Part 1: Systematic Literature Review
How do Individuals with a Diagnosis of Type 2 Diabetes Mellitus Experience Applying Clinically Recommended Self-Management Behaviours?
A Review of Qualitative Evidence

Part 2: Empirical Paper
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

Submitted by Sarah Louise Dickson, to the University of Exeter as a thesis for the degree of Doctor of Clinical Psychology, May 2016

Supervised by Dr. Phil Yates & Dr. Anke Karl

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I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: .................................................................................
Acknowledgements

Firstly, I would like to thank those people who generously gave their time to participate in this study; without your willingness to share your experiences, this endeavour would not have been possible. For their support with the recruitment process, I would like to thank Dr. David Coppini and his wonderful secretary Paula Bowden. I would like to thank Dr. Phil Yates, Dr. Janet Smithson and Dr. Anke Karl for their support and guidance on research matters during my clinical training. Thank you to my family, friends and fellow trainees for your patience, encouragement, knowledge and suggestions. A special thank you goes to Mum and Dad for your unwavering support over the last eight years. I would also like to thank Rebecca Pepper, Laura Lanning, Kate Littler, Tina Vaughan and Sian Hocking for your insightful advice and comments.

To my fiancé, I really couldn’t have done this without your patience, unstinting support and unsurpassable prof-reading skills. To our daughter, your beautiful smile makes my heart sing when the going gets tough.
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Part 1: Systematic Literature Review

How do Individuals with a Diagnosis of Type 2 Diabetes Mellitus Experience Applying Clinically Recommended Self-Management Behaviours?

A Review of Qualitative Evidence

Submitted by Sarah Louise Dickson, to the University of Exeter as a thesis for the degree of Doctor of Clinical Psychology, May 2016

Word count = 4,000
(Excl. Tables, Figures, Abstract, Appendices and References)

Nominated Journal: British Journal of Health Psychology
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

Abstract

Purpose: Self-care for the management of T2DM entails a complex set of behaviour changes. Quantitative evidence suggests that individual treatment effectiveness beliefs predict adherence to these behaviours. Qualitative paradigms examining experiential accounts of adjustment to single self-care behaviours offer the potential to further illuminate the factors impacting on adherence. The aim of this review is to summarize qualitative research evidence exploring how individuals with a diagnosis of T2DM experience adjustment to specific self-care behaviours in order to: (a) highlight any themes that are specific to the experience of applying each behaviour change (i.e., diet, exercise, medication and SMBG); (b) to identify whether there any more general themes that emerge when considering all the behaviours together; and (c) to suggest how these themes could inform psychological practice and future research.

Method: After a search of four databases (PsycINFO, Medline, EMBASE, and CINHAL), the articles are appraised utilising the Critical Appraisal Skills Programme quality appraisal tool for qualitative evidence (CASP, 2013).

Results: 20 Studies are identified for review and quality appraisal conducted for each. Thematic synthesis is utilised to aggregate and organise the findings from each paper into three key areas: (1) the experience of making specific behavioural changes; (2) the burden of responsibility for change; and (3) managing behavioural change within cultural contexts.

Conclusions: The review highlights descriptions of experiences, unique to each specific self-care behaviour; in addition to themes common to all identified
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

behaviours. This indicates that specific self-care behaviours should be considered when exploring non-adherence to self-management in T2DM in research and clinical settings. The personal burden of self-care is described across all self-care behaviours, suggesting practitioners involve the individual’s support network where possible. Cultural beliefs and identity are an important factor in dietary, exercise and medication behaviours; practitioners should take this into account by adopting a culturally sensitive practice.

Keywords: behaviour change; adherence; qualitative research; self-management; type 2 diabetes mellitus
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

Introduction

Rationale for Review

Type 2 Diabetes Mellitus (T2DM) is a long-term health condition (LTHC) resulting from the body's inability to effectively utilise insulin for blood glucose regulation. Poorly-controlled or extended periods of raised blood glucose reduce life-expectancy increasing risk for stroke, coronary heart disease, limb amputation, blindness and renal failure (World Health Organization [WHO], 2016). Estimates suggest that approximately five million people in the UK will have a diagnosis of T2DM by the year 2025 and the average age for diagnosis is decreasing (Diabetes UK, 2016; Holden et al., 2013). Many of the complications associated with T2DM are preventable using a combination of self-management behaviours aimed at regulating diet and exercise, which are associated with better blood glucose control (United Kingdom Prospective Diabetes Study, 1998). The National Institute for Health and Care Excellence (NICE) 2015 guideline for the management of T2DM recommends the following interventions: lifestyle management (including diet and physical exercise), self-monitoring of blood glucose (SMBG) and glucose-control therapies. However, many individuals struggle with these strategies (Cramer, 2004). Diabetes self-care comprises a complex set of behaviours; SMBG and insulin therapy are entirely new routines associated with diabetes care (Rubin, Peyrot & Saudek, 1991).

Research suggests that there are some differences in levels of adherence to the individual treatment recommendations; one large European study revealed that approximately only 15% of participants were following
dietary recommendations (Toeller et al., 1995), whilst Donnan, MacDonald & Morris (2001) found that 31-34% of participants with T2DM reported adherence to oral medications at an ‘adequate’ level. Other studies have indicated that self-reported adherence to oral medication and insulin is higher than for moderating diet and engaging in recommended levels of daily exercise (Peyrot et al., 2005; Vijan et al., 2004).

Quantitative exploration of single-behaviours found that beliefs relating to the effectiveness of each individual self-management treatment recommendation (e.g. dietary self-management) were the strongest predictors of self-reported engagement in the behaviour (Glasgow, Hampson, Strycker & Ruggiero, 1997). Engagement in self-management strategies can be understood using health psychology models and theories. A widely applied approach, the Self-Regulatory Model (SRM; see Figure 1), has been demonstrated to predict treatment adherence and blood glucose control in T2DM (Harvey & Lawson, 2009; Leventhal, Diefenbach & Leventhal, 1992). The model suggests individuals respond to a ‘commonsense’ cognitive representation of an illness threat (structured around five components informed by existing knowledge and beliefs: identity, cause, timeline, consequences and controllability) with two independent, parallel cognitive and emotional processes to regulate responses to danger and emotion. Behaviour is regulated by a dynamic interaction between the parallel cognitive/emotional processes across three stages: cognitive representation, coping and appraisal.
The SRM is a flexible model and can allow for the integration of factors at both individual and social system levels to better inform theories of adjustment. This could include factors specific to individual treatment behaviours. Leventhal et al suggest that conceptualisations of these factors need to be understood from experiential accounts before abstracting them for use in a model (Leventhal et al., 1992). Qualitative approaches offer a method of accessing individual subjective experiences, especially those of groups marginalised within Western psychology (Braun and Clarke, 2013). Therefore it may be useful to consider experiential accounts of adjustment to specific clinically recommended self-care behaviours in order to better understand and support the differences in levels of adherence to each type of behaviour.
Aims and Objectives

The following review aims to summarize qualitative research evidence from the previous 20 years, to explore how individuals with a diagnosis of T2DM experience applying specific clinically recommended self-care behaviours. The objectives are: (a) to highlight any themes that are specific to the experience of applying each behaviour change (i.e., diet, exercise, medication and SMBG); (b) to identify whether there any more general themes that emerge when considering all the behaviours together; and (c) to suggest how these themes could inform psychological practice and future research.

Method

Eligibility Criteria

Inclusion Criteria Studies were included that; (a) used qualitative methodology; (b) explored the accounts of adults above the age of 18 years with T2DM; and (c) focussed on the application of a clinically recommended self-care behaviour (operationalized as: dietary management; exercise; SMBG and medication); (d) published in the English language; and (e) were published between 1996 and 11th March 2016 within peer-reviewed journals.

Exclusion criteria. Child and adolescent samples were excluded on the basis that their accounts may reflect additional developmental changes. Studies were excluded from the review for the following reasons; (a) studies focussing on or including the experiences of T1DM were excluded due to differences in
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both aetiology and treatment recommendations; (b) studies nested within randomised controlled trials (RCTs) were omitted: Peel, Douglas, Parry & Lawton (2010) acknowledge the value of these studies, however, the experiences and motivations of the participants may be different from those experiencing routine healthcare; and (c) studies with mixed samples (for example those including the views of professionals, carers or patients with conditions other than T2DM) were excluded due to uncertainty regarding how the subjective experiences of these groups would be integrated (as was the case in MacNeela, Doyle, O’Gorman, Ruane & McGuire, 2013).

**Information Sources**

The databases searched included: PsycINFO (1806-2016), Medline (1946-2016), EMBASE (1974-2016) all accessed through OVID and CINHAL (1981-2016) accessed through HDAS.

**Search Strategy**

A pre-planned strategy comprised an online search of published peer-reviewed articles dated between 1996 and 11\textsuperscript{th} March 2016. A series of search strategies (Figure 2) were adapted and developed from exemplars used to identify qualitative research in peer-reviewed qualitative meta-syntheses (see Toye et al., 2013). The reference lists of all included studies were hand-searched for additional works in addition to relevant journals published between the specified dates.
Figure 2. Exemplar of the Strategy Used to Search the Psycinfo Database
(adapted from Toye et al., 2013)

Study Selection

All data were extracted independently by the researcher, using a data extraction form. The titles of all articles were scrutinised, followed by the abstracts and finally by a full reading of relevant papers. Studies were rejected at each stage if the criteria were not met (Figure 3 summarizes the flow of information throughout the selection process).
1,169 citations identified via literature search
(Range: 1996-2016)
PsycINFO via OVID: 237 Citations
Embase via OVID: 613 Citations
MEDLINE via OVID: 31 Citations
CINHAL via HDAS: 288 Citations

1,013 unique citations identified

197 passed initial screening of titles

6 additional studies identified via hand-searching references

Abstract screen: 30 studies appeared to meet eligibility criteria

16 Articles excluded:
- Full-text not available (2)
- Included views of others (1)
- Included views of Type 1 diabetics (1)
- Focus of study not on specific behaviours (6)
- Insufficient qualitative data (2)
- Part of Randomized Controlled Trial (2)
- Meta-analyses: focus not on specific behaviours (2)

20 Studies included in the review

Figure 3. Flow of Information Through Each Stage of the Review
Quality Appraisal

The selected studies were appraised utilising the Critical Appraisal Skills Programme’s (CASP) quality appraisal tool (2013). The tool comprises 10 questions to aid screening and systematic appraisal of qualitative evidence, focussing on the validity, findings and contribution of the study. A number of tools have been developed for the appraisal of qualitative research, however, there is some debate as to which tools are most appropriate (Braun & Clarke, 2013; Dixon-Woods et al., 2006). The CASP was selected due to its use in a number of peer-reviewed qualitative meta-syntheses (e.g. Atkins, 2008; Campbell et al., 2003) and utilised to facilitate critical review rather than to exclude studies. Following appraisal, the papers were given an overall assessment rating according to Downe, Simpson and Trafford’s (2007) parameters (see Table. 1).

Table 1

CASP Tool Overall Assessment Ratings (Downe et al, 2007)

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>No or few flaws: the study credibility, transferability, dependability and confirmability are high</td>
</tr>
<tr>
<td>B</td>
<td>Some flaws, unlikely to affect the credibility, transferability, dependability and/or confirmability of the study</td>
</tr>
<tr>
<td>C</td>
<td>Some flaws which may affect the credibility, transferability, dependability and/or confirmability of the study</td>
</tr>
<tr>
<td>D</td>
<td>Significant flaws which are very likely to affect the credibility, transferability, dependability and/or confirmability of the study</td>
</tr>
</tbody>
</table>

1 See Appendix B: copy of the CASP tool
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

The exclusion of papers based on quality appraisal in qualitative synthesises is subject to some debate (see Dixon-Woods et al., 2006). This review has taken Attree’s (2004) stance to synthesis: papers graded ‘A’ and ‘B’ were used to identify the main categories whilst articles graded ‘C’ have been used to support them.

ENTREQ guidelines for reporting the synthesis of qualitative research were utilised to systemically approach and structure the review (see Tong, Flemming, McInnes, Oliver & Craig, 2012).

Thematic Synthesis

The results and discussion sections from each study were extracted into a qualitative data analysis computer software package (NVivo10; QSR International, 2012). The extracted data were aggregated and organised into key themes utilising principles of Thomas and Harden’s (2008) approach to thematic synthesis (see Table 2 for a description).
Table 2.

