, which would be prescribed by the Diabetic specialist team, and seemed particularly aversive to participants.

'I'm definitely gonna control it without my tablets and insulin' (Participant 1, 339-340)

'it's like, okay, I can control it with the tablets and stuff like that but if they put me on like the injections, then you think, I don't know... more serious isn't it yeah.'

(Participant 5, 348-353)

It seems that even when this battle is 'lost' and the participant is taking insulin, there is still some battle against their own body to maintain some control.

'I haven't even eaten anything, why on earth are my sugar levels as they are but I think it's just accepting that, it's about trying to control it, but you can't always necessarily even control it because of your hormones and things so, sometimes it is quite demotivating' (Participant 7, 366-369)

# Emotional Responses

### 'I got used to it now'

As referred to previously, generally the reaction to diagnosis was explained as focus on the practical management issues rather than any exploration of emotional reactions.

When asked about their reactions to diagnosis, all of the participants disclosed shock, anxiety and fear.

'at first I felt quite scared, scared that it might affect the baby' (Participant 5, 65)

'it was a bit of an initial panic when they told me' (Participant 7,280-281)

However, on exploration of these emotional reactions, the majority of participants stated that they've 'got used to it'.

'Actually it doesn't bother me that much now, I got used to it, I got used to it now' (Participant 2, 374)

'getting used to it now' (Participant 4, 83)

Again this seems to highlight the minimisation of the emotional reaction, or the emotional process that these women underwent to move from fear and panic to what presents as being adjusted to their diagnosis.

## Guilt and blame

Within the interviews a subject that repeated itself with the majority of participants was the food that the women were eating, the foods they had eaten prior to diagnosis, and the feelings of guilt and blame that resulted from this. Sometimes this would be explicitly mentioned;

'it's kind of the reaction you get from the elders as well like, I've got my father in law who lives with me as well and he's diabetic, he's 84, and when I told him oh I've got diabetes he wa' like, oh, so have you been having a lot of sugary stuff?' (Participant 7, 713-717)

However, with other participants blame and guilt was implied, though not explicitly discussed;

'I was eating like, I was fasting and then I'd get some food and I'd just take it all down straight away' (Participant 1, 498-499).

## **Discussion**

This study provided an in-depth exploration of participant's experiences of a first diagnosis of GDM. The themes that emerged have important implications for how GDM is managed in this population.

## **Experiences**

The theme of GDM as a warning generated statements of commitment to change health behaviours. However, research suggests that there is a high prevalence of T2DM in these women postpartum<sup>11</sup>. This would suggest that explanation of risk following GDM is not sufficiently motivating to generate behavioural change, which reflects previous research in this area<sup>18, 19</sup>. This can be attributed in part to the medical reality of an increased risk of developing T2DM. In addition the SRM<sup>20</sup> suggests that illness timeline forms a part of our cognitive representation of illness. In GDM there is a clear timeline (from diagnosis until birth); however following pregnancy it is difficult to anticipate when, or if, T2DM may develop. This explains high adherence to treatment amongst participants during pregnancy, and predicts decreased health behaviour changes postpartum.

The experiences of others, both good and bad, also had an impact on participants by helping them to make sense of GDM. This is particularly relevant when considering how social setting may effect both cognitive and emotional representations of illness. It seems clear that social setting, or the experiences of others that participants are exposed to has a clear impact on their emotional representations, as can be seen by the affect that other's experiences have on the anxiety of participants. In addition the experiences of others are likely to have an effect on the cognitive representations of illness, particularly those regarding consequences, timeline, control and cure.

There are themes around changes to pregnancy, in particular seeing GDM as resulting in the loss of a healthy pregnancy, as well as the perception of battling for control of their pregnancy which is associated with a reduced likelihood of positive psychological outcomes<sup>26</sup> and birth experience<sup>27</sup>. Parallels can be seen between loss of control of pregnancy and the loss of control of one's body as a result of GDM. This has implications for the way that GDM pregnancies are managed. The results of this study suggest that pregnancy becomes medicalised, and a focus on protecting the baby overtakes that of the pregnant woman and her experiences. Theory of Reasoned Action and Theory of Planned Behaviour<sup>28</sup> would argue that behaviour stops postpartum as the intention was to protect the baby. Though protecting the baby needs to remain a priority for medical professionals there is a potential here for a shift in focus towards managing pregnancy as a whole, increasing the emphasis on mother's health in order to maintain health behaviour change postpartum. Follow-ups may also facilitate a change of focus from protecting the baby to protecting one's own health, the sub-ordinate theme 'I need to be careful' shows the potential for this to occur.

It's also important to consider the potential impact that the loss of a healthy pregnancy may have on the individual themselves as well as on their perceptions of their health, illness and pregnancy. Literature that considers women with medically complicated pregnancies that are considered 'high risk' suggests that women in this group are likely to perceive their pregnancy as 'imperfect' and have feelings of inadequacy and failure. This also impacts on a woman's self esteem and, if we subscribe to the idea of fertility and childrearing as femininity, this may also have an impact on her view of herself as a woman<sup>29</sup>.

## **Emotional Experience**

All participants disclosed shock and anxiety which diminished with time. Though this reflects other GDM<sup>19</sup> and pregnancy research that has found no differences in anxiety between women with pregnancies that are labelled as 'high risk' due to medical complications and women with 'normal pregnancies'<sup>30</sup>, it may be that participants were in a period of transition (labelled in Hopson and Adams<sup>31</sup> model of transition as minimisation). The short time span of GDM may mean that it is difficult to move through the stages of transition<sup>n</sup> with minimisation and avoidance becoming a way of coping rather than a transition stage.

If, as suggested by themes and participants preference for adhering to more practical management discussion, these women are using avoidant or minimisation coping strategy(s) to manage emotional responses to GDM this has clinical implications. Engaged (rather than avoidant) coping styles have been shown to be critical in managing health threats in other health conditions<sup>32</sup>, with avoidant coping linked with significantly higher levels of negative emotions<sup>33</sup>, more hospital readmissions, treatment non-adherence and reduced decision making<sup>34</sup>. Use of approach coping and problem-focused coping is associated with better adjustment in adults with DM<sup>35</sup>. In the pregnancy literature, women who have 'high risk' pregnancies and have difficulty coping have lower levels of attachment which can continue postpartum<sup>30</sup>. Leventhal<sup>36</sup> has argued that managing emotional responses must take place before effective coping can occur, highlighting the need for services to provide emotional support for better adjustment to illness but also, looking forward, for better continued adjustment and development of the attachment.

-

<sup>&</sup>lt;sup>n</sup> Immobilisation, Minimisation, Depression, Acceptance of Reality, Testing, Searching for Meaning and Internalisation<sup>31</sup>.

In line with a wider cultural discourse (A.Spratt, unpublished data, 2013) all participants felt that DM was caused by eating sugar, leading to feelings of guilt and blame. These feelings may prevent motivation for behaviour change as they are not associated with effective coping<sup>37</sup> and in T2DM self-blame is associated with poor self-management<sup>38</sup>. It is important that this is brought to the awareness of health professionals and emotional support be made available to reduce these feelings of guilt and blame. It is unlikely that cultural beliefs about DM causation may be challenged, but managing those feelings may result in better coping.

Further research in the area of GDM may consider if these experiences of pregnancy are generalisable to women from other ethnic backgrounds, as it seems likely to be a feature of pregnancies with GDM, and not exclusive to the current population.

## **Cognitive Representations of Illness**

Due to the high prevalence of T2DM within their families and culture, participants perceived an inevitability in the diagnosis. Although this fatalistic view may help manage distress, fatalistic coping styles may lead to undesirable medical outcome(s)<sup>39</sup>. There may be perceived lack of influence over development of T2DM, and therefore fewer health behaviour changes Although widespread cultural beliefs are difficult to challenge, an awareness of the implications of such beliefs can help health professionals implement follow-up support to reinforce health behaviours postpartum. This may be compounded further by research that suggests an acceptance of a 'sick' role in a 'high risk' pregnancy tends to increase dependence and leads to learned helplessness, further adding to the lack of adherence to health behaviour changes<sup>40</sup>.

The theme 'I need to be careful', highlights the potential for such interventions. It also reflects the mixed messages of postpartum care; on the one hand health professionals

advocate health behavior change to reduce risk of T2DM, however NICE guidance only suggests a fasting blood glucose test 6 weeks postpartum, and then annually<sup>9</sup>. This reinforces the idea that T2DM is inevitable and confirms the importance of further postpartum care in aiding women to reduce risk of developing T2DM.

## Limitations

One of the major limitations of the study was the use of a family member to translate for one of the participants (Participant4). The participant had sufficient understanding of English to understand questions in the interview, however wasn't able to speak enough English to answer, so her Husband translated her responses in the interview. There is little research currently into the implications of using translators in interviews in qualitative research<sup>41</sup>, and papers that do consider the translation of research tend to consider qualitative data gathered in another language, with results then analysed or written in English for publication<sup>42</sup> rather than at the stage of interview. However, in IPA understanding and making sense of the individual is the main aim of the research<sup>25</sup>, therefore the translation by another individual may have had an influence on both what the participant discussed and what was reported. Despite this, the particular participant in question was keen to discuss her experiences, and the researcher could be reasonably confident that what was reported was accurate as questions asked by the researcher were not translated and the participant stopped her husband once to clarify her answer as she did not feel what he reported accurately conveyed her experience. It therefore seemed reasonable to assume that the participant was happy with the other parts that her husband translated, and therefore this interview was included in the analysis.

The effect of the researchers biases on the findings were minimised through the reflection of personal experiences and the use of discussion with independent

researchers. However, qualitative studies will always be subjective<sup>43</sup> and more difficult to validate in comparison to quantitative research<sup>44</sup>.

There are also considerable limitations to the generalisability of the research as participants were recruited from one hospital. The South Asian community from which all participants were recruited is well established and participants in this study may have different experiences to those in other areas of the UK. This has influenced healthcare provision in this area. In other areas of the UK women may not have access to the same treatment such as specialist GDM clinics.

# Conclusion

This study aimed to understand the experiences and illness perceptions of South Asian women with a first diagnosis of GDM living in the UK. Generally, pregnancy was experienced as medicalised and focused on health rather than pregnancy. Participants described feeling duty-bound to protect their baby by strictly adhering to monitoring and treatment. These behaviours may cease postpartum as their main function is to protect the baby. Both fatalistic and avoidant coping styles were hypothesized to contribute to a lack of continued health behaviour change postpartum. It is recommended that, to help adjustment to diagnosis and to support health behaviour changes, emotional support should be available during pregnancy and postpartum follow-ups should focus on supporting continued changes rather than simply monitoring for development of T2DM.