**Detailed Method for Thematic Synthesis (adapted from Thomas & Harden, 2008)**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage One</td>
<td>PDF documents of extracted literature were imported into nVivo 10</td>
</tr>
<tr>
<td>Stage Two</td>
<td>Free line-by-line coding of all text within extracted literature labelled ‘findings’ or ‘results’. Codes were inductively generated as opposed to using an apriori framework in order to allow the researcher to consider different possibilities. Some sentences may have had 2 or 3 codes applied.</td>
</tr>
<tr>
<td>Stage Three</td>
<td>As each new study was coded, the ‘bank’ of codes was added to and new ones were developed when appropriate. All text was examined for consistency and to ascertain whether further coding was warranted in light of more newly developed codes.</td>
</tr>
<tr>
<td>Stage Four</td>
<td>Similarities and differences between the codes were identified in order to start grouping them into a hierarchical tree structure. Themes were clustered for each of the self-care behaviours and also across the data set as a whole. New codes were created to capture the meaning of groups of initial codes.</td>
</tr>
<tr>
<td>Stage Five</td>
<td>In order to answer the research questions, common categories were inferred for each type of behaviour: during the coding/clustering process, higher order categories were identified for the described experiences within all extracts. The labels were: psychological impact, barriers, motivators and coping strategies and were subsequently used to group experiences by behaviour to form the category ‘The experience of making specific behaviour changes’. Two further categories emerged from clustering higher order themes when findings from all studies were considered as a whole; ‘The burden of responsibility for change’ and ‘Managing behavioural change within cultural contexts’.</td>
</tr>
<tr>
<td>Stage Six</td>
<td>A summary of findings was drafted organised around the descriptive themes.</td>
</tr>
</tbody>
</table>

**Results**

**Study Selection**

Twenty studies were included in the final review. The characteristics of the included studies are summarised in Table 3.
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

Table 3.

**Details and Quality Ratings of Full-Text Articles Selected for Review**

<table>
<thead>
<tr>
<th>Paper No.</th>
<th>Authors</th>
<th>Country</th>
<th>Title</th>
<th>Behaviour</th>
<th>Qualitative Methods</th>
<th>Analysis</th>
<th>N=</th>
<th>Aim(s)</th>
<th>Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Dye et al. (2003)</td>
<td>USA</td>
<td>Insights from older adults with type 2 diabetes: Making dietary and exercise changes</td>
<td>Diet and Exercise</td>
<td>Focus Groups</td>
<td>Framework Analysis</td>
<td>31</td>
<td>Identify factors that affect nutrition/exercise behaviours of T2DM and over 55 yrs (including attitudes, beliefs, environmental factors)</td>
<td>A</td>
</tr>
<tr>
<td>2</td>
<td>Lawton et al. (2004)</td>
<td>UK</td>
<td>‘Urine testing is a waste of time’: Newly diagnosed type 2 diabetes patients’ perceptions of self-monitoring.</td>
<td>Self-monitoring</td>
<td>Repeated in-depth individual interviews</td>
<td>Grounded Theory</td>
<td>40</td>
<td>To explore patients perspectives and views about self-monitoring via urine testing</td>
<td>C</td>
</tr>
<tr>
<td>4</td>
<td>Lawton et al. (2005)</td>
<td>UK</td>
<td>Perceptions and experiences of taking oral hypoglycaemic agents among people of Pakistani and Indian origin: Qualitative study</td>
<td>Oral Medication</td>
<td>In-depth individual interviews</td>
<td>Grounded Theory</td>
<td>32</td>
<td>To explore attitudes of Indian and Pakistani patients towards and experiences of taking oral hypoglycaemic agents</td>
<td>B</td>
</tr>
</tbody>
</table>

3 Quality ratings: A = Few flaws; high quality  
B = Some flaws; good quality  
C = Some flaws; borderline quality  
D = Significant flaws; poor quality
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

<table>
<thead>
<tr>
<th>Paper No.</th>
<th>Authors</th>
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<th>Title</th>
<th>Behaviour</th>
<th>Qualitative Methods</th>
<th>Analysis</th>
<th>N</th>
<th>Aim(s)</th>
<th>Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Morris et al. (2005)</td>
<td>UK</td>
<td>Experiences of people with type 2 diabetes who have changed from oral medication to self-administered insulin injections</td>
<td>Insulin Therapy</td>
<td>Longitudinal study Semi-structured individual interviews</td>
<td>IPA</td>
<td>6</td>
<td>Exploration of the range of subjective experiences of men and women commencing and adjusting to insulin therapy</td>
<td>A</td>
</tr>
<tr>
<td>6</td>
<td>Peel et al. (2005)</td>
<td>UK</td>
<td>Taking the biscuit? A Discursive approach to managing diet in type 2 diabetes.</td>
<td>Diet</td>
<td>Repeated Semi-structured individual interviews</td>
<td>Discourse Analysis</td>
<td>40</td>
<td>Examine how people newly diagnosed with T2DM construct managing their diet. Consider how men and women discuss dietary management (focus on accounts of failure to adhere to prescribed regimes).</td>
<td>B</td>
</tr>
<tr>
<td>7</td>
<td>Lawton et al. (2006)</td>
<td>UK</td>
<td>'I can't do any serious exercise': Barriers to physical activity amongst people of Pakistani and Indian origin with type 2 diabetes.</td>
<td>Exercise</td>
<td>In-depth individual guided interviews</td>
<td>Grounded Theory</td>
<td>32</td>
<td>To explore Indian and Pakistani patients' experiences and views of undertaking physical activity as part of diabetes self-care.</td>
<td>B</td>
</tr>
<tr>
<td>8</td>
<td>Lawton et al. (2008)</td>
<td>UK</td>
<td>'We should change ourselves but we can’t': Accounts of food and eating practices amongst British Pakistanis and Indians with type 2 diabetes</td>
<td>Diet</td>
<td>In-depth individual guided interviews</td>
<td>Grounded Theory</td>
<td>32</td>
<td>To explore Indian and Pakistani patients' experiences and views of dietary practices in relation to type 2 diabetes</td>
<td>B</td>
</tr>
</tbody>
</table>

3 Quality ratings: A= Few flaws; high quality  B= Some flaws; good quality  C= Some flaws; borderline quality  D= Significant flaws; poor quality
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<th>Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Shultz et al. (2009)</td>
<td>USA</td>
<td>Slavic women's understanding of diabetes dietary self-management and reported dietary behaviours</td>
<td>Diet</td>
<td>Individual interviews (semi-structured)</td>
<td>Thematic Content Analysis</td>
<td>10</td>
<td>To understand and describe Slavic women attempting to make behavioural changes as part of diabetes self-care by: a). Identifying beliefs b). Identifying behaviours c). describing influences in beliefs and behaviours</td>
<td>C</td>
</tr>
<tr>
<td>10</td>
<td>Peel et al. (2010)³</td>
<td>UK</td>
<td>Type 2 diabetes and dog walking: patients' longitudinal perspectives about implementing and sustaining physical activity.</td>
<td>Exercise</td>
<td>Repeated Semi-structured individual interviews</td>
<td>Discourse Analysis</td>
<td>40</td>
<td>To explore talk about implementing and sustaining physical activity</td>
<td>A</td>
</tr>
<tr>
<td>11</td>
<td>Gutschall et al. (2011)</td>
<td>USA</td>
<td>Patients' perspectives about dietary maintenance in type 2 diabetes</td>
<td>Diet</td>
<td>Semi-structured Individual interviews</td>
<td>Thematic</td>
<td>23</td>
<td>To understand patients' perspectives regarding maintenance of dietary regimen.</td>
<td>B</td>
</tr>
<tr>
<td>12</td>
<td>Kohinor et al. (2011)</td>
<td>Netherlands</td>
<td>Considerations affecting dietary behaviour of immigrants with type 2 diabetes: a qualitative study among Surinamese in the Netherlands</td>
<td>Diet</td>
<td>Individual in-depth guided interviews</td>
<td>Thematic</td>
<td>32</td>
<td>To explore how Hindustani and African Surinamese participants with type 2 diabetes in the Netherlands manage and perceive their diet.</td>
<td>C</td>
</tr>
</tbody>
</table>

³ Quality ratings: A= Few flaws; high quality  B= Some flaws; good quality  C= Some flaws; borderline quality  D= Significant flaws; poor quality
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<table>
<thead>
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<th>Paper No.</th>
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<th>Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>Miller &amp; Marolen (2012)</td>
<td>USA</td>
<td>Physical activity-related experiences, counselling expectations, personal responsibility and altruism among urban African American women.</td>
<td>Exercise</td>
<td>Focus groups</td>
<td>Thematic Content Analysis</td>
<td>11</td>
<td>To explore physical activity related experiences, perceptions and counseling expectations.</td>
<td>A</td>
</tr>
<tr>
<td>15</td>
<td>Murrock et al. (2013)</td>
<td>USA</td>
<td>Dietary challenges of managing type 2 diabetes in African-American women.</td>
<td>Diet</td>
<td>Focus groups</td>
<td>Thematic/Phenomenological</td>
<td>24</td>
<td>To describe African-American women’s experiences of managing their diabetes in the context of personal lifestyle factors.</td>
<td>A</td>
</tr>
<tr>
<td>16</td>
<td>Ebrahim et al. (2014)</td>
<td>South Africa</td>
<td>Factors influencing adherence to dietary guidelines: A qualitative study on the experiences of patients with type 2 diabetes attending a clinic in Cape Town</td>
<td>Diet</td>
<td>Semi-structured Individual interviews</td>
<td>Thematic</td>
<td>8</td>
<td>To consider contextual influences within the perspective of the ecological model as experienced by a small selected group of people living with type 2 diabetes</td>
<td>B</td>
</tr>
<tr>
<td>17</td>
<td>Ong et al. (2014)</td>
<td>Malaysia</td>
<td>Barriers and facilitators to self-monitoring of blood glucose in people with type 2 diabetes using insulin: A qualitative study</td>
<td>SMBG</td>
<td>Semi-structured individual interviews</td>
<td>Constant Comparative</td>
<td>15</td>
<td>To explore the barriers and facilitators to self-monitoring blood glucose in people with type 2 diabetes using insulin</td>
<td>A</td>
</tr>
</tbody>
</table>

3 Quality ratings: A= Few flaws; high quality   B= Some flaws; good quality   C= Some flaws; borderline quality   D= Significant flaws; poor quality
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<th>Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>Peeters et al. (2015)</td>
<td>Belgium</td>
<td>Understanding medication adherence among patients of Turkish descent with type 2 diabetes: a qualitative study.</td>
<td>Oral Medication</td>
<td>In-depth individual interviews</td>
<td>Grounded Theory</td>
<td>21</td>
<td>Exploring perspectives of Turkish migrants (one of largest ethnic groups outside of EU) and adherence to oral agents</td>
<td>A</td>
</tr>
<tr>
<td>19</td>
<td>Tanenbaum et al. (2015)</td>
<td>USA</td>
<td>Successful self-management among non-insulin treated adults with Type 2 diabetes: a self regulation perspective.</td>
<td>SMBG</td>
<td>In-depth individual interviews</td>
<td>Grounded Theory</td>
<td>14</td>
<td>1). Understand how people with T2DM learned to improve glycaemic control 2). To understand how they evaluated their efforts 3) to explore how SMBG enhanced self-regulation if diabetes self-management efforts</td>
<td>A</td>
</tr>
<tr>
<td>20</td>
<td>Tong et al. (2015)</td>
<td>Malaysia</td>
<td>Why do some people with type 2 diabetes who are using insulin have poor glycaemic control? A qualitative study.</td>
<td>Insulin Therapy</td>
<td>Semi-structured in-depth individual interviews</td>
<td>Thematic Analysis</td>
<td>17</td>
<td>Understanding from the patients’ perspective why glycaemic control difficult for those with T2DM and on insulin</td>
<td>A</td>
</tr>
</tbody>
</table>

1 Participants recruited for an overarching qualitative exploration of participant experiences of diabetes services (Peel, Parry, Douglas & Lawton, 2006)

2 Participants recruited for an overarching qualitative exploration of newly diagnosed type 2 diabetics’ preferences and views (Lawton, Parry, Peel and Douglas, 2005)

3 Articles rated for quality by a second independent rater

3 Quality ratings: A= Few flaws; high quality B= Some flaws; good quality C= Some flaws; borderline quality D= Significant flaws; poor quality
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**Synthesis of Results**

The research designs of the selected studies included the use of focus groups \((n=3)\) and individual, semi-structured interviews \((n=17)\) of which \((n=5)\) were longitudinal in design. Methods of analysis incorporated interpretative phenomenological analysis \((n=1)\), framework analysis \((n=1)\) and discourse analysis \((n=2)\) but mostly thematic \((n=7)\) or grounded theory \((n=9)\) approaches were utilised. Using the CASP quality appraisal criteria (2013) to rate the articles, four studies were assigned the rating ‘C’ due to; lack of clarity regarding the analytic approach, ethical issues and data collection or sampling (Kohinor et al., 2011; Lawton et al., 2004; Shultz et al., 2009). The four most recent studies, (Ong et al., 2014; Peeters et al., 2015; Tanenbaum et al., 2015; Tong et al., 2015) demonstrated reflexivity across the research process\(^2\). The remaining 16 studies did not include any indication of researcher reflexivity; therefore it is impossible to ascertain how researcher influence on the research process may have impacted on the findings. All studies comprehensively related their findings to existing theory and clinical practice. One study did not explore its limitations (Gutschall et al., 2011).

Based on the initial research questions and a thematic synthesis of the findings the literature is categorised into the following areas:

1. The experience of making specific behavioural changes (dietary therapy, exercise, insulin therapy oral medication and self-monitoring of blood glucose)
2. The burden of responsibility for change
3. Managing behavioural change within cultural contexts.

\(^2\) See Appendix C: A summary of the quality appraisal of included studies using the CASP (2013) tool
1. The Experience of Making Specific Behavioural Changes

The studies selected for review explored the experiences of individuals with a diagnosis of T2DM and their adjustment to specific, clinically recommended self-management behaviours: diet, exercise, SMBG, oral hypoglycaemic agents (OHAs) and insulin therapy (Table 4 gives a summary of the themes). Changes to diet were associated with the experience of psychological distress, especially if eating was used as a coping strategy in response to negative affect: loss of pleasure was a theme particular to eating and was associated with deprivation and constriction, leading to food becoming a source of distress.

Adhering to exercise behaviours was viewed as a choice and characterised by accounts of lack of motivation, confidence and self-limiting beliefs. Incentives to exercise were described as avoiding insulin therapy but also the intrinsic benefit to well-being.

Changes in medication were met with fear, more so in the case of insulin therapy, with needles and hypoglycaemia a particular concern. The transition was experienced by participants as a reflection of their personal failure to control their diabetes and that medication was being used as a form of punishment. Self-adjusting medication and poor adherence to OHAs was attributed to forgetfulness, dislike of poly-pharmacy and anxiety about the short- and long-term side-effects (a particular concern of participants from South Asian and Turkish communities).

Interestingly, SMBG played a role in facilitating change in other self-care behaviours helping participants to develop a sense of self-efficacy and make their
diabetes visible in the case of asymptomatic diabetes. However, negative emotional responses were experienced for those gaining continuous high readings and were associated with increased rumination and worry, leading to abandonment of testing.

Across all behaviours, a range of cognitive and behavioural coping strategies were described utilising both problem-solving and avoidance strategies. Use of behavioural strategies for prompting memory was described for supporting adherence to OHAs and SMBG.
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**Table 4**

*Aggregation of Qualitative Findings for Specific Self-Care Behaviours (article identifiers in parentheses)*

<table>
<thead>
<tr>
<th>Self-Management Behaviour</th>
<th>Dietary Therapy</th>
<th>Exercise</th>
<th>Oral Hypoglycaemic Agents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overwhelmed with information [8,15,16]</td>
<td></td>
<td>Negative beliefs</td>
</tr>
<tr>
<td></td>
<td>Loss of pleasure [1,8,9,11,12,14,15,16]</td>
<td></td>
<td>Beginning of a cascade of interventions [9]</td>
</tr>
<tr>
<td><strong>Barriers to adherence</strong></td>
<td>Psychological</td>
<td>Psychological</td>
<td>Psychological</td>
</tr>
<tr>
<td></td>
<td>practical</td>
<td>Ambivalence [10]</td>
<td>Feeling ‘well’ [8,18]</td>
</tr>
<tr>
<td></td>
<td>Financial cost of recommended and fresh food [8,15,16]</td>
<td>Lack of confidence in using gym equipment [1]</td>
<td>Forgetfulness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fear of pain [10]</td>
<td>Asymptomatic T2DM [8,18]</td>
</tr>
<tr>
<td><strong>Motivators for adherence</strong></td>
<td>Psychological</td>
<td>Psychological</td>
<td>Psychological</td>
</tr>
<tr>
<td><strong>Coping strategies</strong></td>
<td>Practical</td>
<td>Psychological</td>
<td>Practical</td>
</tr>
<tr>
<td></td>
<td>Avoidance of shopping when hungry [1,11]</td>
<td>Self-limiting beliefs [7,10,13]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Changing eating environment [1,14]</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Meal-planning [14]</td>
<td>Using the imagination [14]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eating smaller amounts of unhealthy food [8,11]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Avoidance of shopping when hungry [1,11]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Changing eating environment [1,14]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Meal-planning [14]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Using smaller plates [14]</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extreme restriction [8]</td>
<td></td>
</tr>
</tbody>
</table>
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Table 4 (cont.)

Aggregation of Qualitative Findings for Specific Self-Care Behaviours (article identifiers in parentheses)

<table>
<thead>
<tr>
<th>Self-Management Behaviour</th>
<th>Insulin</th>
<th>Self-Monitoring of Blood Glucose</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Negative beliefs: Insulin is the ‘end of the line’ [5]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Punishment for poor self-care [5]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sense of failure [5]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disempowerment [5]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Loss of personal freedom [5]</td>
<td></td>
</tr>
<tr>
<td>Barriers to adherence</td>
<td>Psychological Barriers to adherence: Fear: Needles [5,20]</td>
<td>Psychological Barriers to adherence: Fear of needles [17]</td>
</tr>
<tr>
<td></td>
<td>Diabetes burn-out [20]</td>
<td>Distress and disillusionment associated with inexplicable</td>
</tr>
<tr>
<td></td>
<td>Mental health difficulties [20]</td>
<td>readings [2,3]</td>
</tr>
<tr>
<td></td>
<td>Practical 1</td>
<td>Practical 1</td>
</tr>
<tr>
<td></td>
<td>Busy lifestyle [20]</td>
<td>Cost of testing strips [17]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Finding time</td>
</tr>
<tr>
<td></td>
<td>Staying healthy [5]</td>
<td>Confirmation of blood-glucose levels in relation to</td>
</tr>
<tr>
<td></td>
<td></td>
<td>symptoms [19]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increasing understanding of impact of behaviour change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>[3,15,17]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Indication of self-efficacy [19]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pairing testing with other daily routines [19]</td>
</tr>
</tbody>
</table>
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2. The Burden of Responsibility for Change

Personal responsibility. Across a variety of social contexts, an emphasis on individual responsibility for following and adhering to self-management guidelines was common to all behaviours (Castro-Sanchez & Avila-Ortiz, 2013; Ebrahim et al., 2014; Gutschall et al., 2011; Lawton et al., 2008a, 2010; Ong et al., 2014; Peel et al., 2005; Shultz et al., 2009). Peel et al., (2004) noted that SMBG appeared to reinforce this perception for the individuals within their study, with many participants attributing blame for high readings to self-care behaviours rather than to equipment failure.

Craving and temptation. Participants described a need to exert self-control in the face of uncontrollable cravings, biological urges and habitual consumption of forbidden foods, particularly sweet tasting products (Castro-Sanchez & Avila-Ortiz, 2013; Ebrahim et al., 2014; Murrock et al., 2013; Lawton et al., 2008; Ong et al., 2014; Peel et al., 2005), even if such cravings were non-existent prior to the T2DM diagnosis (Castro-Sanchez & Avila-Ortiz, 2013). One study represented this as particular to female experience (Peel et al, 2005). Overwhelming urges to eat forbidden foodstuffs were described as embodied experiences,

I love bacon. I eat bacon sometimes, on occasion. You know, sometimes I just want it so bad, that I think my heart will start talking soon.

(Shultz et al. 2009, p.403)
and causing negative affect (Castro-Sanchez & Avila-Ortiz, 2013). Participants gave accounts of the challenge presented by temptations to consume foods surrounding them, attributing success and failure to individual willpower,

You have to have a willing mind.’ or ‘Just say no, you can’t have it (sweets).

(Dye et al., 2003, p122).

Exerting self-control. Strategies used to exert self-control were strict self-monitoring, planning ahead to avoid making poor choices, eating small amounts of the restricted foods and complete abstinence from eating (Castro-Sanchez & Avila-Ortiz, 2013; Dye et al., 2003; Gutschall et al., 2011; Lawton et al., 2008). Self-monitoring was described as fostering a sense of control over dietary changes and T2DM itself (Ong et al., 2014; Tannenbaum et al., 2015). In addition to self-control, participants also felt controlled by others, for example, family members enforcing healthy diets, reprimands for dietary transgressions and perceived threatening or authoritarian interactions with health care professionals (Castro-Sanchez & Avila-Ortiz, 2013; Dye et al., 2003; Ebrahim et al., 2014; Lawton et al., 2008; Morris et al., 2005; Peel et al., 2005). In contrast to the theme of individual responsibility, there were also accounts of relinquishing responsibility to healthcare professionals (for approval of medication adjustments or to manage a sense of personal failure) or to female partners for managing dietary requirements (Morris et al., 2005; Peel et al, 2005).
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**Sharing the burden.** Though participants described the burden of responsibility being situated within them, there were many instances where the need for others was expressed, for example, through supportive understanding by peers with shared lived-experience. Other areas for support identified within the selected literature were: motivating to engage with exercise (Miller & Marolen, 2012; Peel et al., 2010); more contact with healthcare professionals for problem-solving, meal-planning, and emotional or psychological support (Gutschall et al., 2011; Murrock et al., 2013; Peeters et al., 2015). The family was viewed as crucial for practical activities (e.g., purchasing healthy foods, reminding to take medication and assisting with injections or SMBG), and for psychological support with maintaining change. This was of particular importance to immigrant communities (Murrock et al., 2013; Ong et al., 2014; Peel et al., 2004; Peel et al., 2005; Peeters et al., 2015; Shultz et al., 2009).

In one study, dogs were identified as providers of companionship and support for regular exercise (Peel et al., 2010). Some participants talked about the importance of faith for maintaining their willpower to adhere to both dietary and exercise changes (Dye et al., 2003). The absence of family support was noted in some studies impacting on self-control and coping with behavioural changes (Dye et al., 2003; Gutschall et al., 2011; Lawton et al, 2008). Some participants felt unsupported by HCPs regarding blood glucose parameters, physical activity and encouragement for perceived efforts (Miller & Marolen, 2012; Peel et al., 2004; 2010).
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The participants interviewed individually or as part of focus groups do not exist in isolation. They are members of communities with particular norms, values and identities; the included studies drew upon the experiences of individuals from a diverse range of both immigrant and established communities (e.g., British, Mexican, Slavic, Indian, Pakistani, African American, South African, Surinamese, Turkish and Malaysian).

Whilst cultural context was important for exercise and oral medication, it seemed particularly relevant for the application of dietary changes.

**Expressing cultural identity.** Hospitality towards others is highly valued within the Surinamese community. An essential part of identity and feeling connected to country of origin is the ‘cooking culture’ to facilitate social interactions (Kohinor et al., 2011). Other studies describe an interpretation of the consumption of traditional foods as symbolic of self and cultural membership,

> We will have our roti because without some things we cannot be
> (Lawton et al., 2008, p.311)

Lawton et al. (2008) reference Caplan’s (1997) assertion that ‘food is never just food’; in addition to the symbolic meaning of certain foods, cultural identity and belonging is also expressed through a variety of rituals such as sharing family evening meals and exchanging sweet gifts to mark special occasions (Lawton et al.,
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2008; Murrock et al., 2013). Therefore to change one’s diet or refuse foods at social events would entail a shift in self-identity and ultimately risk of alienation (Lawton et al., 2008). Although the consumption of traditional foods may conflict with clinical recommendations, participants from several studies found adapting their diets challenging due to the close links between food, self- and collective identity (Kohinor et al., 2011; Lawton et al., 2008). Compensatory behaviours identified within the studies include cessation of eating, eating restricted amounts of the same foods, using substitutes during the day but returning to normal practices at night in line with family customs and modifying restricted foods (Lawton et al., 2008; Kohinor et al., 2011; Castro-Sanchez & Avila-Ortiz, 2013; Shultz et al, 2009). Additionally, some participants declined professional nutritional support due to a perception that the advice given would not be commensurate with religious practice (Ebrahimi et al., 2014)

**Beliefs about the impact of certain foods.** Certain foods were associated with detrimental effects on diabetes, for example within Hindustani Surinamese culture, overuse of spices was attributed to a higher prevalence and negative influence on T2DM (Kohinor et al., 2011; Lawton et al., 2008;). Almost universally across the studies, sweets and sugar were referred to as either causing or worsening T2DM (Dye et al., 2003; Peel et al., 2005; Tong et al., 2015) with some foodstuffs perceived as transforming directly into sugar (e.g. roti, chapatti and rice in Lawton et al., 2008 and Kohinor et al., 2011). These beliefs were generally attributed to properties of the food (e.g., spiciness or bitterness, strength) rather than their nutritional constituents (Kohinor et al., 2011; Lawton et al., 2008). Traditional foods
were perceived as dangerous, damaging and in direct opposition to efforts to control T2DM, and presented an additional dilemma for the participants given the connection between food and self- or cultural identities (Kohinor et al., 2011; Lawton, 2008).