## **References**

- Diabetes UK. Diabetes in the UK 2012: Key Statistics on Diabetes. London:
   Diabetes UK, 2012. Retrieved from
   <a href="http://www.diabetes.org.uk/Documents/Reports/Diabetes-in-the-UK-2012.pdf">http://www.diabetes.org.uk/Documents/Reports/Diabetes-in-the-UK-2012.pdf</a> Last accessed 30<sup>th</sup> May 2013.
- Department of Health [DOH] (2011) Quality, Innovation, Productivity and
   Prevention (QIPP). Retrieved from
   http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPP/index
   .htm Last accessed on 21st January 2013.
- 3. Hex, N., Bartlett, C., Wright, D., Taylor, M. & Varley, D. (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs.

  \*Diabetic Medicine\*, 29(7), 855-862.
- 4. National Institute for Health and Clinical Excellence. (2012). NICE Public Health Guidance 38: Preventing type 2 diabetes: risk identification and interventions for individuals at higher risk. London; UK, National Institute for Clinical Excellence.
- Narayan, K. M. V., Boyle, J. P., Thompson, T. J., Gregg, E. W. & Williamson,
   D. F. (2007). Effect of BMI on Lifetime Risk for Diabetes in the U.S.
   Diabetes Care, 30(6), 1562-1566.
- 6. Kapustin, J. F, (2007). Postpartum management for gestational diabetes mellitus:

  Policy and practice implications. *Journal of the American Academy of*Nurse Practitioners, 20, 547-554.

- 7. Crowther, C. A., Hiler, J. E., Moss, J. R., McPhee, A. J., Jeffries, W. S. & Robinson, J. S., (2005). Effect of Treatment of Gestational Diabetes

  Mellitus on Pregnancy Outcomes. *The New England Journal of Medicine*, 352 (24), 2477-2489
- 8. Langer, O., Yogev, Y., Most, O. & Xenakis, E. M. (2005). Gestational diabetes: the consequences of not treating. *American Journal of Obstetrics and Gynaecology*, 192(4), 989-997.
- 9. National Institute for Clinical Excellence (NICE) (2008). NICE Guideline 63;

  Diabetes in Pregnancy; Management of diabetes and its complications

  from pre-conception to the postnatal period. London; UK, National

  Institute of Clinical Excellence.
- 10. National Institute for Clinical Excellence (NICE), (2010). NICE Guideline 15;
  diagnosis and management of type 1 diabetes in adults. London; UK,
  National Institute for Clinical Excellence.
- 11. Kim, C., Newton, K. and Knopp, R., (2002). Gestational Diabetes and the Incidence of Type 2 Diabetes. *Diabetes Care*, 25 (10), 1862-1868.
- 12. Peters, R. K., Kjos, S. L., Xiang, A. and Buchanan, T. A., (1996). Long-term diabetogenic effect of single pregnancy in women with previous gestational diabetes mellitus. *The Lancet*, 347 (8996), 227-230.
- Kim, C., Berger, D. K. & Chamany, S. (2007). Recurrence of Gestational Diabetes Mellitus; A systematic review. *Diabetes Care*, 30(5), 1314-1319.

- 14. Bellamy L, Casas J-P, Hingorani AD, Williams D., (2009). Type 2 diabetes mellitus after gestational diabetes: a systematic review and meta-analysis. *The Lancet*, 373, 1773-79.
- 15. Blood Pressure Association (2008). Discovering high blood pressure (hypertension). Retrieved from http://www.bloodpressureuk.org/microsites/u40/Home/high/Hypertensio n Last accessed on 30th April 2013.
- 16. British Heart Foundation (2013). Cardiovascular Disease. Retrieved from http://www.bhf.org.uk/heart-health/conditions/cardiovasculardisease.aspx Last accessed on 1<sup>st</sup> May 2013.
- 17. Jones, E. J, Roche, C. C. and Appel, S. J, (2009). A Review of the Health Beliefs and Lifestyle Behaviours of Women with Previous Gestational Diabetes. *Journal of Obstetric Gynaecologic and Neonatal Nursing*, 38, (5) 526-526.
- Kim, C., McEwan, L. N., Piette, J. D., Goewey, J., Ferrara, A. and Walker, E.
   A., (2007). Risk Perception for Diabetes Among Women With
   Histories of Gestational Diabetes Mellitus. *Diabetes Care*, 30 (9), 2281-2286.
- Kim, C., McEwan, L. N., Kerr, E. A., Piette, J. D., Chames, M. C. and Ferrara,
   A., (2007). Preventative Counselling Among Women With Histories of
   Gestational Diabetes Mellitus. *Diabetes Care*, 30 (10), 2489-2495.
- Cameron, L. D. & Jago, L. (2008). Emotion regulation interventions: A
   common-sense model approach. *British Journal of Health Psychology*,
   13(2), 215-221.

- 21. Persson, M., Winkvist, A. and Mogren, I., (2010). 'From stun to gradual balance' women's experiences of living with gestational diabetes mellitus. *Scandinavian Journal of Caring Sciences*, 24, 454-462.
- 22. Bandyopadhyay, M., Small, R., Davey, M-A., Oats, J. J. N., Forster, D. A and Aylward, A., (2011). Lived experience of gestational diabetes mellitus among immigrant South Asian women in Australia. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 51, 360-364.
- 23. Oldfield, M. D., Donley, P., Walwyn, L., Scudamore, I. & Gregory, R., (2007).
  Long term prognosis of women with gestational diabetes in a multiethnic population. *Postgraduate Medical Journal*, 83(980), 426-430.
- 24. Office for National Statistics (ONS) (2010) Standard Occupational Classification 2010 (SOC2010) VOLUME 1 Structure and Descriptions of Unit Groups. Available at http://www.ons.gov.uk/ons/guidemethod/classifications/current-standardclassifications/soc2010/index.html Last accessed 22nd August 2013.
- 25. Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. Los Angeles: Sage.
- 26. Green, J. M., Coupland, B. A. & Kitzinger, J. (1990) Expectations, experiences and psychological outcomes of childbirth: a prospective study of 825 women. *Birth*, *17*,(1), 15-24.
- 27. Lavender, T., Walkinshaw, S. A. &Walton, I. (1999) A prospective study of women's views of factors contributing to a positive birth experience.

  \*Midwifery, 15,(1), 40-46.

- 28. Ajzen, I. (1991). The Theory of Planned Behaviour. *Organizational Behaviour* and Human Decision Processes, 50,(2), 179-211.
- Raphael-Leff, J. (1991). Psychological Processes of Childbearing. Anna Freud
   Centre, London, UK.
- 30. Kemp, V. H. & Page, C. K. (1987) Maternal Prenatal Attachment in Normal and High-Risk Pregnancies. *Journal of Obstetric, Gynecological, & Neonatal Nursing*, 16(3), 179-184.
- 31. Hopson, B. & Adams, J. (1976) "Towards an Understanding: defining some boundaries of transition dynamics" in Adams, J., Hayes, J. & Hopson, B., Eds (1976) *Transition: Understanding and managing personal change* London: Martin Robertson.
- 32. Lazarus, R. S. (1993) Coping Theory and Research: Past, Present and Future.

  \*Psychosomatic Medicine, 55(3), 234-247.
- 33. Doering, L. V., Dracup, K., Caldwell, M. A., Moser, D. K., Erickson, V. S., Fonarow, G. & Hamilton, M. (2004) Is Coping Style Linked to Emotional States in Heart Failure Patients? *Journal of Cardiac Failure*, 10(4), 344-349
- 34. Levine, J., Warrenburg, S., Kerns, R., Schwartz, G., Delaney, R., Fontana, A., Gradman, A., Smith, S., Allen, S. & Gasgoine, R. (1987). The Role of Denial in Recovery from Coronary Heart Disease. *Psychosomatic Medicine*, 49(2), 109-117.

- 35. Duangdao, K. M. ^ Roesch, S. C. (2008) Coping with diabetes in adulthood: a meta-analysis. *Journal of Behavioral Medicine*, 31(4), 291-301.
- Leventhal H. (1990) Emotional and behavioral processes. In: Wallace L, ed.
   (1990) Stress and medical procedures. New York: Oxford University
   Press.
- 37. Conradt, M., Dierk, J-M., Sclumberger, P., Rauh, E., Hebebrand, J. & Rief, W. (2008) Who Copes Well? Obesity-Related Coping and Its Associations With Shame, Guilt and Weight Loss. *Journal of Clinical Psychology*, 64(10), 1129-1144.
- 38. DePalma, M. T., Rollison, J. & Camporese, M. (2011) Psychosocial Predictors of Diabetes Management. *American Journal of Health Behaviour*, 35(2), 209-218.
- 39. Niederdeppe, J. & Levy, A. G. (2007) Fatalistic Beliefs about Cancer Prevention and Three Prevention Behaviours. *Cancer Epidemiology, Biomarkers & Prevention*, 16(5), 998-1003.
- 40. Philipp, A. D. & Carr M. L. (2001). Normal and medically complicated pregnancies. *In psychological aspects of women's health care. The interface between psychiatry and obstetrics and gynaecology*. Second edition. Editors N. L. Stotland and D. E. Stewart. American Psychiatric Press, Washington.
- 41. van Nes, F., Abma, T., Jonsson, H. & Deeg, D. (2010) Language differences in qualitative research: is meaning lost in translation? *European Journal of Ageing*, 7(4), 313-316.

- 42. Regmi, K., Naidoo, J. & Pilkington, P. (2010) Understanding the Processes of Translation and Transliteration in Qualitative Research. *International Journal of Qualitative Methods*, 9(1), 16-26.
- 43. Yardley L. Dilemmas in qualitative health research. *Psych Health.* 2000; 15: 215-228.
- 44. Salmon P. Judging research quality: how do we recognise good research? *The Psychologist.* 2003; 16: 24-27.