**The cultural context of exercise.** South Asian participants in Lawton et al.’s (2006) study associated T2DM with irreversibly ageing and weakening the body, thus presenting a barrier to taking exercise, whilst others associated sweating or breathlessness from physical exertion with illness states and to be avoided. The unpredictable British climate also discouraged some participants from exercising outdoors and was attributed as cause of T2DM itself (Lawton et al., 2006). Lawton et al., (2006) found that gender was a factor for engagement in physical activity, referring to gender-specific cultural norms (e.g., womens’ socialization to exercise in school). Lack of familiarity with their local area and social isolation was perceived by Lawton et al., (2006) to present a barrier to taking part in light physical activity such as walking.

**Influence of culture on adherence to OHAs.** Side-effects concerned participants in several studies; Turkish migrant respondents attributed their use of herbal medicines to these concerns (Peeters et al., 2015). South Asian participants in Lawton et al.’s (2005) study preferred to take their medications alongside ‘strengthening’ traditional foods in order to provide a balance to the perceived negative effects. However, one study revealed that western medications were
perceived as more effective and higher in quality than those from the ‘home’ country; health professionals from western countries were also viewed as being more trustworthy (Lawton et al., 2005).

Participants described adjusting their medication regimes to cater for religious fasting and generalised this to other occasions, without seeking professional support (Lawton et al., 2005; Peeters et al., 2015). Lawton et al. (2005) highlight that self-medication is common practice on the Indian Subcontinent, in contrast with the experiences of Caucasian respondents in their study who described adhering more closely to professional guidance (Lawton et al., 2010). Self-adjusting medication was also evident in Peeters et al. (2015), with respondents reporting that they did not take OHAs when visiting family in the warmer climate of Turkey due to a causal belief that inclement climates are responsible for T2DM.

Discussion

Globally, T2DM is an increasing problem resulting in personal and social burden, in addition to the considerable economic demands placed on public healthcare systems. Adherence to treatment recommendations reduces the risk of complications, however many individuals struggle with making these changes. Health psychology models are used to understand and predict adherence, however continued refinement is needed to incorporate individual and social factors for specific health conditions. These factors can be illuminated by qualitative exploration of individual experiences. The aim and objectives of this review are to use principles of thematic synthesis to aggregate qualitative findings in order to
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highlight themes specific to participants’ experiences of applying single behavioural changes in addition to those shared more generally across all self-care behaviours. The findings will be discussed with regard to theoretical, clinical and research implications.

The studies selected for review explored the experiences of individuals with a diagnosis of T2DM in the context of adjusting to specific, clinically recommended self-management behaviours (diet, exercise, SMBG, OHAs and insulin therapy). The findings revealed that the psychological impact of making dietary changes was associated with a range of negative emotions, loss of pleasure and reduction in self-worth. Transitioning to OHAs and insulin were described in terms of shock, anger and fear and associated with negative meanings such as punishment, illness worsening, personal failure and loss of freedom. Physical exercise, however, was not associated with negative psychological impact. Unlike the other specified behaviours motivations for exercising were described in terms of approaching values (an end in itself and altruism) as opposed to avoiding negative consequences (e.g. death) as found in the other behaviours. Self-limiting beliefs were described as barriers to engaging in new exercise regimes. SMBG was described as an activity supporting other behavioural changes and as both a source of reassurance (making asymptomatic diabetes visible and heightening sense of self-efficacy) and distress when readings were continuously inexplicable.

One theme common to all behaviours was the individual’s sense of responsibility for making behavioural changes and exercising self-control, together with a need to feel less isolated. This finding supports involving the individual’s support network to facilitate the adjustments to behavioural change. The cultural
context of the participants was also an important theme, with strong links made between food, cultural identity, and beliefs regarding the impact of certain foods on T2DM. This presented the participants with a dilemma, either risk social alienation or their health. Cultural context also impacted on engagement in exercise due to beliefs about gender and exercising in public, lack of socialization to exercising and the inclement British climate.

**Theoretical Implications.**

The findings from this review indicated that insulin therapy and oral medication had particular psychological impacts associated with them (e.g., negative affect, impact to sense of self and beliefs associated with the meaning of taking medication). This may provide some explanation as to why some studies have found better adherence to medication than to dietary and exercise recommendations (Peyrot et al., 2005; Vijan et al., 2004). Leventhal et al. (1992) suggest the SRM is a flexible model, adaptable to reflect specific representations of a variety of LTHCs. Treatment impact is considered as a component of illness representations within the SRM (i.e., illness controllability); however, it appears that beliefs associated with the meaning of the treatments themselves are not considered. This is evident in the tools developed for assessing illness perceptions in diabetes which include items such as ‘My treatment can control my diabetes’ (Revised Illness Perception Questionnaire, Moss-Morris et al., 2001). From the evidence reviewed, insulin and OHAs seem to pose a threat to psychological and physical wellbeing and therefore could be considered as health threats or representations in their own right.
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With time, many people with T2DM may require firstly OHAs and then insulin due to the progressive reduction in the body’s capacity to control blood glucose levels (NICE, 2015). The differing responses and coping strategies evidenced in this review’s findings could be better conceptualised using crisis theory (Moos and Schaefer, 1984); each treatment transition represents a new aspect of illness with attached meanings and beliefs, contextualised by personality and culture. The individual then generates alternative tasks and strategies for coping with adjustment to each new aspect of their illness.

The findings regarding SMBG were important due to the current debate regarding the necessity and availability of this specific behaviour. Tannenbaum et al.’s (2015) paper utilised the SRM to explore participant experiences and formulated that SMBG improved the participants’ sense of illness coherence: by using SMBG they were able to generate coherent understandings between illness and the impact of their self-care behaviours. The authors interpreted that this has positive implications for participants’ beliefs regarding their sense of controlling T2DM and self-efficacy. The current review supports the role of SMBG for developing a sense of coherence but also Tannenbaum et al.’s suggestion that SMBG should be clinically supported (2015).

**Recommendations for Clinical Practice and Further Research**

The differing sub-themes within the overarching themes of psychological impact, motivators, coping strategies and barriers for each of the specific behaviours, lends credence to the argument that adjustment to a diagnosis of T2DM
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is a complex issue. This indicates a need for increased emotional and behavioural support when individuals with T2DM are faced with adapting to new challenges posed by changes to their treatment plans. A desire to share this burden located in the participant accounts also implicates involving the individual’s family support network to facilitate adjustment to behavioural changes. The findings also highlighted the importance of cultural beliefs to personal illness models and practitioners at every level of care should take this into account by adopting a culturally sensitive practice; clinical psychologists could facilitate this by providing training. This review also highlighted a tension between the experience of SMBG as a tool for reassurance and as a source of emotional distress. Therefore, one further implication for clinical work might be to support individuals to manage SMBG-associated distress with psychological formulation and intervention to enable engagement with an otherwise potentially helpful intervention.

The review highlighted different emotional, cognitive and behavioural experiences for applying specific behaviour changes; further empirical study should investigate participant understandings and beliefs regarding specific treatment recommendations and seek to integrate these understandings within health psychology models to better support adherence to treatment plans in T2DM. Given the debate regarding the utility of SMBG, further quantitative investigation of the emotional and behavioural impact of using SMBG on health beliefs such as perceptions of treatment benefits and illness controllability is important. Finally, this review suggests that adjustment experiences to applying specific behaviours differ according to the treatment behaviour applied. This highlights the importance of
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studies addressing adherence and self-management in T2DM to consider specific behaviours rather than more generic descriptions of self-care.

Limitations

ENTREQ guidelines were utilised in order to increase transparency and enhance the systematic approach taken during the review. However the findings and recommendations should be considered in the light of the following limitations. Extensive search strategies were used in an attempt to locate as many papers as possible to explore specific self-care behaviours; however, during the initial selection process papers with a broad focus on self-care were excluded for lack of specificity but may have contained material relevant to the review. This was a compromise made by the researcher between retrieving all possible accounts and material relevant to the research aim. Although level of agreement was checked with one other independent assessor during the appraisal stage, the remainder of the review was conducted independently by the researcher. Therefore a limitation may be found in the confirmability of the synthesis findings. Campbell et al. (2003) recognise that qualitative synthesis can be an interpretive endeavour. The findings are a third-order interpretation of participant experience understood through the lens of the researchers own experiences which consequentially influences this interpretation (Smith et. al, 2009). The researcher conducted the review as part of clinical psychology training during which they received training in CBT; this aspect of

3 Due to researcher influence on the review process, the term confirmability (Guba & Lincoln, 1981) is used in preference to the term ‘objectivity’.

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training influenced the clustering of themes for the individual behaviours using cognitive and behavioural concepts. To increase confirmability in the absence of additional reviewers it would have been appropriate to present the review findings to a service user forum and other healthcare professionals or academics in the field. An additional method might have been to check the themes for cogency with the original authors.

Several papers were included from the same research group and this may have led to an interpretation based on a narrow range of understandings. Although different approaches were taken to the data, there was a lack of reflexivity demonstrated in these papers regarding the impact of repeated analysis on the findings (e.g. possible bias in researcher interpretations). Many of the papers evidenced a lack of clarity in describing which research methods were selected and why; this may have resulted in a more superficial analysis. The researcher attempted to mitigate for this by including papers with a quality rating ‘C’ to support rather than inform the main themes. All of the studies utilised either focus groups or individual interviews, therefore the findings are based upon a narrow range of data collection methods. Nine of the selected papers focused on changes to diet, and therefore the synthesis of findings for this particular behaviour change may be of greater depth and richness than the other individual behaviours.

Conclusions

This systematic review of qualitative research has focused on adjustment to specific healthcare recommendations in T2DM and revealed that there are both
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unique and common factors to experiences of adjustment to each behavioural change. Recommendations within the included studies call for more psychological intervention to facilitate adjustment, therefore exploration of appropriate psychological models is needed that can take into account socio-cultural factors where; (a) the modification of beliefs may be inappropriate or (b) there is a necessity to engage in self-care behaviours that are experienced by the individual as distressing and constrictive.
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Appendices

Appendix A: CASP (2013) Appraisal Tool

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist 31.05.13

CASP Criteria

A  Is this research relevant to the synthesis topic

B  Does this paper report on findings from qualitative research and did that work involve both qualitative methods of data collection and analysis

1  Was there a clear statement of the aims of the research?

   • What was the goal of the research?
   • Its relevance?
   • Why was it thought important?

2  Is a qualitative methodology appropriate?

   • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
   • Is qualitative research the right methodology for addressing the research goal?

3  Was the research design appropriate to address the aims of the research?

   • If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4  Was the recruitment strategy appropriate to the aims of the research?

   • If the researcher has explained how the participants were selected
   • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
   • If there are any discussions around recruitment (e.g. why some people chose not to take part)

5  Was the data collected in a way that addressed the research issue?

   • If the setting for data collection was justified
   • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
   • If the researcher has justified the methods chosen
   • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
   • If methods were modified during the study. If so, has the researcher explained how and why?
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6 Has the relationship between researcher and participants been adequately considered?
- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions (b) Data collection, including sample
  recruitment and choice of location
- How the researcher responded to events during the study and whether they
  considered the implications of any changes in the research design

7 Have ethical issues been taken into consideration?
- If there are sufficient details of how the research was explained to participants for the
  reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g., issues around informed
  consent or confidentiality or how they have handled the effects of the study on the
  participants during and after the study
- If approval has been sought from the ethics committee

8 Was the data analysis sufficiently rigorous?
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived
  from the data?
- Whether the researcher explains how the data presented were selected from the
  original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence
  during analysis and selection of data for presentation

9 Is there a clear statement of findings?
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers
  arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation,
  respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question
10 How valuable is the research?

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
Appendix B: Quality appraisal of the 20 studies included for review

<table>
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<tr>
<th>Specific self-care behaviour</th>
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A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

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A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

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¹ Partially met ² Unclear
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

DOCTORATE IN CLINICAL PSYCHOLOGY

Part 2: Major Research Project

A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

Submitted by Sarah Louise Dickson, to the University of Exeter as a thesis for the degree of Doctor of Clinical Psychology, May 2016

Word count: 7972
(Exc. Abstract, Appendices and References)

Main Supervisor: Dr Phil Yates, University of Exeter
Secondary Supervisor: Dr Anke Karl, University of Exeter

Nominated Journal: British Journal of Health Psychology

The author certifies that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.
Abstract

Objectives: To explore how adjustment to type 2 diabetes mellitus (T2DM) can be understood using psychological (in)flexibility, the theoretical model underlying acceptance and commitment therapy (ACT). The specific research questions are: (a) what are participant experiences of adjustment and coping in T2DM? and (b) how can participant experiences be understood in terms of the processes underlying the model of psychological (in)flexibility?

Design: This interview study utilised a cross-case qualitative methodology.

Methods: Semi-structured interviews were conducted with 11 purposively recruited individuals with a diagnosis of T2DM. Interview transcripts were subjected to an interpretative phenomenological analysis (IPA) methodology.

Results: Three primary themes were identified from the IPA: (a) ‘Eating myself into diabetes’: Managing the self in relation to perceived diabetes stigma; (b) My other illness is the real problem: diabetes minimised in the context of co-morbid diagnoses; and (c) Knowledge reduces attachment to the patient-role self-story.

Conclusion The interpretation of the qualitative data generated suggests that adjustment to a diagnosis of T2DM is a complex process incorporating intra-individual and systemic factors. Whilst psychological flexibility may be a useful model for understanding and supporting adjustment, interventions are required that also
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

address wider systemic issues such as the integration of care, health-related stigma and relationships with health professionals.

*Keywords:* adjustment; interpretative phenomenological analysis; psychological flexibility; qualitative research; type 2 diabetes mellitus.
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

**Introduction**

**Type 2 Diabetes Mellitus (T2DM)**

T2DM is a long-term health condition (LTHC) usually emerging in adulthood, which compromises the body’s ability to effectively utilise insulin for blood glucose regulation. T2DM is attributable to a variety of factors (including excess body weight) and in many cases is initially managed without medication (Diabetes UK, 2014). T2DM differs in aetiology to type 1 diabetes mellitus (T1DM): the latter is attributable to an autoimmune response (usually in childhood) resulting in the irreversible destruction of insulin-producing cells and treatment with insulin (Diabetes UK, 2014). The number of individuals diagnosed with T2DM in the UK is increasing, with a rise in diagnoses below the age of 40 years (Holden et al., 2013; Diabetes UK, 2012; 2016). In addition to the personal burden (coping with physical symptoms, risk of serious complications and adhering to treatment) estimates suggest that spending on T2DM was UK£8.8 billion during 2010/2011. Approximately 80% of that figure was allocated to treating complications. Indirect costs to the UK economy were estimated at £9 billion (Diabetes UK, 2014).

**Key Issues in Managing T2DM**

Despite evidence indicating that concordance with a self-management plan promoting good blood glucose control is associated with the prevention of complications and better quality of life outcomes, non-concordance with recommended treatment is estimated at approximately 50% (Brar, 2005; Rubin &
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

Peyrot, 1999; Stratton et al., 2000). Yet, concordance within the context of T2DM comprises a combination of education at diagnosis, self-monitoring, dietary management, blood glucose control, and medication (NICE, 2015; Rhee et al., 2005; Holman et al., 2008), requiring considerable lifestyle and behavioural adjustment on the part of the individual. The term ‘adjustment’ is widely used to represent both outcomes and psychological processes implicated in an individual’s attempts to restore equilibrium to their internal, social and interpersonal environments in response to changes in demands such as those implicated by a diagnosis of T2DM (Lazarus, 1966; Seaton, 2009). De Ridder and colleagues (2008) identify five key outcome indicators of successful adjustment in LTHCs: successful performance of adaptive tasks; absence of psychological symptoms; low negative affect and high positive affect; adequate role functioning; and life-satisfaction. There is, however, a complex interplay between these outcomes and individual concordance with treatment recommendations; for example, the presence of psychological symptoms in the form of depression and ‘burn-out’ is consistently associated with less adherence to educational interventions, treatment regime and dietary guidance and increased severity of diabetes complications (De Groot et al., 2001; Park, Hong, Lee, Ha and Sung, 2004; Snoek, 2002). Therefore, how well an individual adjusts to making the changes required by their T2DM, is crucial to both their level of concordance with treatment and to physical and psychological outcomes.

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4 Polonsky (1999) describes diabetes ‘burn-out’ as the psychological response to a continued exposure to negative diabetes-related experiences
Self-Regulation and Adjustment to T2DM

Whilst variables such as psychological symptoms are important indicators of successful adjustment, their measurement does not explain how individuals achieve successful adjustment outcomes or what might influence this process. Health-psychology frameworks such as Leventhal, Meyer & Nerenz’s (1980) self-regulatory model of illness behaviour (SRM; 1980), Moos and Schaefer’s crisis theory of illness (1984) and Taylor et al.’s cognitive adaptation theory (1984) can be used to understand how an individual responds to the challenges presented by a LTHC. Whilst it is not feasible to describe these models in detail, there are several overlapping themes that can be considered.

Central to these frameworks is the notion that illness represents a threat to the individual’s sense of equilibrium with their internal or external environments. Drawing upon their existing knowledge and belief structures, individuals construct multi-dimensional cognitive representations of an illness threat (illness cognitions) which, in addition to their emotional responses, influence the cognitive or behavioural coping strategies deployed in an attempt to return the self to a state of normality (Leventhal et al., 1980; Moos & Schaefer, 1984; Ogden, 2012; Sharpe & Curran, 2006; Taylor et al., 1984). The coping strategies described by these frameworks are generally categorised either as adaptive and directed towards addressing the threat (e.g., acceptance, information seeking and problem-solving); or as maladaptive strategies, directing attention away from the threat in order to alleviate associated emotional distress (e.g. avoidance, denial and distancing; see Lazarus & Folkman (1984); Leventhal et al., 1980; Moos & Schaefer, 1984). Indeed, research has
A Qualitative Exploration of Psychological Flexibility and Adjustment Experiences in Type 2 Diabetes.

highlighted the importance of beliefs and coping styles to adjustment outcomes in T2DM (Walker, Jackson & Littlejohn, 2004); for example, personal beliefs regarding perceived control over and causation of T2DM are associated with poorer psychosocial functioning, adherence to dietary recommendations, and glycaemic control (Hampson, Glasgow & Foster, 1995; Watkins et al., 2000). However, Lazarus & DeLongis (1983) suggest that focussing on whether coping responses are intrinsically adaptive is meaningless, as a response construed as maladaptive in one context may serve an adaptive function in another.

The causal relationship between illness cognitions and coping responses described by many health psychology models, has influenced the widespread adoption of cognitive behavioural therapy (CBT) as a model of psychotherapy targeting ‘maladaptive’ cognitions and behaviours to support adjustment to LTHCs, such as T2DM (NICE, 2009, 2015; Sharpe & Currie, 2006). However, whilst the evidence indicates some efficacy for classical CBT approaches in reducing diabetes-related distress and improving glycaemic control, support is not overwhelming for cognitive change as the specific mechanism for clinical improvement when compared to interventions utilising a purely behavioural approach (Elliot., 2012; Guadiano, 2011; Ismail et al., 2004;). Furthermore, Gregg, Callaghan, Hayes and Glenn-Lawson, 2007 suggest that using a classical CBT approach may result in the individual perceiving diabetes-related distress as irrational, which may

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Beck’s (1979) cognitive model of depression suggests that rather than events directly eliciting affective responses, they are mediated by the individual’s appraisal of the situation. If these thoughts and appraisals are not an accurate reflection of reality, the distortions give rise to and maintain distressing emotional responses. Therefore if clients are able to become aware of their thoughts and beliefs (originating in childhood) then they will be able to develop more adaptive ways of thinking, which can then be tested out in-vivo.
unintentionally increase their subjective distress and therefore impact on their ability or willingness to engage in self-care behaviours. The complex interrelationship between psychological factors implicated in adjusting to a diagnosis of T2DM is further compounded when considered in the context of socio-cultural understandings and differential meanings ascribed to each of the clinically recommended self-care behaviours (Dickson, personal communication; 2016). Consequentially, adjustment to a diagnosis of T2DM is highly individualised, meaning that challenging or modifying thoughts and feelings (as in CBT) may not always be an appropriate or adequate approach to supporting this process.

**Psychological Flexibility** as a Model for Understanding and Supporting Self-Regulation in T2DM

Taking into account the limitations of existing causal frameworks for understanding and supporting adjustment in T2DM, an alternative perspective on the process of adjusting to a diagnosis of T2DM might also be provided by psychological flexibility, the underlying theoretical model central to acceptance and commitment therapy (ACT). ACT is an evidence-based contextual CBT approach to assessment,

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6 Psychological flexibility should not to be confused with cognitive flexibility although aspects of each are theorised to overlap (see Whiting, Deane, Simpson McLeod and Ciarrochi, (2015) for a discussion).

7 Hayes, Strosahl and Wilson (2012) describe psychological flexibility as ‘simultaneously a model of psychopathology, a model of psychological health and a model of psychological intervention’ (p.62). Therefore, references within the text citing the model of psychological flexibility, implicitly refers to the inverse processes of psychological inflexibility.

8 Psychological flexibility and therefore ACT are theoretically and philosophically underpinned by Relational Frame Theory and Functional Contextualism. It is not feasible to describe these at length here; however, a brief description of both is located in the glossary (Appendix A).
formulation and intervention which emphasises changing the function of private events (e.g. thoughts and feelings) as opposed their content or frequency in order to reduce psychological distress (Hayes, Strosahl & Wilson, 1999). Hayes, Strosahl and Wilson (2012) present psychological (in)flexibility as a ‘unified’ model comprising six interconnected processes theorised to underlie human functioning and adaptability, or a lack thereof (see Table 5).

In summary, ‘Acceptance’ is conceptualised as the willingness to experience private events without attempting to alter their form or frequency and is a key core process. Cognitive ‘defusion’ focuses on the verbal aspects of experience and entails disentangling from private events and changing the function of them (i.e., viewing them as mental activity rather than literal truths). ‘Contact with the present moment’ entails focussing attention to events as they happen in the ‘here-and-now’ rather than entanglement with a remembered past experience or an imagined future, whilst ‘self-as-context’ aims to establish a connection to a transcendent sense-of-self that notices the experience of private events. These processes are employed in the service of ‘doing what matters’: ‘Values’ work seeks to identify or clarify chosen life directions whilst ‘committed action’ engages the client in behaviours in the service of these values regardless of ‘symptoms’ or unwanted private experiences (Harris, 2009; Hayes, Strosahl & Wilson, 1999).

In contrast, Hayes and colleagues (2012) suggest that human suffering occurs when an individual’s level of psychological rigidity prevents them from adapting to changes in internal and external contexts. Psychological rigidity (or inflexibility) in the form of persistent over-attachment or ‘fusion’ to cognitive processes (e.g. problem-solving) and attempts to avoid or suppress unwanted thoughts and feelings
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(experiential avoidance) may bring short term relief from suffering, but paradoxically, can result in more rather than less of these unwanted private experiences (Hayes et al., 2012). Chronic experiential avoidance may result in the individual’s life becoming constricted by self-destructive or self-defeating behaviours leading to less engagement in valued activity. Therefore, Hayes et al. (2009) suggest that an increase in psychological flexibility and therefore a reduction in psychological inflexibility (for example, by increasing one’s willingness to experience private experiences as they are, rather than struggling with their content by disputing or attempting to control them) increases capacity to respond flexibly to these private experiences with values-led, life-enhancing actions as opposed to life-restricting self-defeating behaviours (e.g. avoidance and numbing).
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Table 1
Underlying Processes Implicated in the Model of Psychological Flexibility

<table>
<thead>
<tr>
<th>Process</th>
<th>Psychological Flexibility</th>
<th>Psychological Inflexibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexible Attention to the Present Moment</td>
<td>Consciously connecting with what is happening in the present moment, bringing awareness to physical and psychological worlds. Awareness of what is happening now enables defusion, acceptance and values led behaviour</td>
<td>Dominance of the conceptualised past and future; limited self-knowledge Past and future are memories, stories and constructions occurring in the present. Rigid attention to the past (rumination) or the future (worrying) means that the individual misses out on what is happening now, or is unable to notice the consequences of actions. Lack of contact with the present results in limited self-awareness and ultimately self-knowledge</td>
</tr>
<tr>
<td>Values</td>
<td>Knowing what one wants life to stand for; leading principles that give life a sense of direction, though socially constructed they are freely chosen (i.e. not forced upon and individual)</td>
<td>Lack of values clarity/contact Lack of clarity regarding one’s values; neglecting or acting inconsistently with values. Via fusion, values can become rigid rules.</td>
</tr>
<tr>
<td>Committed Action</td>
<td>Taking effective action consistent with identified values</td>
<td>Unworkable Action The consequence of fusion, avoidance and loss of contact with values is characterised by becoming stuck in patterns of ineffective behaviours such as avoidance (passivity, inaction, withdrawal) or excessive engagement (impulsive behaviours, bingeing, overuse of numbing behaviours) in order to reduce aversive states.</td>
</tr>
<tr>
<td>Self-As-Context</td>
<td>The unchanging “I” that notices thoughts, feelings, physical sensations in any moment. (The “I” that noticed “x” yesterday is the same “I” that notices “x” today, even though “x” may have changed.) Also conceptualised as the observing self or transcendent sense of self.</td>
<td>Attachment to the Conceptualised Self Attachment to rigid self-descriptions or self-story (beliefs, memories, judgments, ideas, facts contributing to self-concept).</td>
</tr>
<tr>
<td>Defusion</td>
<td>Consciously noticing the mental act of verbally organizing the world. Thats’s, viewing thoughts from the perspective that they are words or pictures that may, or may not be true as opposed to absolute truths about the self. Considered in terms of whether they are helpful or unhelpful in terms of pursuing a valued life-path. For example; “I’m no good” vs. “I’m noticing that I am having the thought that I’m no good”</td>
<td>Cognitive Fusion Verbal events (thoughts) are experienced as absolute truths and subsequently dominate behaviour. Fusing with the thoughts is the problem, rather than the thought itself.</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Actively making the choice to be open to all private experiences without attempting to change their form or frequency enabling the individual to take action to improve their life situation as much as possible.</td>
<td>Experiential Avoidance The individual is unwilling to remain in contact with a particular private experience (e.g. physical sensation, emotion, thought, or memory) taking action to change their form or frequency (e.g. by suppression, numbing, or distraction) at the cost of values-guided living.</td>
</tr>
</tbody>
</table>
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Taking into account Hayes et al.’s (2012) claim that a focus on process rather than symptoms gives ACT the potential to be used trans-diagnostically, and findings from exploration of psychological flexibility processes in other LTHCs such as chronic pain ([CP] McCracken & Keogh, 2009; McCracken and Velleman, 2010; McCracken & Vowles, 2008; McCracken & Yang, 2006) suggest that ACT could be helpful for understanding and supporting individuals with other LTHCs such as T2DM. In terms of T2DM, in addition to fear and anxiety, an individual with the diagnosis may experience thoughts that they are unable to control their condition; as a consequence they may avoid reminders of their health status as a means of avoiding thinking about T2DM or experiencing distress. Reminders may include important self-care activities (for example foot-care) and although this may decrease their distress briefly, in the long-term this may impact on their physical health and subsequently restrict their ability to engage in meaningful activities. This inflexible stance to experiencing painful thoughts and feelings has the unintended effect of decreasing psychological wellbeing and reinforces the sense that T2DM is uncontrollable. Increasing psychological flexibility might enable an individual to manage diabetes-related avoidance and distress more effectively in order to engage more fully in self-care behaviours in line with their personal values.