# Part Three:

# Appendices

1.1 Diabetic Medicine Author Guidelines	88										
2.1 Qualitative Research Quality Assessment Tool	99										
2.2 Quality Assessment Table for Included Papers											
3.1 British Journal of Obstetrics and Gynaecology											
Instructions for Authors											
4.1 Shortened Introduction for Journal Submission	115										
5.1 Epistemological Statement	119										
6.1 Participant Information Sheet	122										
6.2 Participant Consent Form	126										
6.3 Interview Schedule	128										
7.1 NHS Ethical Approval	131										
7.2 Research Governance Approval for Bradford Teaching Hospitals	137										
NHS Foundation Trust (BTHFT)											
7.3 Letter of Access for BTHFT	140										
8.1 Worked Example of IPA	143										
9.1 Reflective Statement	149										

# Appendix 1.1: Diabetic Medicine Author Guidelines

Skip to Main Content



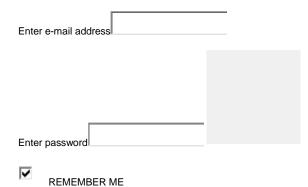
## HomeHelp

PUBLICATIONS

BROWSE BY SUBJECT

RESOURCESABOUT US

LOGIN



NOT REGISTERED?
 FORGOTTEN PASSWORD?
 INSTITUTIONAL LOGIN >

- Home >
- Endocrinology >
- Diabetes >
- Diabetic Medicine

## **JOURNAL TOOLS**

- Get New Content Alerts
- Get RSS feed
- Save to My Profile
- Get Sample Copy
- Recommend to Your Librarian

# **JOURNAL MENU**

Journal Home

#### FIND ISSUES

- Current Issue
- All Issues
  Virtual Issues

## FIND ARTICLES

- Early View
- Accepted Articles
- Most Accessed

#### **GET ACCESS**

Subscribe / Renew

## FOR CONTRIBUTORS

- OnlineOpen
- Author Guidelines
- Submit an Article

## ABOUT THIS JOURNAL

Society Information

Overview
 Editorial Board
 Permissions
 Advertise
 Contact

## **SPECIAL FEATURES**

- Editor's Choice
- Diabetes UK Position Statements & Other Guidelines
   Management of Diabetic Ketoacidosis in Adults Poster
- Wiley Job Network
- World Diabetes Day 2012



# **Diabetic Medicine**

© 2013 Diabetes UK



Editor-in-Chief: Professor Graham A. Hitman, London, UK

Impact Factor: 2.902

ISI Journal Citation Reports © Ranking: 2011: 53/122 (Endocrinology & Metabolism)

Online ISSN: 1464-5491

**Author Guidelines** 

#### **QUICK LINKS**

**Submission Checklist** [optional]

Copyright [req] see section 6 below

Online Submission [req]

**CONSORT Checklist** [req for RCTs]

STROBE Checklists (Cohort, Case-control, Cross-sectional) [req for observational studies]

PRISMA Checklist [req for systematic reviews/meta-analyses]

**Open Access Order Form** 

**Peer-review Process Map** 

**Contact the Editorial Office** 

1. ABOUT DIABETIC MEDICINE

#### Aims & Scope

Diabetic Medicine, the official journal of **Diabetes UK**, is published monthly in simultaneous print and online editions

The journal publishes a range of key information on all aspects of diabetes mellitus and issues regularly include original articles, reviews, reports, editorials, comment, news and correspondence. All material is peer-reviewed. The journal seeks to provide a forum for the exchange of information between clinicians and researchers worldwide and all health professionals responsible for the care of patients with diabetes.

Surplus generated from the sale of Diabetic Medicine is used by Diabetes UK to care for, connect with and campaign on behalf of all people affected by and at risk of diabetes.

#### 2. MANUSCRIPT CATEGORIES

Diabetic Medicine invites the following types of submission:

#### Research articles

Original research articles relevant to diabetes mellitus science and practice are the journal's primary mode of communication. Clinical science and clinically-relevant basic science papers will be considered. Original articles must include a structured abstract (maximum 250 words), should not exceed 3,000 words of text and should be limited to 30 references. Inclusion of supplementary materials in the form of underlying datasets, multimedia files or accompanying slidesets is encouraged.

Authors of qualitative research articles are advised to contact the Editorial Office for guidance on manuscript length prior to submission.

Manuscripts should adhere to reporting standards. Randomised controlled trials should adhere to the **CONSORT Checklist**. Observational studies should adhere to the relevant **STROBE Checklist**. Systematic reviews and meta-analyses should adhere to the **PRISMA Checklist**. Checklists must be completed and submitted electronically with the manuscript using file designation 'Supporting Document NOT for Publication'.

For purposes of presentation only, accepted research articles are divided into the following sections:

Care Delivery

Complications

Educational and Psychological Aspects

**Epidemiology** 

Genetics

**Health Economics** 

Metabolism

Pathophysiology

Treatment

#### Reviews

The journal aims to publish concise, high-quality review articles of recent advances in laboratory or clinical research. Review articles are usually solicited by the Editor-in-Chief but unsolicited reviews are welcome. All will undergo peer-review. Review articles must include an unstructured abstract (maximum 250 words),

should not exceed 5,000 words of text and should be limited to 50 references. Use of illustrations and figures is encouraged.

#### **Short reports**

Concise reports of original or important observations, short reports should not exceed 1,500 words and are limited to one figure, one table and 30 references. A structured abstract is required.

### **Case reports**

Case reports submitted after 1 May 2012 will be published online-only in Diabetic Medicine. The abstracts of case reports will continue to be published in the relevant print issue. Case reports remain fully citable and will continue to be indexed by PubMed.

Case reports should describe unusual clinical cases and must carry a new or important message. Cases that present a diagnostic, ethical or management challenge, or that highlight aspects of mechanisms of injury, pharmacology or histopathology are deemed of particular educational value. Descriptions of a series of cases stand a greater chance of being accepted. The Editors reserve the right to ask authors to revise a single case report into a Letter to the Editor.

Case reports should not exceed 1,500 words and are limited to 3 tables and/or 3 figures and 20 references. A structured abstract (maximum 250 words) must be provided using the following subheadings: Background, Case Report, Discussion. The submission of supplementary materials (additional figures, tables, datasets, multimedia files, etc.) which add value to cases is encouraged.

#### Letters

Items of correspondence may be in response to issues arising from recently published articles, or short, free-standing pieces expressing an opinion. Letters should be formatted in one continuous section and should not exceed 800 words, 1 figure/table and 10 references. No abstract is required. Please give the name(s) and affiliation(s) of authors at the end of the letter. All letters are subject to peer-review.

#### **Editorials/Commentaries**

Editorials and commentaries provide expert opinion to hot topics. Whilst typically commissioned by the Editors, unsolicited submissions are welcome. Editorials and commentaries should not exceed 1,000 words and 10 references. No abstracts are required.

### 3. SUBMISSION OF MANUSCRIPTS

All submissions must be made online at the **Diabetic Medicine ScholarOne Manuscripts site**. New users should first create an account. Once a user is logged onto the site, submissions should be made via the Author Centre.

Submissions **must** be accompanied by a completed **Exclusive License Agreement**. Completed forms must be uploaded to ScholarOne Manuscripts at the same time as manuscript submission using file designation 'Supporting Document NOT for Publication'.

A **Submission Checklist** is available to help authors comply with the journal style and the submission requirements.

## 4. PREPARATION OF MANUSCRIPTS

Manuscripts must be written in English.

Manuscript text must be saved in Word (.doc or .docx) or Rich text Format (.rtf). Please do not submit text in PDF format (.pdf).

Figures must be saved as separate figure files.

Abbreviations must be defined when first used in the abstract and in the main text, as well as when first used in table and figure captions.

Manuscripts must be as succinct as possible. Repetition of information or data in different sections of the manuscript must be carefully avoided. Text must comply with the word limits defined in Section 2, and, where appropriate, include:

## Title page

The first page of all manuscripts should contain the following information:

- 1) the title of the paper (maximum 50 words)
- 2) a running head not exceeding 75 characters
- 3) names of authors as initial(s) followed by surnames
- 4) names of the institutions at which the research was conducted, clearly linked to respective authors
- 5) name and email address of corresponding author
- 6) manuscript word count
- 7) a statement of all funding sources
- 8) any conflicts of interest disclosures (see Section 5)
- 9) a bulleted novelty statement (maximum 100 words) which describes the novelty of the data presented and their impact on the field (Research Articles, Short Reports and Case Reports only).

#### **Abstracts**

Authors submitting research articles and short reports should note that structured abstracts (maximum 250 words) are required. The structured abstract should adopt the format: Aims, Methods, Results, Conclusions.

Structured abstracts for case reports should adopt the format: Background, Case Report, Discussion.

Abstracts should contain no citations to previously published work.

Review articles require abstracts but they need not be structured. Letters do not require abstracts.

## Text

This should in general, but not necessarily, be divided into sections with the headings: Introduction, Patients and Methods, Results, Discussion, Funding, Conflicts of Interest, Acknowledgements, References, Tables, Figure Legends.

# Tables & figures

Tables and figures should not be inserted in the appropriate place in the text but should be included at the end of the manuscript, each on a separate page.

Tables and figures should be referred to in text as follows: Fig. 1, Figs. 2–4; Table 1, Table 2. Each table and/or figure must have a legend that explains its purpose without reference to the text; legends should include include keys to symbols and indicate the statistical significance of differences. Where a figure has more than one panel, each panel should be labelled in the top left-hand corner using lower case letters in parentheses, i.e., (a), (b), etc., and a brief description of each panel given in the figure legend.

Colour illustrations are welcomed and all colour is published free of charge to the author.

Authors are themselves responsible for obtaining permission to reproduce previously published figures or tables. When an individual is identifiable in a photograph written permission must be obtained (see Section 5 below).

#### References

References should be in Vancouver format and appear in the text as consecutive numbers in square brackets, e.g., 'in our previous reports [1,2] and those of Smith et al. [3–6]' and should be listed numerically in the reference list at the end of the article.

Format references as below, using standard (Medline) abbreviations for journal titles. If multi-authored, include the first six authors followed by *et al.* 

- 1. Department of Health. The New NHS: Modern, Dependable. London: The Stationery Office, 1997.
- 2. Fogari R, Mugellini A, Destro M, Corradi L, Lazzari P, Zoppi A et al. Losartan and amlodipine on myocardial structure and function: a prospective, randomized, clinical trial. Diabet Med 2012; 29: 24–31.
- 3. Eye Care Wales. Screening for Diabetic Retinopathy. March 2009. Available at http://www.wales.nhs.uk/sites3/page.cfm?orgid=562&pid=12776 Last accessed 1 January 2012.