Rationale for the Current Study

Supporting optimal adjustment in T2DM both benefits the individual and reduces burden to the NHS (Fellow-Smith et al., 2012). In addition to the limitations of causal explanations of adjustment to LTHCs, the level of complexity presented by adjusting to a diagnosis of T2DM presents a major challenge for healthcare professionals (HCPs) supporting individuals to optimize coping behaviours in T2DM
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(Harvey, 2015). The prevalence of psychological distress in T2DM and the higher incidence of T2DM in individuals with severe and enduring mental health difficulties (Anderson, Freedland, Clouse & Lustman, 2001; Delahanty et al., 2007; NHS Diabetes, 2010; Shin et al., 2012) means that these clients may seek support from HCPs working within primary- or secondary-care mental health settings, and these professionals may not have knowledge of existing specialist health psychology frameworks. As a psychological model of self-regulation currently utilised within both mental and physical health services, ACT may represent a more familiar and useful framework from which to understand and support people experiencing difficulties adjusting to T2DM.

Whilst there is a corpus of quantitative evidence supporting the outcomes and process of ACT across a variety of mental and physical health settings (including some support for using the approach in T2DM), there is a lack of process validation for using the ACT model within this population specifically (Gregg et al., 2007; McCracken & Keogh, 2009; McCracken and Velleman, 2010; McCracken & Vowles, 2008; McCracken & Yang, 2006; Ruiz, 2010). Hayes et al., (2012) highlight that although the model targets underlying processes as opposed to the content of beliefs or symptoms, the relevance of these constructs still need to be explored with specific populations, as certain processes may be emphasised for particular client-groups. Therefore, analysing experiential accounts of adjustment to T2DM through the lens of psychological flexibility could potentially inform clinical practice and research to support adjustment to challenging lifestyle changes.

The value of using qualitative methodology in studying psychological aspects of T2DM has been further highlighted by Vermeire et al (2003) as illuminating the subtleties of participants’ beliefs regarding illness, treatment and barriers to
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adherence in the absence of consistent predictors of adherence within quantitative paradigms. Braun and Clarke (2013) identify that qualitative methodology allows access to participants’ subjective worlds and facilitates the focus of enquiry on interactions, narratives and the patterning of meanings as a way of making sense of the complexity of human experience. Therefore using qualitative methodology would enable an initial exploration of participant experiences of adjusting to a diagnosis of T2DM through the lens of the model of psychological flexibility.

**Aim and Research Questions**

The aim of the current study is to gain an in-depth qualitative understanding of participants' experiences of adjusting to T2DM in relation to the processes underlying the model of psychological flexibility and inflexibility fundamental to psychopathology and change in ACT interventions (Ciarrochi et al., 2010) to highlight implications for clinical practice and further research. Therefore, the main research questions are as follows:

1. **What are participant experiences of adjustment and coping in T2DM?**

2. **Can participant experiences be understood in terms of the processes underlying the model of psychological (in)flexibility, specifically acceptance, defusion, self-as-context, values, committed action and contact with the present moment?**
Method

Participants and Recruitment

Purposive sampling was utilised with the aim of identifying 16 potential participants. Inclusion criteria were (a) a diagnosis of T2DM; (b) aged 18 and above years; and (c) fluency in the English language. Participants were excluded from the study if they (a) had a diagnosis of type 1 diabetes mellitus or gestational diabetes; and (b) if they did not have fluency in the English language. Participants were recruited using the following three pathways:

Local specialist clinic \((n=6)\). Participants were recruited in collaboration with a specialist diabetes clinic (Poole Hospital NHS Foundation Trust). Following their routine appointments, the hospital diabetes consultant gave 15 potential participants an information pack containing a letter on behalf of the researcher, a patient information sheet and a ‘contact details’ form, giving consent to the researcher to contact to arrange an interview\(^9\). Seven participants returned forms and six agreed to interview. The seventh participant could not be contacted.

University newsletters \((n=2)\). An advertisement with a brief synopsis and the researcher’s contact details\(^{10}\) was placed in two electronically distributed University of Exeter (UoE) newsletters.

\(^9\) See Appendix C: Participant information pack
\(^{10}\) See Appendix A4: Bulletin Advertisement
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**Personal contacts** \((n=3)\). Leaflets\(^{11}\) detailing the aims of the study and the researcher’s contact information were made available to staff and trainee clinical psychologists associated with the UoE training programme.

A total of 11 participants were recruited giving sufficient data to identify and consider instances of convergence and divergence within each case and across the sample.

All participants were given an information sheet and asked to either return the ‘contact details’ form using the prepaid envelope or contact the researcher directly. Participants returning the form via the diabetes centre were contacted seven days after receipt. Initial contact was made with all potential participants via their preferred method (telephone or email) in order to answer any remaining questions and arrange a suitable date for the interview either at the clinic \((n=4)\), their home \((n=5)\), or by telephone \((n=2)\). Demographic and diabetes-related information was collected prior to and during the interview (Table 6)\(^{12}\). All participants gave either written or audio-recorded consent\(^{13}\) immediately prior to the interview, and reminded that they could withdraw consent or terminate the interview at any point.

**Ethical Approval**

Ethical approval was gained from the National Research Ethics Committee – South West (NRES-SW), Poole Hospital NHS Foundation Trust Research and

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\(^{11}\) See Appendix A5: Study Leaflet
\(^{12}\) See Appendix D2: Information about the Participants – Extended Table
\(^{13}\) See Appendix C6: Informed Consent Form
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Development department and the University of Exeter, School of Psychology Ethics Committee\textsuperscript{14}.

Table 6

\textit{Participant Demographic Information}

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age Group</th>
<th>Duration of diabetes (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew</td>
<td>Male</td>
<td>60s</td>
<td>8</td>
</tr>
<tr>
<td>Anna</td>
<td>Female</td>
<td>50s</td>
<td>13</td>
</tr>
<tr>
<td>Brian</td>
<td>Male</td>
<td>70s</td>
<td>20</td>
</tr>
<tr>
<td>Dawn</td>
<td>Female</td>
<td>60s</td>
<td>33</td>
</tr>
<tr>
<td>Esther</td>
<td>Female</td>
<td>50s</td>
<td>23</td>
</tr>
<tr>
<td>Frank</td>
<td>Male</td>
<td>50s</td>
<td>15</td>
</tr>
<tr>
<td>Jack</td>
<td>Male</td>
<td>80s</td>
<td>2</td>
</tr>
<tr>
<td>Josephine</td>
<td>Female</td>
<td>60s</td>
<td>14</td>
</tr>
<tr>
<td>Norma</td>
<td>Female</td>
<td>70s</td>
<td>12</td>
</tr>
<tr>
<td>Paula</td>
<td>Female</td>
<td>40s</td>
<td>7</td>
</tr>
<tr>
<td>Robert</td>
<td>Male</td>
<td>60s</td>
<td>14</td>
</tr>
</tbody>
</table>

\textsuperscript{1} Mean duration of diagnosis = 14.6 years

Procedure

Audio-recorded, one-to-one interviews were conducted between the participant and researcher, either in person, or by telephone. Individual interview was selected as an appropriate method of data collection as it would facilitate a focus on

\textsuperscript{14} See Appendix B: Ethical Approval
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the participants’ views and perspectives of aspects of their lived experience (Frith & Gleeson, 2004).

**Interview**

A semi-structured interview schedule\(^{15}\) was developed and shaped utilising the six core processes underlying the model of psychological flexibility as a framework (Hayes et al., 2012). Although formulated to probe specific areas of the participants’ life-world, the questions were open-ended and used flexibly: a non-prescriptive approach to conversation guided by the participant is recommended to facilitate exploration of experiences and any interesting areas that arise (Biggerstaff & Thompson, 2008; Smith, 1996). Additional prompts were used when necessary to elicit deeper reflection on participants’ thoughts and feelings.

Interviews took place either in a hospital consulting room, the participant’s home or over the telephone. Nine face-to-face interviews were conducted and two via telephone. Interviews were transcribed verbatim and lasted an average length of 58 minutes. All data was anonymised and each participant given a pseudonym.

\(^{15}\) Appendix D1: Interview Schedule
Approach to Analysis

Several qualitative approaches could have been selected. Grounded theory (see Charmaz, 2006) was discounted due to the larger sample sizes needed to substantiate theoretical-level claims. The researcher’s aim of focussing on a particular aspect of lived experience as opposed to the role of language in the construction of social reality led to the decision to exclude discourse analysis as an approach (Willig, 2012).

Therefore, interpretative phenomenological analysis (IPA) was selected for the following reasons: (a) it has been used to explore a variety of subject matters within clinical and health psychology fields, contributing to biopsychosocial understandings of health conditions and placing service-users’ voices at the heart of clinical research (Brocki & Wearden, 2006; Reid et al., 2005); (b) it may offer an opportunity to explore processes unfolding over time in addition to adjustment outcomes (Thompson, Kent and Smith, 2002); and (c) IPA offers a theoretical framework and systematic approach to research design and analytic procedure providing a framework for the novice researcher (Pietkiewicz & Smith, 2014; Willig, 2013).

IPA. IPA is a qualitative approach with the explicit aim of examining and understanding how people make sense of their particular lived experiences through detailed and systematic exploration of their accounts (see Smith, Flowers & Larkin, 2009). IPA is considered to occupy a critical-realist ontological position and is theoretically underpinned by phenomenological, hermeneutic and idiographic

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16 There is an authentic world independent of human beings with underlying patterns and deep structures to be apprehended. (Alvesson & Skoldberg, 2010; Braun & Clarke, 2013).
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traditions. Smith et al., (2009) assert that gaining a first-order perspective (as suggested by a phenomenological approach) is limited by the research process itself: a dynamic interaction shaped by the participant’s account of their inner world and the researcher’s attempts to interpret the participant’s sense-making through the lens of their own conceptions, resulting in a ‘double hermeneutic’. Provided that participant experience remains central to the researcher’s interpretation, psychological theory can be explicitly foregrounded to inform IPA interview schedules and analysis (Reid, Flowers & Larkin., 2005; Smith et al., 2009). This approach is documented in several studies exploring the experiences of participants in healthcare settings including T2DM (Green, Payne & Barnitt, 2004; Janes et al., 2013; Senior, Smith, Michie & Marteau, 2002; Warwick, Joseph, Cordle and Ashworth, 2004; Wyer, Earl, Joseph & Harrison, 2001).

Reflexivity Statement

I am a white, British female clinical psychology trainee preferring an integrative approach to working. I live in a multicultural area of a relatively ethnically homogenous town in southern England. I came to training later in my working life and have had varied life experiences up until this point, including living in another European country.

My interest in diabetes began due to personal experience of the impact of diagnosis on friends and their families; witnessing their struggle to accept the diagnosis, their successes and failures in maintaining control and some of the distressing complications which could have been prevented. Some years later, whilst selecting my area of interest for the doctoral thesis, heightened media interest in the
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‘diabetes epidemic’ and promising evidence for reversing T2DM with the restricted calorie ‘Newcastle Diet’ (Lim et al., 2011) returned T2DM to the fore of my thinking and I began to research how various psychological models might be utilised to understand and support adjustment experiences. One intervention utilised an ACT approach and this connected with my own experiences with the model with a variety of client groups both prior to and during training. I found using the model conceptually challenging and have questioned its utility trans-diagnostically.

I have previously conducted research using quantitative methodology, and whilst I have completed a thematic analysis for a previous academic assignment I am a novice in the IPA method. The interview schedule was developed in line with my area of interest, but I endeavoured to approach each interview with the aim of gaining an understanding of the participants’ life worlds and adjustment experiences commensurate with the IPA approach. It is important to note, however, that my position of ‘psychologist’ may have elicited preconceptions and beliefs for each participant and therefore impacted on the responses they gave. Additionally my non-verbal communications may also have impacted upon the responses given and perhaps relates to the importance of maintaining a balance between ‘closeness and separateness’ in the interview process (Smith et al., 2009). An example of this was during interview with Steven, when he disclosed difficulties with erectile dysfunction. When I listened to the recorded interview I was struck how my voice changed and after a brief exploration of this area of importance to him I turned to the next question on my interview schedule. I kept a reflexive journal throughout the research process in order to notice how my own beliefs and assumptions influence the research process. As a result when another male participant talked about the same concern, I was perhaps less ‘surprised’ which enabled a more in depth conversation.
Data Analysis

In accordance with IPA’s idiographic stance, a case-by-case approach consistent with Smith et al.’s (2009) guidelines for conducting IPA was adhered to. Each transcript was read several times in order to familiarise with the accounts and informal notes made regarding points of interest and initial interpretations. A detailed set of exploratory notes were then produced using descriptive, linguistic and conceptual comments, with emphasis placed on attending to the participant’s unique experiences. These exploratory notes were then reduced to emergent themes: single words or phrases bringing together the sense-making of the participant and the researcher’s conceptual understanding of this. The next step involved structuring the emergent themes into groups that made sense conceptually using the processes of abstraction, subsumption and polarisation, resulting in the development of superordinate themes. These themes formed a precursor to the subsequent cross-case analysis: after repeating this process for all 11 transcripts, the super-ordinate themes for each participant compared across cases for patterns of re-occurrence. A master-table of themes for the all interviews was produced by identifying connections and instances where themes from one case supported or illuminated those in another. These higher order themes were subsequently checked against the individual transcripts to ensure that the essence of meaning was retained.
Results

Three master themes were selected from the cross-case analysis of the super-ordinate themes derived from eleven participants’ accounts of adjusting to a diagnosis of T2DM (see Table 7).

The three themes form one possible account of how people experience adjustment to a diagnosis of T2DM as interpreted through the lens of the theoretical model of psychological flexibility. Other researchers with different theoretical foregrounding may highlight other aspects of the participant accounts. The themes were selected as they further illuminated how participant experience might be understood in terms of psychological flexibility or inflexibility.
Table 7

*Master Themes and related Superordinate Themes*

<table>
<thead>
<tr>
<th>Master Themes</th>
<th>Superordinate Themes</th>
<th>No. of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ‘Eating myself into diabetes’; managing the self in relation to perceived diabetes stigma</td>
<td>An unacceptable aspect of self</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Difference to others emphasised</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Distancing the self from the diagnosis: bringing the self closer to normality.</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Confronting the stereotype: bringing others closer to the self.</td>
<td>2</td>
</tr>
<tr>
<td>2. My Other Illness is the Real Problem; diabetes minimised in the context of co-morbid diagnoses</td>
<td>‘That’s got nothing to do with diabetes’: Comparison of illness impact.</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Impact on coping</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Previous coping impacts positively on current</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other illness depletes resources for diabetes self-care</td>
<td></td>
</tr>
<tr>
<td>3. Knowledge Reduces Attachment to the Patient-Role Self-Story</td>
<td>Attachment to ‘patient’ as self-description.</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Defusing from self-as-patient through developing self-knowledge</td>
<td>7</td>
</tr>
</tbody>
</table>
1.0 ‘Eating Myself Into Diabetes’ Managing the self in Relation to Perceived Diabetes Stigma

1.1 An unacceptable aspect of self. Participants described unwanted feelings of shame, embarrassment, and fear in relation to negative self-judgments and those reflected in the gaze of others, both implicit and explicit, demonstrated by stranger’s request to refrain from injecting in public,

   You do feel that people judge you. You do. I mean whether they are or not. (Paula)

   She said, you’re disgusting and I said I’m not a heroin addict… I said this ain’t out of choice….I said...

   (Esther)

   The participants’ sense of shame centres on a pervasive social stereotype of diabetes as self-inflicted, originating with the individual’s lack of self-control and greed.

   A lot of people view diabetes as it’s, diabetes two as it’s your fault, you’ve eaten all the wrong things

   (Norma)

   The stereotype’s pervasive nature is illustrated by incongruence within some participants’ accounts; the perception of others’ blame for self-inflicting the disease conflicts with agreement with the stereotype,

   I mean there are far too many fat people in the country, sorry.

   (Norma)

   This unacceptable aspect of self appears to be reinforced by healthcare professionals attributing poor blood-glucose control to the participants’ self-control.

   This is subsequently internalized by the individual,
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Well, the inference always was, ‘You’re really not doing what we asked you to do. You’ve obviously been overeating,’

(Frank)

Later describing his difficulty in understanding high readings, he expresses his frustration,

Whatever it’s been, I still think, ‘What have I eaten?’

(Frank)

Norma recognises the risk to the self, posed by internalising such stereotypes,

I think if you went with that you’d go really down and depressed.

(Norma)

Some participants seem immune, their T2DM excused by natural processes of ageing or in the case of Anna, feeling comparatively less stigmatised by her T2DM diagnosis than her depression,

I think being diabetic is much more socially acceptable than having been sectioned and kept in hospital for six months.

(Anna)

1.2 Difference to others emphasised. Many participants described feelings of difference to others within their immediate social contexts and the wider system. Social occasions emphasise difference and isolation, with participants unable to engage in social-eating in the same way as before their diagnosis,

Your friends will say, ‘You mustn’t eat that. You’re diabetic’

(Josephine)
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On a wider level, participants described feeling financially penalised in the present due to the cost of healthy foods, testing equipment and insurances; they also feared future penalties for self-inflicting their diabetes. Additionally they felt scrutinised by employers and public agencies, attributing this to institutional anxiety regarding the risks posed by diabetics to themselves and to others. This feeling of difference is vividly emphasised,

Ousted ….like I was a leper

(Esther)

1.3 Distancing the self from the diagnosis: bringing the self closer to normality. Most participants described themselves as different to stereotypes: they are not overweight or a diabetic shape; tell others they have T1DM rather T2DM; are not the average diabetic; and can exert self-control in the face of temptation,

I don’t sit down and eat complete chocolate cakes, you know like you see those people on the television?

(Dawn)

Though asserting that they may be in some way helpful to others, several participants did not see any personal need to join support groups or forums (though recognised they may be helpful to others). Most made downward comparisons to other diabetics positioning themselves as better controlled, more accepting of the diagnosis and more adherent to medications. One participant described using toilets to inject rather than drawing attention to himself in public.

1.4 Confronting the stereotype: bringing others closer to the self.

Several participants described trying to confront or educate others regarding their
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diabetes, to foster better understanding of the condition and acceptance. For Esther this had a positive effect at work,

The attitude of people that I work with, especially with the current company, it shows that, I go to festivals and they've been absolutely brilliant, they've been very supportive,

(Esther)

2.0 My Other Illness is the Real Problem; Diabetes Minimised in the Context of Co-Morbid Diagnoses

2.1 ‘That’s got nothing to do with diabetes’: Comparison of illness impact. Most participants disclosed experiencing co-morbid long-term health conditions. They described comparing simultaneous or past illness experiences in terms of their impact to physical and psychological wellbeing, and reduced opportunities for fulfilled living. For some the psychological impact was worse: Norma found her experience of Myalgic Encephalopathy (ME) affected her in a way that diabetes doesn’t,

That was terrible and erm diabetes is, the brain is not the same thing

(Norma)

Whilst others viewed diabetes as just another diagnosis, several participants experienced co-morbid cancer as more frightening, distressing, and physically intrusive than diabetes. Dawn makes sense of this by describing differences in the immediacy of threat and manageability,

17 See Appendix D2: Extended participant information
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It doesn’t, kind of, bump you into a frame of mind where you are thinking you are really seriously ill.  

(Dawn)

This is supported by Jack’s view of T2DM as a lesser illness; worry about cancer overrides that about diabetes. In contrast, Anna views the risk posed to her health by diabetes as meaningless in light of severe depression and suicidality,

If I was dead, then the fact that I was diabetic didn’t mean anything, did it?  

(Anna)

2.2 Impact on coping

2.21 Previous coping impacts positively on current. Due to a long-standing focus on his health, Frank described the positive impact of learning to cope with illness at an early age, on his current coping with T2DM,

I think perhaps if I’d been completely healthy and then got diagnosed, I’d had nothing else wrong with me and then got diagnosed, I probably would have felt quite different about things,  

(Frank)

Later Frank described acceptance of his mortality at an early age; the uncertainty posed by the future, evident in others’ accounts,, does not present the same threat to Frank’s sense of self.

The impact of prior coping on current is supported elsewhere in the accounts,

I was that determined, I used to sit in the bath and just tell it to go away, I’d say ‘you’ it’s all these illnesses, you’ve just got to be very positive with them, you’ve got to talk to yourself, as I was saying, you’ve got to.  

(Norma)
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For Norma, there is a sense that maintaining a positive attitude and talking back to illness are workable coping strategies for her. Other examples highlight that despite viewing diabetes as irrelevant; engaging in self-care behaviours for co-morbid conditions brings benefits,

> It got me walking, and obviously losing a bit of weight was good for my self-esteem, as well as cutting calories. So, that made a bit of difference to my blood sugar, I think

(Anna)

Whilst Dawn described feeling incentivised to engage in better self-care by the impact on recovering from cancer surgery.

### 2.22 Other Illness Depletes Resources for Diabetes Self-Care.

In contrast to accounts of positive impact on coping, participants highlighted a cost to personal resources for engaging in healthy behaviours, mainly the capacity to engage in physical activity. Many participants acknowledged that exercising would be helpful; however, their co-morbid condition had reduced their ability to do so;

> So it is exercise that does help. But because I’m stuck, I can’t do the exercise.

(Andrew)

> I couldn’t keep doing the up and down dog, you know what that is. I couldn’t take the weight on my hands anymore, because I’ve got arthritis in one of my fingers

(Josephine)

For Anna, her mental-state impacts on both commitment and motivation for taking diabetes medication,

> Because of my depression I was just very worried that in a low state I might be tempted to give myself more than I should. And that’s probably not a good idea, is it? [Laughter].
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(Anna)

For others, more concerning health needs are prioritised before diabetes-specific needs suggesting finite personal resources for coping; multiple illnesses are compartmentalized in order to manage them. Anna’s account reflects that her depression has left her feeling depleted,

Because if I only had the one health issue it would be something I'd be prepared to cope with.

(Anna)

3.0 Knowledge Reduces Attachment to the Patient-Role Self-Story

3.1a Attachment to ‘patient’ as self-description. All participants within the study situated themselves to some extent within a patient-healthcare provider power dynamic. In many accounts, participants used the passive voice or prepositions (e.g. ‘under’) conveying a sense of submission to the power of medical knowledge. Accounts described professionals setting the parameters and deciding what is good-enough control, whilst fear of complications were utilised to threaten the participants into compliance. The passive tone highlights the adoption of responsibility by healthcare professionals for activities such as checking and monitoring, and a general sense that things are done to the participants.

While I was in there, they were checking my blood, because you have to understand before that I wasn’t checking my own bloods.

(Frank)

This dynamic is supported by descriptions of professionals viewed in parental roles,
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I do feel that if the medics that look after me will give me what I want, then I can actually behave very well

(Paula)

There is a sense that the participants are moved about the system with little or no choice about the decisions made regarding their care, and that professionals hold the decision-making power.

Paula described an acute response of rage and distress on perceiving an abuse of position by her GP when she disagreed with his recommendations,

So I felt frustrated, I felt angry. I felt outraged that he was threatening me

(Paula)

Others also described their shock at the use of power to frighten into compliance,

‘Oooh you might only have a short time to live.’ That’s incredible to tell someone isn’t it?

(Brian)

The consequences of attachment to a patient self-description are described by Frank, whose engagement with health services began in his teenage years. He described himself as ‘always being under medical attention,’ his self-story is one of coping with illness and treatment during a developmentally sensitive period for self-concept. This passive position is maintained by the medical profession and he continued to trust that the medical system holds his best interests in mind. Whilst reflecting on these experiences, however, Frank expresses his resentment at a lengthy period of poor control due to lack of choice and opportunity to take more control of his health,

I do think, even right from the beginning, so if I went back 15 years, and we were looking at just controlling it with diet, and then with tablets, and things, if I’d been
more aware of what my blood sugars were, if I was able to test myself a little bit more regularly, I really do think that would have helped, because I could have then seen more of a pattern, if you like, whereas I didn’t have that opportunity to do that.