#### Reporting standards

Manuscripts should adhere to reporting standards. Randomised controlled trials should adhere to the **CONSORT Checklist**. Observational studies should adhere to the relevant **STROBE Checklist**. Systematic reviews and meta-analyses should adhere to the **PRISMA Checklist**. Checklists must be completed and submitted electronically with the manuscript using file designation 'Supporting Document NOT for Publication'.

## Style guide

Diabetic Medicine does not recognise the term 'diabetic' as a noun. Preferred style is 'patient with diabetes' or 'in the group without diabetes', rather than 'diabetic patient' and 'non-diabetic group'. The terms 'Type 1' and 'Type 2 diabetes mellitus' (abbreviated to Type 1 and Type 2 DM) are preferable to IDDM and NIDDM. 'Men' and 'women' should be used in preference to 'males' and 'females'.

#### **Abbreviations & units**

Except for units of measurement, abbreviations are strongly discouraged. Avoid abbreviations in the title of the manuscript and in the Abstract. The spelled-out abbreviation followed by the abbreviation in parentheses should be used on first mention unless the abbreviation is a standard unit of measurement.

SI units must be used throughout except for blood pressure (mmHg) and haemoglobin (g/l). Gas or pressure values should be given as mmHg with kPa in parentheses or vice versa. Where molecular weight

is known, the amount of a substance should be expressed in mol or appropriate subunit (mmol). Energy should be expressed in kcal or joules (J). The solidus may be used in a unit as long as it does not have to be employed more than once (e.g. mmol/l is acceptable), but ml/min/kg is not acceptable and should be replaced with ml min-1 kg-1.

#### **HbA1c Measurement**

Diabetic Medicine has adopted dual reporting of glycated haemoglobin (HbA1c) measurement. HbA1c measurements must be reported in IFCC units (mmol/mol - no decimal point) in addition to derived NGSP units (% - one decimal). IFCC units should be listed first followed by NGSP units in parentheses. A HbA1c conversion table is **available here**. NGSP SD's can be converted directly to IFCC SD's. To do so the slope of the Master Equation to convert NGSP results to IFCC units must be used. For example: 0.3% SD NGSP = 0.3 X 10.93 = 3.3 mmol/mol SD IFCC (then round to the nearest integer).

#### 5. DECLARATIONS & PUBLICATION ETHICS

#### **Original publication**

Submission of a manuscript will be held to imply that it contains original unpublished work and is not being submitted for publication elsewhere at the same time. The author must supply a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work. Data that have been published as an abstract of no more than 300 words in a scientific meeting are acceptable; the abstract reference should be quoted under the abstract.

#### **Conflicts of interest**

Authors are responsible for disclosing all financial and personal relationships between themselves and others that might be perceived by others as biasing their work. To prevent ambiguity, authors must state explicitly whether potential conflicts do or do not exist.

#### **Ethics**

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) and with the Helsinki Declaration of 1975, as revised in 1983. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate whether the institution's or a national research council's guide for, or any national law on, the care and use of laboratory animals was followed. A statement describing explicitly the ethical background to the studies being reported should be included in all manuscripts in the Materials and Methods section. Ethics committee or institutional review board approval should be stated.

Patients have a right to privacy that should not be infringed without informed consent. Identifying information should not be published in written descriptions, photographs and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Identifying details should be omitted if they are not essential but patient data should never be altered or falsified in an attempt to attain anonymity. Complete anonymity is difficult to achieve and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of patients is inadequate protection of anonymity.

## **Authorship**

All persons designated as authors should qualify for authorship and all those who qualify should be listed. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. One or more authors should take responsibility for the integrity of the work as a whole, from inception to published article. Authorship credit should be based only on 1) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; 3) final approval of the version to be published. Conditions 1, 2 and 3 must all be met. Acquisition of funding, the collection of data or general supervision of the research group, by themselves, do not justify authorship. All others who contributed to the work who are not authors should be named in the Acknowledgements section.

### Committee on Publication Ethics (COPE)

As a member of the Committee on Publication Ethics (COPE), adherence to these submission criteria is considered essential for publication in Diabetic Medicine; mandatory fields are included in the online submission process to ensure this. If, at a later stage in the submission process or even after publication, a manuscript or authors are found to have disregarded these criteria, it is the duty of the Editor to report this to COPE. COPE may recommend that action be taken, including but not exclusive to, informing the authors' professional regulatory body and/or institution of such a dereliction.

The website for COPE may be accessed at: http://publicationethics.org/

#### 6. ADDITIONAL INFORMATION ON ACCEPTANCE

## Copyright

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

## For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

CTA Terms and Conditions http://authorservices.wiley.com/bauthor/faqs\_copyright.asp

## For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

- Creative Commons Attribution Non-Commercial License OAA
- Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services http://authorservices.wiley.com/bauthor/faqs\_copyright.aspand visit http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit: http://www.wiley.com/go/funderstatement.

For RCUK and Wellcome Trust authors click on the links below to preview the terms and conditions of this license:

#### Creative Commons Attribution License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services http://authorservices.wiley.com/bauthor/faqs\_copyright.aspand visit http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html.

### OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive.

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services <a href="http://authorservices.wiley.com/bauthor/faqs\_copyright.aspand">http://authorservices.wiley.com/bauthor/faqs\_copyright.aspand</a> visit <a href="http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html">http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html</a>. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

#### **Note to NIH Grantees**

Pursuant to NIH mandate, Wiley-Blackwell will post the accepted version of contributions authored by NIH grant-holders to PubMed Central upon acceptance. This accepted version will be made publicly available 12 months after publication. For further information, **click here**.

#### **Proofs**

The corresponding author will receive an email alert containing a link to a web site where the proofs can be downloaded as an Acrobat PDF. A working e-mail address must therefore be provided for the corresponding author. In the absence of the corresponding author, please arrange for a colleague to access the e-mail to retrieve the proofs.

Acrobat reader can be downloaded (free of charge) from the following website:http://www.adobe.com/products/acrobat/readstep2.html. This will enable the file to be opened, read and corrected on screen. Further instructions will be sent with the proof.

Please note that you have final responsibility for what is stated in the proofs of your manuscript. Significant textual alterations are unacceptable at proof stage without the written approval of the Editor-in-Chief, and they are likely to result in the delay of publication.

#### **Author Services**

Author Services enables authors to track their article—once it has been accepted—through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit **Author Services** for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

#### **Accepted Articles**

Further to acceptance in Diabetic Medicine, manuscripts are immediately made publicly available online. 'Accepted Articles' have been peer-reviewed and accepted for formal publication, but have not been subject to copyediting, composition or proof correction. The service provides for the earliest possible dissemination of research data following article acceptance. Accepted Articles appear in PDF format only and are given a Digital Object Identifier (DOI), which allows them to be cited and tracked. The DOI remains unique to a given article in perpetuity and can continue to be used to cite and access the article further to print publication. More information about DOIs can be found online at <a href="http://www.doi.org/faq.html">http://www.doi.org/faq.html</a>. Accepted Articles will be indexed in PubMed.

Neither Diabetes UK nor Wiley can be held responsible for errors or consequences arising from the use of information contained in Accepted Articles; nor do the views and opinions expressed necessarily reflect those of Diabetes UK or Wiley.

## **Early View**

Research Articles (Research: Subcategory and Short Report: Subcategory) accepted by Diabetic Medicine are covered by Wiley-Blackwell Publishing's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so Early View articles cannot be cited in the traditional way. They are therefore given a Digital Object Identifier (DOI), which allows the article to be cited and tracked before it is allocated to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article.

#### **Offprints**

A PDF offprint of the online published article will be provided free of charge to the corresponding author via **Author Services**. Paper offprints of the printed published article may be ordered online. Please click on the following link, fill in the necessary details and ensure that you type information in all of the required fields: <a href="http://offprint.cosprinters.com">http://offprint.cosprinters.com</a>. If you have queries about offprints please e-mail offprint@cosprinters.com.

SEARCH

# **Appendix 2: Supplementary Information for Systematic Literature Review**

Appendix 2.1: Qualitative Research Quality Assessment Tool

Appendix 2.2: Quality Assessment Table for Included Papers

Appendix 2.1: Qualitative Research Quality Assessment Tool

	<u>list</u>				
Paper Title					
Author(s)					
Date:					
Journal:					
		Quality rat	ing		
		Excellent	Sound	Poor	No/Unsure
		3	2	1	0
Quality assessment question	ons			<u> </u>	
<ul> <li>Clearly focused resequestion/aims/obje</li> <li>Clearly focused rationale/hypothes</li> <li>Qualitative method most appropriate</li> <li>Underpinning value assumptions discus</li> </ul>	ectives es ology s and				
Participants					
<ul> <li>Participants demog stated</li> <li>Inclusion and exclusion criteria stated</li> <li>Sample representate to the population be assessed</li> <li>Participant rate/drown rate reported</li> </ul>	sion iveness eing				

<ul> <li>Time of course of the study reported</li> <li>Sampling strategy reported</li> <li>Data collection methods reported</li> </ul>	
Ethical approval reported	
<ul> <li>Data analysis</li> <li>Data analysis strategy reported</li> <li>Data analysis appropriate to data collected</li> <li>More than one rater</li> <li>Rigorous analysis</li> <li>Rich data</li> </ul>	
Main findings coherent/valid/relevant	
Main conclusions relate to main question	
Implications of study reported	
Limitations of study reported	
Total score (Maximum total score: 21 x 3 = 63)	
Comments	

Appendix 2.2: Quality Assessment Table for Included Papers

Questions	Introduction				Participants					ethodo	ology	Ethics		Dat	a Anal	lysis		Results & Conclusions				Total
Paper	a	b	c	d	a	b	c	d	a	b	c		a	b	c	d	e	a	b	c	d	sound=42, excellent=63)
Lawton, Ahmad, Hanna, Douglas, Bains & Hallowell, 2008	3	3	2	3	3	2	3	0	3	3	3	3	3	3	3	2	3	3	3	2	3	56
Lawton, Ahmad, Hanna, Douglas & Hallowell, 2005	2	3	2	2	3	2	2	0	0	3	3	2	2	2	3	3	3	3	3	2	1	46
Choudhury, Brophy & Williams, 2009	3	3	2	2	2	0	2	0	3	1	1	2	1	1	1	1	2	3	3	1	1	35
Keval, 2009	1	1	2	3	3	1	2	0	0	3	3	3	3	3	0	2	2	2	2	2	1	39
Greenhalgh, Helman & Chowdhury, 1998	1	0	3	2	3	1	2	3	0	3	3	1	3	3	3	3	3	3	1	3	2	46
Chowdhury, Helman & Greenhalgh, 2000	1	2	2	2	2	1	2	0	0	1	2	0	2	2	3	2	2	2	2	3	1	34

Duthie-Nurse, 1998	1	1	2	1	2	1	2	2	0	2	2	0	0	0	0	0	0	2	2	2	1	23
Lawton, Ahmad, Peel & Hallowell, 2007	2	3	2	3	2	1	0	0	3	1	2	0	2	2	3	2	2	3	3	3	1	40
Meetoo & Meetoo, 2005	2	3	2	2	2	1	2	0	0	0	3	3	3	2	2	2	2	3	2	2	2	40
<b>Total</b> ( <b>Max</b> = <b>27</b> )	16	19	19	20	22	10	17	5	9	17	22	14	19	18	18	17	19	24	21	20	13	387

Appendix 3.1: British Journal of Obstetrics and Gynaecology Instructions for Authors



**Home** > Instructions for Authors

access, log in

# **Instructions for Authors**

- 1. Is your paper suitable for BJOG?
- 2. How to submit your paper to BJOG
- 3. How to layout your paper
- 4. How to improve your paper
- 5. What happens after your paper is accepted?

Download a copy of the **Instructions for Authors**.

# Is your paper suitable for BJOG?

BJOG welcomes submissions of papers on all subjects relating to women's health. We give priority to papers containing original data, systematic reviews and commentaries suggesting innovative approaches to women's health problems. We have a global remit and publish papers from all around the world, including from both developed and developing countries.

Our readership is predominantly clinical but we welcome basic science submissions that have clinical implications. We are happy to consider qualitative studies provided they are written with the clinician in mind. The best way of

appreciating the sort of papers we publish is to read some of our **recent issues**. We particularly appreciate a clear writing style with a minimum of jargon. Initial assessment of submissions is done by our three Deputy Editors-in-Chief, who reject about 20% of papers at that time if they consider them not appropriate for our readership. This means you will get a quick assessment of your paper's suitability for the journal, giving you the opportunity to submit elsewhere with a minimum of delay if it is not suitable. Papers judged to be on a suitable topic will then be allocated to an editor for more detailed assessment. A further 10% will be rejected at this point if the presentation, the methodology etc are judged to be inadequate. The remaining 70% will then be sent to referees, and following receipt of their reports, if one or more of the referees recommend publication, the paper will then be discussed between editors, with the final decision being based on at least a majority of five opinions. We currently accept about 15% of submitted papers.

For our editorial process please see the following flow chart.

# How to submit your paper to BJOG

Submissions to BJOG must be made online through Allen

Track: http://bjog.allentrack.net. Paper manuscripts and email submissions are not accepted.

Authors must register on the site. Once this has been done you can use your login and password to access your home page (please avoid creating duplicate accounts). From the home page, you will have access to the status of your manuscripts throughout the editorial process and, therefore, you need to retain your login and password for future reference.

It is essential that the email address for the corresponding author is entered correctly and is updated via the home page if it becomes invalid at any time. All correspondence regarding the submission will go to this email address.

If you have any problems accessing your AllenTrack home page please email:bjog@editorialoffice.co.uk.

Before submitting your manuscript please read both these instructions to authors and the BJOG editorial policies.

Once you have logged into AllenTrack click on 'Submit Manuscript'. After reading the instructions on this page you will need to select the appropriate article type at the bottom of the page and click 'Continue'. You will be asked to enter specific information about the manuscript (e.g. title, type of manuscript, clinical category) prior to uploading your actual manuscript files. There are also publication ethics questions to be answered.

You will upload manuscript files from your computer as the last stage of the submission process. Once your files are uploaded to the database, they will be converted by the system to PDF files that can be viewed, downloaded and printed.

- Manuscript files and your cover letter should be in MS Word or RTF format.
- Table files can be submitted as MS Excel files or MS Word files.
- Figures must be submitted separately from the text as TIFF, EPS or JPEG files. They should be in order and clearly labelled.

Converting most files takes under ten minutes, but sometimes a large file will take longer. Conversion time also depends on the speed of your connection. The system will ask you to confirm that all files have converted correctly - please check your files to make sure that the system has converted each element properly. Your paper will be considered officially submitted only after the system receives this confirmation when you click on 'Approve the Converted Files'.

If your submission is not in the correct format, the file will be returned to your home page for you to make any necessary corrections, as detailed in an email from bjog@editorialoffice.co.uk.

Please follow the instructions below to increase the chances of your paper passing this initial quality control stage first time, avoiding delays to your submission. Once a paper has been correctly submitted through the online

system, it is assigned a tracking number and is accessed by one of our Deputy Editors-in-Chief.

## Back to the top.

# How to layout your paper

The format and word count of the paper will depend upon the type of paper submitted; however certain requirements are compulsory for all manuscripts. For full details go to **How to layout your paper**.

BJOG publishes a range of article types, and specific requirements can be found below:

- Main research article
- Review
- Systematic Review
- Surgical Techniques
- Randomised Controlled Trials
- Commentaries
- Mini Commentaries
- Case Reports
- Letters to the Editor

BJOG no longer accepts papers in a short communication format. Back to top.

# How to improve your paper

# Writing style and terminology

Manuscripts should be written in clear concise English. If you are not a native English speaker you may wish to have your manuscript professionally edited before submission. For more information regarding this see Wiley-

Blackwell Author Services.

Some style guidelines specific to BJOG can be found below:

- 'Fetus' and 'fetal' should be spelt without 'o', and 'ise' spellings are preferred to 'ize' spellings.
- Numbers one to ten should be spelled out; for more than ten people, objects, days, months, etc., use Arabic numerals.
- 'Women' is generally preferred to 'patients' when reporting on obstetrics.
- 'Termination of pregnancy' is preferred to 'therapeutic abortion' and 'miscarriage' is preferred to 'spontaneous abortion'.
- Authors should always use the generic names of drugs unless the proprietary name is directly relevant.
- Any specialised equipment, chemical or pharmaceutical product cited in the text must be accompanied by the name, city and country of its manufacturer.
- Any abbreviations or acronyms used should be defined at first use in the main body of the article.

Please refer to this **paper** for terminology of lower urinary tract function and this **paper** for early pregnancy events.

Further guidance on scientific writing can be found on the **Equator**Network website.

## Search engine optimization

To help improve the search engine ranking of your paper you should ensure you optimize your title and abstract. For more information and tips on how to do so please refer to Wiley Blackwell **Author Services**.

## Study design and statistics

The design of investigations, methods of analysis and the source of data should be described in sufficient detail to permit the study to be repeated by others, and must include specification of all statistical methods. Measurements should be expressed in SI units with the exception of haemoglobin (g/dL) and blood pressure (mmHg).

If human participants were involved, manuscripts must be accompanied by a statement that the experiments were undertaken with the understanding and appropriate informed consent of each. If experimental animals were used, the materials and methods (experimental procedures) section must clearly indicate that appropriate measures were taken to minimize pain or discomfort, and details of animal care should be provided.

Please see below for commentaries published in the journal that have been written by BJOG editors to provide further insight into best research practice:

• Summarising features of high quality study design and reporting for survey research:

# **Surveying clinical surveys**

- Focusing on assessing the reliability and validity of clinical tests:
  - Evaluation of a clinical test. I: Assessment of reliability

    Evaluation of a clinical test. II: Assessment of validity
- An analysis of Randomised Controlled Trials:
   Can we trust the results of trials that are stopped early?
- An introduction to STARD:

Evidence-based obstetric and gynaecologic diagnosis: the STARD checklist for authors, peer-reviewers and readers of test accuracy studies

## Supporting Information (online only)

Please note that the length of papers in the printed journal is restricted, and authors are encouraged to consider selecting information for publication on the web only version, as supporting information. Supporting Information must be important, ancillary information that is relevant to the parent article but which is not essential in the print edition of the journal.

All supporting information must be referred to in the manuscript, and labelled Table S1, Table S2, Figure S1, Video S1 etc. Please note that tables, figures

etc. have separate numbering sequences. Please do not include supporting information within the main manuscript file, but upload as supporting information file(s). Videos will be included as supporting information. For further instructions please refer to Wiley Blackwell **Author Services**.

**Videos: New Channels** 

The BJOG editorial team are committed to optimising the discoverability of your article, and therefore encourage the submission of videos relevant to your paper. The readers of BJOG are busy professionals and access content for different reasons, from keeping up to date with the latest original research to preparing for a lecture or journal club. To help meet these needs, we have developed several different routes to BJOG content. The latest initiative is to host BJOG videos submitted as supporting information on a new dedicated iTunes channel and the Wiley YouTube channel.

Effective from April 1st 2012 all videos submitted as supporting information will be made available on a dedicated iTunes channel and the Wiley YouTube channel. If you wish to opt out of this initiative please contact the **BJOG**Editorial Office.

#### Good reporting guidelines

For a better understanding of the reporting guidelines, please refer to the EQUATOR Network website, the resource centre for good research reporting:http://www.equator-network.org/.

Any paper reporting the results of a questionnaire survey should include a copy of the questionnaire used, together with the manuscript.

The reporting guidelines which are valuable for designing your study include:

- CONSORT statement, checklist and flow diagram for RCTs
- PRISMA statement, checklist and flow diagram for systematic reviews and meta-analyses
- MOOSE checklist is required for meta-analysis of observational studies

- STARD flow diagram and checklist are required for evaluations of diagnostic tests (diagnostic accuracy studies)
- STROBE observational studies in epidemiology (cohort, case-control, and cross-sectional studies)
- STREGA genetic association studies
- TREND statement and check list for nonrandomized controlled trials
- COREQ statement and check list for qualitative research (focus groups and interviews)
- SQUIRE check list for quality improvement studies
- REMARK check list for tumour marker prognostic studies
- ORION infection control intervention studies
- STRICTA controlled trials of acupuncture
- RedHot homeopathic treatments

#### Back to top.

#### What happens after your paper is accepted?

View a flow chart of our **production process**.

#### Copyright licensing

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper. Where OnlineOpen is required please see our **Editorial Policies**.

#### For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

CTA Terms and

## Conditionshttp://authorservices.wiley.com/bauthor/faqs\_copyright.asp

#### For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

Creative Commons Attribution Non-Commercial License OAA

Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author

Serviceshttp://authorservices.wiley.com/bauthor/faqs\_copyright.asp and visithttp://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright –License.html.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant selfarchiving policy please visit: http://www.wiley.com/go/funderstatement.

For RCUK and Wellcome Trust authors click on the link below to preview the terms and conditions of this license:

Creative Commons Attribution License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author

Serviceshttp://authorservices.wiley.com/bauthor/faqs\_copyright.asp and visithttp://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright—License.html.

#### **Proofs**

The Scientific Editors reserve the right to edit a manuscript for grammar, house style, scientific and statistical clarity, and overall length, while maintaining the scientific accuracy of the report. Authors may be asked to incorporate editorial amendments of spelling, grammar, house style and to check minor inconsistencies in the text or reference list, together with scientific and/or statistical corrections, before returning a revised manuscript for final approval by the Editor. Failure to make either scientific/statistical or editorial amendments could result in delayed acceptance and publication.

Once the manuscript has been typeset the corresponding author will receive an email alert that their proofs are ready. A working email address must therefore be provided for the corresponding author. This email will contain a link to a web site and the proof can be downloaded as a PDF file.

Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following

website: www.adobe.com/products/acrobat/readstep2.html. This will enable the file to be opened, read on screen and edited electronically. You may prefer to print the pdf and add your corrections offline.

Further instructions will be sent with the proof. To avoid publication delays proofs should be checked immediately and returned by email, fax or by express post to the address indicated on the proofs. Do not send proofs to the BJOG editorial office. Telephone corrections will not be accepted.

Authors are advised that they are responsible for proofreading of the text, references, tables and figures for absolute accuracy. New material cannot be accepted at this stage and substantial rewriting of paragraphs is not permitted. Should authors insist in doing so, then the costs will be charged to the author and the journal will not be responsible for typesetting errors arising from these changes.

#### **Early View**

Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. On average it takes 6-8 weeks from acceptance to a paper appearing online. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. They are given a Digital Object Identifier (DOI), which allows the article to be cited and tracked. After publication, the DOI remains valid and can continue to be used to cite and access the article.

## Errata/Corrigenda

Authors should advise the publisher (**BJOG@wiley.com**) of corrections, apologies and retractions to the publisher who will publish them as the next available opportunity. The Editor-in-Chief may be consulted as appropriate. **Author services** 

Online production tracking is available for your article through Wiley-Blackwell **Author Services**.

Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print.

Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production so they don't need to contact the production editor to check on progress.

Visit the **Author Services** area for a wealth of resources including FAQs and tips on article preparation, submission and more.

#### Offprints

Free access to the final PDF offprint of your article will be available via author services only. Please therefore sign up for author services if you would like to access your article PDF offprint and enjoy the many other benefits the service offers.

#### **Further resources**

## The Library of Health Research Reporting

This page is regularly updated and includes the following resources:

- Reporting guidelines
- · Guidance on scientific writing
- Guidance developed by editorial groups
- Research ethics, publication ethics and good practice guidelines
- Examples of editorials introducing reporting guidelines
- Examples of good research reporting
- Examples of guidelines for peer reviewers
- Useful and interesting presentations

## **EQUATOR Network resource for authors**

This page can help you with:

- Planning and conducting your research
- Writing up your research
- Ethical guidelines and considerations

#### Back to top.

Last updated 03 January 2013

#### Appendix 4.1: Shortened Introduction for Journal Submission

The incidence of T2DM is rising within the UK, and the costs of screening, diagnosis and management are increasing along with it<sup>1,2</sup>. The National Institute for Clinical Excellence (NICE)<sup>3</sup> suggests that health professionals should be providing guidance for individuals with higher risk of developing T2DM on how to reduce risk and delay onset of the disease. One of the groups at risk are women who have had a diagnosis of GDM<sup>4</sup>, however research considering a woman's perception of risk of developing T2DM following GDM suggests that understanding of risk may not be sufficient to motivate these individuals to carry out behaviours that reduce their risk<sup>5</sup>. One explanation for this is by considering the Self-Regulatory Model of Illness Behaviour (SRM)<sup>6</sup> (see Fig 1 below), which suggests an interaction between cognitive and emotional illness representations leads to behaviour. This model would suggest that by understanding both cognitive and emotional illness representations, professionals may be able to develop more effective interventions to motivate behaviour change in this population.

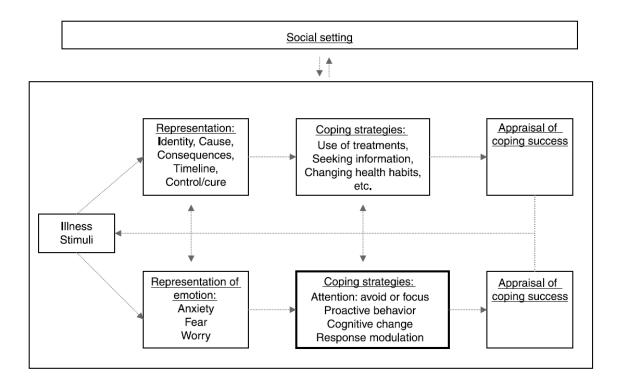


Fig 1 – The SRM<sup>6</sup>.

Qualitative research into white British women with GDM suggests that a diagnosis of GDM creates a number of difficulties that women must manage, and the women involved in this research made a decision to overcome these for their health and that of their baby<sup>7</sup>. Bandyopadhyay and colleagues<sup>8</sup> explored experiences of South Asian women with GDM living in Australia, considering rationale for lack of health behavior change following diagnosis. This research found that advice given contradicted Asian women's cultural beliefs about food consumption and exercise in pregnancy. However, there is still currently a dearth of knowledge related to GDM in ethnic minority groups. Research indicates that up to 65% of the GDM population in the UK is South Asian<sup>9</sup> which highlights the need for similar qualitative research that considers cognitive and emotional representations of illness in the UK. With South Asian women significantly more likely to go on to develop T2DM following a pregnancy with GDM than their Caucasian counterparts this research has clear potential clinical and cost implications.

Therefore, this research aims to explore South Asian women's experiences of GDM, with a focus on emotional experience as well as cognitive representations (via illness perceptions) and how these may impact on expectations of future health.

#### References

- Diabetes UK. Diabetes in the UK 2012: Key Statistics on Diabetes. London:
   Diabetes UK, 2012. Available at
   http://www.diabetes.org.uk/Documents/Reports/Diabetes-in-the-UK-2012.pdf
   Last accessed 30<sup>th</sup> May 2013.
- 2. Hex, N., Bartlett, C., Wright, D., Taylor, M. & Varley, D. (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabetic Medicine*, 29(7), 855-862.
- 3. National Institute for Health and Clinical Excellence. (2012). NICE Public Health Guidance 38: Preventing type 2 diabetes: risk identification and interventions for individuals at higher risk. London; UK, National Institute for Clinical Excellence.
- 4. Kapustin, J. F, (2007). Postpartum management for gestational diabetes mellitus:

  Policy and practice implications. *Journal of the American Academy of Nurse Practitioners*, 20, 547-554.

- Kim, C., McEwan, L. N., Kerr, E. A., Piette, J. D., Chames, M. C. and Ferrara, A.,
   (2007a). Preventative Counselling Among Women With Histories of
   Gestational Diabetes Mellitus. *Diabetes Care*, 30 (10), 2489-2495.
- 6. Cameron, L. D. & Jago, L. (2008). Emotion regulation interventions: A commonsense model approach. *British Journal of Health Psychology*, *13*(2), 215-221.
- 7. Persson, M., Winkvist, A. and Mogren, I., (2010). 'From stun to gradual balance'
   women's experiences of living with gestational diabetes mellitus.
   Scandinavian Journal of Caring Sciences, 24, 454-462.
- 8. Bandyopadhyay, M., Small, R., Davey, M-A., Oats, J. J. N., Forster, D. A and Aylward, A., (2011). Lived experience of gestational diabetes mellitus among immigrant South Asian women in Australia. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 51, 360-364.
- Oldfield, M. D., Donley, P., Walwyn, L., Scudamore, I. & Gregory, R., (2007). Long term prognosis of women with gestational diabetes in a multiethnic population. *Postgraduate Medical Journal*, 83(980), 426-430.

#### Appendix 5.1: Epistemological Statement

Epistemology is the theory of knowledge, of how we come to know things and believe them to be true. Its contribution to research is theoretical, but research methodology and implementation are influenced by epistemology and varying epistemological viewpoints (Carter & Little, 2007). I have utilised a qualitative methodology for my empirical paper, and will discuss the underlying epistemological assumptions that underlie these methods.

Qualitative research has an emphasis on 'knowledge' and aims to develop knowledge as opposed to quantitative research which has a greater focus on 'evidence' (Scott-Findlay & Pollock, 2004). Qualitative methodology comes from the viewpoint that reality is subjective and individual and based within experience rather than there being an absolute 'truth'. This reflects a relativist perspective, and appeared to match the aims of the empirical paper; to explore the experiences and health perceptions of South Asian women with a first diagnosis of gestational diabetes mellitus (GDM).

Within this epistemological stance, interpretative phenomenological analysis (IPA) was the chosen analysis method. This was chosen by the researcher as the most appropriate method of analysis as it attempts to explore other's experiences and how they attribute meaning to these experiences (Smith, Flowers & Larkin, 2009). The main theoretical assumptions that underpin IPA are that of phenomenology, hermeneutics and idiography. Phenomenology is the study of experiences, focusing on how we experience the world, while hermeneutics is concerned with interpretation. In IPA the researcher enters into a double hermeneutic, as they attempt to make sense of a person who has already begun to make their own interpretations about their experiences. On

one occasion in this research a triple heuristic was present through the use of one participant's husband to translate his wife's words into English for the benefit of the researcher. Though this was only present one way as the participant was able to understand English, this dynamic required the participant's husband to make sense of his wife making sense of her experiences, followed by myself as the researcher making sense of the husband's interpretation of his wife's interpretation of her experiences. Finally, idiography focuses on an individual's experiences rather than the universal experiences of a population. Through interviewing participant's separately from one another this research focussed on the individual experience of diagnosis of GDM.

Though quantitative research is important and contributes to 'evidence', for this research, and for my clinical training in general, a relativist perspective has seemed a better fit, and has encouraged a more individual approach.

#### References

- Carter, S. M. & Little, M. (2007). Justifying Knowledge, Justifying Method, Taking

  Action: Epistemologies, Methodologies, and Methods in Qualitative Research. *Qualitative Health Research*, 17(10), 1316-1328.
- Scott-Findlay, S. & Pollock, C. (2004). Evidence, Research, Knowledge: A Call for Conceptual Clarity. *Worldviews on Evidence-Based Nursing*, 1(2), 92-97.
- Smith, J.A. Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis:*Theory, Method and Research. Los Angeles: Sage.

# **Appendix 6: Supplementary Information for the Empirical Paper**

Appendix 6.1: Participant Information Sheet

Appendix 6.2: Participant Consent Form

Appendix 6.3: Interview Schedule



#### **Participant Information Sheet**

We would like you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with other if you wish. Please ask us if there is anything that is not cleat or if you would like more information.

Thank you for taking the time to read this.

# Study Title: What are the experiences and health perceptions of South Asian women with Gestational Diabetes Mellitus (GDM)?

How do South Asian women who have GDM, or Diabetes that has developed in pregnancy, experience their pregnancy and what are their views about their health?

#### What is the purpose of the study?

The research aims to identify the experiences of women with GDM, to look at their views of their health, and to look at the likelihood that they will begin lifestyle changes (such as exercise and dietary changes) that may prevent complications in pregnancy and reduce the risk of post-pregnancy diabetes. This is an under-researched area, with little qualitative research considering women's experiences. Qualitative research aims to gather a more in-depth knowledge and develop an understanding of how and why certain things happen, as opposed to other quantitative studies that mainly use numbers and statistics to determine the what, where and when things happen.

In addition there is also little research in this area with South Asian women, however there is a high rate of GDM amongst these women, and understanding

their experience may have implications for services in terms of information provision and intervention.

We would like to invite you to meet with us to discuss your experiences of having GDM and in what ways it has affected your life, though we will have a particular focus on its effects on your views about your own health. This interview will be audio recorded on a digital audio recorder until it can be transcribed for the researcher to study.

#### Why have I been invited?

You have been invited to take part in our study as you have recently been diagnosed with GDM in your first pregnancy. We are hoping to meet with ten women like yourself who have recently been diagnosed in their first pregnancy.

#### Do I have to take part?

No, taking part in the study is voluntary; it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form when we first meet. You can decide to withdraw from the study at any time, without giving a reason. This would not affect the standard of care you receive.

#### What will happen if I decide to take part?

If you agree to take part, we will contact you to arrange a time and place that is suitable to meet. When we meet you will be given the opportunity to ask any questions and obtain more information about the study. At this time you will be given a consent form to sign. Once you have signed this consent form, you will be given the opportunity to discuss with us your experiences of pregnancy with GDM and your health perceptions. This meeting will last for approximately one hour.

#### What are the possible disadvantages and risks of taking part?

The research consists of a one hour interview. There could be a risk that discussing your diagnosis and how it has affected your life may be upsetting. If you do become upset during the interview, you have the right to stop at any

time, and we will ensure you have access to any support that you might feel you need.

#### What are the possible benefits of taking part?

Whilst there are no immediate benefits for participants taking part in the study, hopefully the information you give us will improve the understanding of the experiences with women with GDM and may help to improve the service provided by the Bradford hospital team.

#### What will happen if I decide I no longer wish to take part?

At any point during the interview, you can decide to withdraw from the study. Your data would then be erased and not be used in future analysis.

#### What if there is a problem?

If you have a concern about any aspect of this study, you should contact the main researcher, Amy Spratt, on the contact details below, and she will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the main reception desk of Bradford Royal Infirmary.

#### Will my taking part in this study be kept confidential?

Your GP will be informed that you are taking part in this study. This is to ensure that, should you become distressed and need any support in the future your GP is aware of your participation in this study, however they will not be informed of anything that you discuss in the interviews. You may have a copy of the letter that will be sent to your GP and the main researcher, Amy Spratt, will be happy to discuss any concerns you may have about this.

All data will be handled according to ethical and legal practice. All information which is collected about you during the course of the research will be anonymous. Your completed questionnaires will be given an identification number which will be used throughout the analysis of the results. The data will be stored securely on University Departmental premises for five years after completion of the study.

However, it is important to note that should you disclose anything which the researcher feels puts yourself or others at risk, then confidentiality would have to be broken. You would be informed if this is the case.

#### What will happen to the results of the study?

The results will be written up as part of a doctoral qualification and are intended to be published in a scientific journal. You will not be personally identified in any of the results. If you wish to obtain information about the results, they will be available in the Women's and Newborn Unit upon completion in summer 2013, and there will be the option to opt in to a follow up session explaining the results and recommendations made due to the research carried out.

#### Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded through the University of Hull and through the Bradford Women's and Newborn Unit.

#### Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Research Ethics Proportionate Review Sub-Committee.

#### Further information and contact details

If you have any further questions or queries, please contact Amy Spratt on 07538788506 or email a.spratt@2007.hull.ac.uk.

Participant Identification number for this study:

# **CONSENT FORM**

**Title of project:** What are the experiences and health perceptions of South Asian women with Gestational Diabetes Mellitus (GDM)?

Please place initials

Name of Researcher: Amy Spratt	in the box
1. I confirm that I have read and understand the information sheet dated 23/04/2012 Version 2, for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes and data collection during the study may be looked at by individuals from the regulatory authorities or NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I give permission for my GP to be informed that I am taking part in this study.	
5. I am aware of the potential risks and benefits of taking part.	
6. I agree to the interview being audio recorded	

7. I agree to the use of anonymised quotes in publications			
8. I agree to take part in t	he above study		
Name of participant	 Date	 Signature	
Name of person Taking consent	Date	Signature	

#### **Interview Schedule: Participants experience of GDM in pregnancy**

#### Experience

Can you tell me a little bit about your background?

Prompt: Family, work, social life, interests?

Could you tell me a little bit about when you were diagnosed with GDM?

How did you react to what the doctors were telling you about your diagnosis?

Prompt: Were you angry, upset, worried, relief?

Now you've had chance to adjust to your diagnosis, can you describe how you feel about it?

Prompt: physically, emotionally, mentally?

How does it affect your everyday life?

Prompt: work, interests, relationships, family?

After your diagnosis, how did you feel about the information and advice you received?

Has your diagnosis changed your attitude towards your pregnancy?

Prompt: eg. awareness, careful, committed?

Has your diagnosis changed your attitude towards yourself?

Prompt: eg. more motivated to change your lifestyle, more critical of yourself?

#### **Health Perceptions**

How much do you think about your own physical health?

Do you think of yourself as being ill?

Prompt: always, sometimes, would you say were an ill person?

Do you feel that your health has changed?

Prompts: physically, mentally, emotionally?

Do you feel your health limits you in any way?

Prompts: socially, family, work, interests?

What thoughts do you have about your future health?

What thoughts do you have about the health of your baby?

# **Appendix 7.1 Ethical and Research Governance Approval**

Appendix 7.1: NHS Ethical Approval

Appendix 7.2: Research Governance Approval for Bradford Teaching Hospitals

NHS Foundation Trust (BTHFT)

Appendix 7.3: Letter of Access for BTHFT

# Appendix 7.2: Research Governance Approval for Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) Page 1

# Appendix 7.2: Research Governance Approval for Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) Page 2

# Appendix 7.2: Research Governance Approval for Bradford Teaching Hospitals NHS Foundation Trust (BTHFT) Page 3

# Appendix 7.3: Letter of Access for BTHFT Page 1

Appendix 7.3: Letter of Access for BTHFT Page 2

Appendix 7.3: Letter of Access for BTHFT Page 3

#### Appendix 8.1: Worked example of IPA

A section of transcript from one of the participants is used to illustrate each stage of the IPA process from participant 7, aged 26. In this extract participant 7 is describing her experiences of being diagnosed with GDM.

#### **Participant 7 Interview Extract**

P - I kind of panicked a bit, but the first time, when they went through everything em, yeah it was a lot to take because, like I say, I can be a bit forgetful at times and I thought, how am I gonna remember all of this? I can't even operate the machine, I'm gonna struggle, and then erm, that was probably the hardest part but then erm, yeah initial panic, that's what it is with I'm like, ooh I'm dead, but, I'm not (laughs) you just have to sort of.... Whe, when I came home I just thought about it, it took me maybe about a day to digest everything and I thought.... I spoke to people like, my auntie and I said oh, cos, I always speak to her, she's like a nutritionalist so she'll always advise me about.... Little things

#### I - right

P - and erm, she kind of said that some of her friends have got gestational diabetes and it's much more widespread than you think and er, that made me feel better.

# I - yeah

P - so, talking things through with people kind of helped me from say, the beginning of the day, when I was told everything to the end of the day when I'd come home, spoke to about 3 or 4 people and then I thought, right, maybe this is, something that a lot of pregnant women get

#### I - mmmm

P – and I adjusted much better

Stage One: The researcher immersed themselves in the data by reading and re-reading the transcripts, noting anything of significance and/or interest in the left hand margin on the second reading. Comments were then separated into descriptive (focused on the content of the transcript) linguistic (concerned with the use of specific language) and conceptual (which were interested in the comments of participant's at a more interrogative level).

Panic and fear P - I kind of panicked a bit, but the first time, when they went through everything em, yeah it *Lot of information – too much to* was a lot to take because, like I say, I can be a bit understand? forgetful at times and I thought, how am I gonna remember all of this? I can't even operate the machine, I'm gonna struggle, and then erm, that Uncertain of her ability to manage was probably the hardest part but then erm, yeah initial panic, that's what it is with I'm like, ooh I'm Laughing to manage anxiety dead, but, I'm not (laughs) you just have to sort of.... Whe, when I came home I just thought about Took time to take it all in - adjust? it, it took me maybe about a day to digest everything and I thought.... I spoke to people like, *Advice from others important* my auntie and I said oh, cos, I always speak to her, she's like a nutritionalist so she'll always

Usual coping strategy? Family	advise me about Little things
support	I - right
	P - and erm, she kind of said that some of her
Others have GDM	friends have got gestational diabetes and it's much
Common – means that she needs to	more widespread than you think and er, that made me feel better.
be less anxious?	
	I - yeah
Processes it with others	P - so, talking things through with people kind of
	helped me from say, the beginning of the day,
'adjusting' in a day?	when I was told everything to the end of the day
	when I'd come home, spoke to about 3 or 4
Common in pregnancy. This makes	people and then I thought, right, maybe this is,
it okay?	something that a lot of pregnant women get
	I – mmmm
Adjustment??	P – and I adjusted much better

Stage Two: Transcripts were re-read again by the researcher and any emerging themes were documented on the transcripts. These were also discussed with three independent researchers in order to ensure that themes emerging formed valid interpretations of the transcripts.

Panic and fear	P - I kind of panicked a bit, but the	Fear and anxiety
	first time, when they went through	
	everything em, yeah it was a lot to	
Lot of information –	take because, like I say, I can be a bit	Overload of
too much to	forgetful at times and I thought, how	information
understand?	am I gonna remember all of this? I	
Uncertain of her	can't even operate the machine, I'm	
ability to manage	gonna struggle, and then erm, that	
	was probably the hardest part but then	
	erm, yeah initial panic, that's what it	
Laughing to manage	is with I'm like, ooh I'm dead, but, I'm	
anxiety?	not (laughs) you just have to sort of	
Took time to take it all	Whe, when I came home I just	Adjustment
in – adjust?	thought about it, it took me maybe	
Advice from others	about a day to digest everything and I	
V	thought I spoke to people like, my	Family support
important	auntie and I said oh, cos, I always	
Usual coping	speak to her, she's like a nutritionalist	
strategy? Family	so she'll always advise me about	
support	Little things	
	I - right	
	P - and erm, she kind of said that	
Others have GDM	some of her friends have got	Experiences of others
Others have GDM	gestational diabetes and it's much	
L	L	i

Common – means that	more widespread than you think and	with GDM
she needs to be less	er, that made me feel better.	Prevalence of GDM
anxious?	I - yeah	
	P - so, talking things through with	
Processes it with	people kind of helped me from say,	
others	the beginning of the day, when I was	Family support
'adjusting' in a day?	told everything to the end of the day	
	when I'd come home, spoke to about	Adjustment
Common in	3 or 4 people and then I thought,	11ajusimeni
pregnancy. This makes	right, maybe this is, something that a	
it okay?	lot of pregnant women get	
	I – mmmm	
Adjustment??	P – and I adjusted much better	Adjustment

Stage Three: The researcher then looked for patterns and similarities across themes emerging from within and across the seven transcripts. Participant's quotes were used to support identified themes.

Emerging Theme	Supporting Quotes
'I got used to it now'	'I adjusted much better'
'he went through so much, so I can go through so much' - experiences of others	'some of her friends have got gestational diabetes and it's much more widespread than you think and er, that made me feel better.'
Duty to protect	'I always think well it's protective for the baby really because, I find if I wasn't pregnant, maybe I'd be a bit more naughty but because I'm pregnant, I, err, that's the sorta motive'
Battle for control over blood sugars and pregnancy	'it's about trying to control it, but you  can't always necessarily even control it  because of your hormones and things so,  sometimes it is quite demotivating'

Stage Four: The most pertinent themes from across all 7 participants were then combined and re-organised to form super-ordinate and subordinate themes. Throughout analysis the researcher discussed the process with a peer group in order to ensure a valid interpretation.

#### Appendix 9.1: Reflective Statement

This reflective statement documents my thoughts and experiences throughout research and on completion of this project. I will particularly focus on the challenges I've faced and give an overview of what I feel I've learnt along the way.

#### **Beginnings of Research**

At the beginning of this process I'd had few thoughts about the area that I might want to research. Previously I'd carried out research into the area of Alzheimer's disease and thought that I might wish to carry out more research in the area, however it is a highly researched area and I was unsure that I would be able to identify a gap in the existing research to focus on. Hence when potential supervisors presented their ideas for possible research projects I was sure to identify areas that might interest me and carry out more reading of my own into the area. Eventually I selected the area of gestational diabetes mellitus (GDM), as the area of Health Psychology I have known to be one my main interests from starting my clinical training, and this seemed to fit within my area of interest and be an already well considered project. I believe this identifies my weakness in creativity, and suggests that maybe I struggle to initiate my own, viable ideas within a broad area such as Psychology, or even Health Psychology. However I would also put some of this choice down to the knowledge that there were already a number of people (including a researcher, diabetes consultant and specialist diabetes nurses in Bradford) who would be interested in and hence supportive of this research. As I was aware even at this point that the thesis project would be difficult and time consuming, I believed that having additional support and expertise would be a great

help in terms of recruitment, but also with regards to ethics applications, write-up and publication.

At this initial stage I had little understanding of GDM, other than that it presented as diabetes in pregnancy. I carried out some reading of my own, but feel that I gained most of my understanding from attending some of the clinics. Here I sat in with either the specialist diabetes nurses or the consultant while they talked women through their diagnoses. I was given the opportunity to 'follow' a young woman through clinic on her first attendance, and felt that this gave me a 'feel' for what was required of these women and for all the information they are given in the first clinic they attend. The nurse's rapport with and empathy for their patients along with discussions I had with them about the risk of future diabetes helped me to see where some psychological research may have clinical implications and use. Meeting some of these women also further ensured my commitment to the area as I became interested and intrigued by their story and background, and wished to understand further how this might fit in with their other experiences.

#### **Research Design**

Though I had only ever previously carried out quantitative research, I was keen to try a different method, and having received teaching in the area of qualitative methodology I felt this would fit a lot better with the epistemological stance I wished to take for this project (see epistemological statement). In meetings with the consultant and specialist nurses, my field supervisor and research supervisor, it seemed clear that they all felt the same way. I was particularly struck by the consultant's statement that I was required for qualitative research as that was beyond the realms of their prior experience. At this point I was still in the early stages of both planning my project and my training, and to

have the idea that I had more experience in an area than a consultant didn't just seem daunting, it seemed laughable! However, through discussions with both my research supervisor and peers in the year above, I decided that it was probably something that I could bring to the table, as it were.

I feel that, throughout, I've had a much better experience of research by carrying out a qualitative study than if I had carried out quantitative research. This is mainly because of the interpersonal nature of qualitative research, particularly IPA, where you, effectively, take a great interest in the experiences and the 'story' that the participant brings, which I think that, as Clinical Psychologists, we inherently are. Despite this, there have also been difficulties that I feel have come partly from the design of the research, particularly recruitment. Asking women who are heavily pregnant and being required to attend multiple appointments due to additional complications with their pregnancy to give up around an hour to participate in an interview did not have many potential participants jumping at the opportunity. I feel that I may not have had these difficulties had I been carrying out a quantitative study that required less of the individual's time I may have had a higher uptake rate, however I also feel that the aims of the study could only have been achieved through a qualitative design. I still feel unsure as to whether or not the balance was struck right, however as the number of participants required was achieved eventually, I feel that the research was successful.

#### **Systematic Literature Review**

Deciding upon a research question or my systematic literature review (SLR), again, proved quite difficult for me. I feel this probably reinforces the statement I made earlier that I struggle to narrow down such a wide area, however in this case I did have an idea around the areas I would like to research. Initially I had wished to consider third wave

CBT interventions with individuals with diabetes mellitus (DM), with the idea that if these were shown to have a good level of efficacy this could also have clinical implications for interventions with individuals identified as having a high risk of developing Type 2 diabetes mellitus (T2DM) following GDM. However, there was little research available to carry out a SLR, and reviews had already been carried out considering CBT interventions. Hence I decided to approach it from the other 'side' as it were, instead of looking at interventions that may be implicated by the empirical paper, I felt it could be helpful to approach the experiences and health perceptions of South Asian individuals living in the UK with diabetes. The experiences and health perceptions of South Asian women with GDM then seemed to follow nicely from this review. This was very helpful when it came to writing the empirical paper as I already had a background knowledge from reading my literature review papers. This had already been highlighted by my supervisor, and she pointed out again that the reading I had done for my literature review was money in the bank, and informed my empirical paper well.

#### **Analysis of Data and Write Up**

Something I hadn't anticipated was the time that transcribing interviews requires despite warnings from those in the previous year. I found that, as well as the additional difficulty of typing quickly and keeping track of what was being said, the participants had quite strong accents (a combination of Yorkshire and South Asian) and as English was generally not their first language, sometimes sentence construction was very different to someone like myself, for whom English is the native language. At times I found myself typing words that I expected to hear as I knew, from interview what the participant was describing, however the participant would construct the sentence

differently to what I expected, hence for the first few interviews I transcribed I found myself going backwards and forwards and it was slow work. However this did give me a very good sense of the data which was particularly helpful when I began analysis.

I found that the findings from the SLR gave me good background knowledge about South Asian culture, particularly regarding DM and cultural norms about eating, food and exercise. As I carried out my analysis I was aware of how this might have caused me to identify certain themes and ideas as they fit with my existing understanding, however these ideas were confirmed by peer review, so it seemed that my concerns about my preconceived ideas were unnecessary.

Initially I did not identify any parallel processes within my research, however on reflection with peers who also reviewed my data it became evident that the high anxiety within my participants and the feelings of loss of control mirrored my own anxieties about completing the project and feeling quite out of control of the other areas of my life while I concentrated on the research. Similarly I found myself pushing and concentrating on the end point of my research, much as the women within my research concentrated on the end point of their pregnancy.

I expected to find the writing-up process really very difficult, but was pleasantly surprised that I enjoyed putting my analysis into words, and though I did have considerable difficulty fitting my results, discussion and conclusions into the word limits imposed by the journals I selected, this seemed to have a positive effect on m writing style as it meant I had to refine my work and be concise. Hopefully this experience means that in future my work might be more concise in the first instance rather than needing to do the huge amount of editing required in this project.

#### **Journal Choice**

I chose Diabetic Medicine to submit my SLR to, as a number of the studies that made up my introduction were published here and one of the reviewed papers was published here. I had initially hoped to submit to the journal that had published the majority of the papers reviewed, however every paper was published in a different journal, hence to gain some consensus I considered where other similar literature was published.

The British Journal of Obstetrics and Gynaecology was my choice for my empirical paper. I made this decision based on a review of which journals papers of a similar nature were published. As many of these were carried out and published in Australia, these were published in the Australian and New Zealand Journal of Obstetrics and Gynaecology. Hence I searched for an equivalent journal in the UK, and contacted them to ensure they published qualitative research. It also had a high impact factor (3.407), which means my research would be disseminated to a wide audience.