(Frank)

The patient-role self-story translates from medical settings into other social environments,

My boss has always made sure that I’m fed on time, that I’m fed and watered on time, that I have all my insulin, anything, anything…that I just radio them and they’re there.

(Esther)

3.2 Defusing from self-as-patient through developing self-knowledge

Participants provided descriptions of researching the condition by accessing publicly available knowledge or through experientially developed understandings of causal relationships between blood-glucose level and behaviours. Through her own research and also by accessing an alternative self-description of medical professional, there is a sense that Paula becomes her own doctor and feels enabled to take responsibility for her own health.

I said, ‘But this really is very high.’ And he said, ‘Oh.’ I said, ‘What, for a diabetic?’ ‘Oh.’ He said, ‘Oh. Well, what are you on, then?’ I said, ‘I’m not on anything for my blood pressure, this is why I’ve come to see you.

(Paula)

This is mirrored in other accounts of increasing knowledge post-diagnosis, learning to speak the medical language of diabetes and engaging in positive actions for self-care; experienced within some accounts as empowering,
It gives me the questions to ask if I ever need to ask them

(Dawn)

Participants described the importance of the patient-professional relationship to their individual coping, responding positively to collaboration, empathy, and understanding of their personal contexts rather than as biological processes or cases to be treated rigidly in terms of clinical guidance.

Discussion

The following section will focus on discussing the study findings in light of the original research aim and in relation to relevant theory, evidence-base and suggest implications for clinical practice and further research. Qualitative analysis often leads to new or unexpected themes; therefore, additional relevant literature will be considered (Smith et al., 2009).

More to ‘Self-Management’ Than Symptoms

The researcher’s interpretation of the experiential accounts of individuals with T2DM of varying ages and duration of diagnosis revealed that rather than experiencing distress as direct result of a diagnosis of T2DM, adjustment experiences were located elsewhere in the experience of stigma, coping with multiple health conditions and within their relationships with professionals.

The participant accounts suggest that managing stigma-related shame is an important part of adjusting to a diagnosis of T2DM; most participants described experiences in relation to negative social perceptions of disease causality, maintenance and associated self-care behaviours. This lends support to findings in
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other qualitative studies which explore participant experiences of psychological distress associated with felt or enacted stigma in non-insulin and insulin-managed T2DM (Browne, Ventura, Mosely & Speight, 2013; Tak-Ying Shiu, Kwan & Wong, 2003; Singh, Cinnirella & Bradley, 2012; Weiler & Crist, 2009). Many of the accounts were characterised by feelings of isolation, shame, hopelessness and anger in addition to a sense of the self as ‘defective’ and evidence a degree of internalised stigma within this group of participants. This is an important issue due to emerging evidence that self-stigmatizing attitudes are associated with lower activation levels for self-care and with diabetes-related distress (Brown et al, 2013; Kato et al., 2016; Weiler & Crist, 2009).

Qualitative studies exploring other aspects of illness and disability experience (Seigal, Lune & Meyer, 1998; Taub, McLorg & Fanflik, 2010) suggest that individuals manage the negative effects of social stigma arising from a socially discreditable identity or characteristic by engaging ‘stigma management’ strategies. Goffman (1963) suggested that such strategies are dependent on how visible or obvious to others the discreditable attribute is; those with easily identifiable attributes (the ‘discredited’) may attempt to manage stigma utilising strategies aimed at controlling their social interactions (e.g. employing socially acceptable attributes such as humour or kindness (see Taub et al., 2010)). Individuals with less identifiable attributes (the ‘discreditable’) may engage in controlling information that would expose the self to negative interactions (Goffman, 1963). Dependent on their illness course, individuals with T2DM potentially could experience the self in both positions.

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18 Internalised stigma is described by Corrigan & Watson (2002) as, ‘the internalization of shame, blame, hopelessness, guilt and fear of discrimination’ (p.35)

19 Kato et al (2016) propose that ‘activation level’ (comprising self-reported knowledge skills, confidence and illness management behaviours) is a reliable predictor of self-care behaviour.
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As in Seigal, et al.’s (1998) study of individuals with a similarly less visibly identifiable illness status (HIV), participants in the current study engaged in both reactive (hiding their illness status, presenting their illness as less stigmatizing and distancing the self from more damaging aspects of stigma) and pro-active stigma management strategies (challenging the validity of the stigma by educating others and service-user participation). Despite the importance of this issue for the participants (some of whom have been diagnosed for many years) there appears to be a lack of research in this area.

Most participants included in the study described experiences of managing their diabetes in the context of coping with other LTHCs. Estimates suggest that as many as 78% of individuals diagnosed with T2DM have a co-morbid condition and approximately 40% have at least three; increasing age is identified as a contributory factor (Struijs et al., 2006; Bralić Lang & Bergman Marković, 2016). In this study, the main impact of co-morbidity on participants appeared to be compromised personal resources for coping. Participants described compartmentalising and prioritising their various conditions at the expense of engaging in self-care behaviours for T2DM. This finding supports others that the number and perceived severity of co-morbidity negatively impacts on prioritisation of T2DM and engagement in self-management behaviours (Albright et al., 2001; Kerr et al., 2007). The compartmentalisation of illnesses is mirrored in health care provision and means that opportunities could be missed for parsimonious interventions benefitting multiple conditions simultaneously. Current commissioning guidelines emphasise the importance of recognising the complexity that co-morbidity and diabetic complications add to the formulation of care-plans and advise developing strategies accordingly (Diabetes UK, 2013).
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The third important theme to emerge from the accounts was the experience of the self as a patient interacting with professionals within the healthcare system. Satisfaction with care and effective communication with health professionals is associated with concordance with treatment, symptom improvement and reductions in psychological distress (Albright, Parchman & Burge, 200; Kaplan, Greenfield & Ware, 1989). During the last 25 years healthcare policy has shifted from traditional disease-models emphasising the expertise of the practitioner and passivity of the patient to a more person-centred approach to care (Fisher & Glasgow, 2007; Stewart, 2001). The findings of the current study suggest that for this group of participants this is not experienced in practice and support the findings in other qualitative work of an implicit or explicit expectation that patients will do as instructed by HCPs (Janes et al., 2013; Ryan, 2014). This is reflected in the threatening approach and perceived abuse of power resulting in the powerlessness experienced by Paula.

Using Psychological Flexibility to Understand Adjustment Experiences

To facilitate the exploration of participant experiences in relation to the six core processes underlying the model, the interview schedule was grounded within a theoretical framework: psychological flexibility. The participant accounts prioritised aspects of adjustment that could be understood in terms of this model; seeking knowledge was formulated as a behaviour (or committed action) promoting ‘fusion/defusion’ from ‘attachment to the conceptualised self’ as patient, consistent with participant ‘values’ regarding autonomy and independence. ‘Experiential avoidance’ was noted in accounts of distancing the self concept from a diabetic stereotype in order to manage unwanted thoughts and feelings associated with
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stigma, for example, Esther describes telling others that she has T1DM rather than expose herself to public disgust.

This study provides some initial support for the relevance of these constructs in the adjustment experiences of individuals with T2DM and therefore interventions hypothesised to increase psychological flexibility (or decrease inflexibility) may help to optimize adjustment. For example, in the case of self-stigmatizing attitudes, if an individual experiences shame as a result of negative self-evaluations from identifying with the diabetic stereotype this may result in attempts to suppress or avoid present a barrier with consequences for engaging in values-guided living (Luoma et al., 2008). Rather than challenging the content or frequency of these self-evaluations it may be more effective to focus on increasing willingness to experience these unwanted private experiences in order to focus on behaviours that will move them in a valued direction (e.g. injecting insulin somewhere more public and hygienic than a restaurant toilet as in David’s experience).

The experiences described by participants could also be understood in terms of other frameworks and theory. For example, information seeking interpreted as a problem-focused coping response in Leventhal et al.’s self-regulation model (1980), making downward social-comparisons to others with T2DM as an attempt to enhance self-esteem (Taylor et al., 1984) and the interpersonal relationships between HCPs and patients informed by attachment theory (Bowlby, 1979). There may be overlapping theoretical mechanisms underlying these models and this warrants further exploration in order to provide a clinically useful model for psychologists working with individuals struggling to adjust to T2DM in primary and secondary care settings.
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One benefit to clinicians using psychological flexibility and ACT to understand adjustment in T2DM is that following assessment and case formulation an intervention can be individualised without having to then refer to another model to target specific symptoms (e.g. as in ‘classical’ CBT approaches). As a trans-diagnostic approach several difficulties could be targeted simultaneously due to a focus on process, context and function rather than more causal accounts of behaviours. This goes some way to address Lazarus and DeLongis’ (1983) concern that pre-occupation with the valence of coping responses neglects the nuances of the context of behaviour. However, whilst psychological flexibility appears to draw together theories of identity, behaviour and attention, one criticism of the approach is that it is too broad and therefore in danger of being both unwieldy and unfalsifiable.

The Importance of Context

A common underlying assumption of health psychology frameworks and the model of psychological flexibility is that adaptation to LTHCs is a self-regulatory process intended to return the individual to equilibrium with socially constructed states of ‘normality’. Most models acknowledge the importance of socio-cultural and systemic factors to the development of beliefs and coping responses. The focus, however, on intra-individual factors in the assessment, formulation and intervention for supporting adjustment locates responsibility for change within the individual rather than attempting to address that which is ‘socially constructed’. These models have been informed by wider clinical and biomedical contexts emphasising individual change, whilst the current policy recommendations for person-centred care and media propagation of diabetes stereotypes promulgates a wider discourse of taking
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individual responsibility (Gollust & Lantz, 2009; Schabert, Browne, Mosely & Speight, 2013).

The current study reveals that there are important, systemic issues to consider; representing participants’ experience within an adapted socio-ecological model (see Figure 4) can further our understanding of the complex interrelation between the individual as part of a system and wider environmental factors (Bronfenbrenner, 1979). Viewing their experiences from this perspective highlights an opportunity to intervene on a wider scale rather than the focus on the individual suggested by current recommendations (NHS Diabetes, 2010); as Levy (1993) notes change in the wider social system is necessary to support individual interventions in managing adjustment experiences such as stigma.

Figure 4. Socio-Ecological Model Locating Participant Experiences Within the Wider Context (adapted from Bronfenbrenner, 1979).
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Implications for Clinical Practice and Further Research

The current study found that participants described their adjustment experiences in ways that could be understood using the concepts of psychological flexibility (and inflexibility). Individuals with T2DM are adjusting to a range of challenges that are indirectly related to their diabetes; therefore it may be helpful for clinicians working with this population to utilise a trans-diagnostic contextual approach such as ACT (and its underlying theoretical model of psychological flexibility) rather than using single-models to address specific symptoms such as depression or anxiety. The majority of participants in this study described themselves as having good glycaemic control and these themes were supported across the majority of accounts. It would be important to extend this research to a sample of individuals with T2DM who struggle with glycaemic control to provide a comparison between the two groups and further inform using interventions grounded in psychological flexibility for adjustment difficulties. Future research exploring these processes in T2DM could focus on a quantitative enquiry and utilising exemplars of parallel research in CP would be appropriate (see McCracken & Vowles, 2008).

The findings indicated that experiencing felt or enacted stigma was part of adjustment for these participants; this aspect of T2DM requires that clinicians should consider the impact of stigma when working with individuals experiencing psychological distress or difficulties with self-management, for example by encouraging patients to complete a recently validated measure such as the Diabetes Stigma Assessment Scale (Browne, Ventura, Mosely & Speight, 2016). Further research should be conducted to increase understanding of the relationship between stigma and coping behaviours in T2DM (e.g. whether experiencing stigma mediates the relationship between psychological distress and self-management). Furthermore,
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exploration and formulation of stigma-related distress in T2DM with regards to the processes of 'learned helplessness' (Seligman, 1975) and 'internalized oppression' (Morris, 1991) may provide further illumination of the differences in illness coping and adjustment behaviours whilst taking into account social processes (Yates, 2003). Subsequent outcomes could provide further support for tailoring psychological interventions in T2DM to include the management of stigma-related distress as opposed to targeting depression or anxiety.

Most participants experienced multiple demands whilst managing co-morbid health conditions. Changes to the commissioning of health and social care services provide an opportunity to integrate multiple care-planning needs. In practice this would entail co-ordinating a variety of services around the needs of the service-user to reduce duplication of appointments, tests and information with the aim of improving outcomes in the management of LTHCs (Diabetes UK, 2013; Goodwin et al., 2012). This presents an opportunity for HCPs to offer parsimonious interventions that benefit multiple conditions wherever possible. It would be important to evaluate the individual and economic impact of integrated care on psychological adjustment to multiple LTHCs.

Finally, this study has highlighted a need for multi-level intervention. This could include the delivery of training and supervision to GPs, consultants and specialist nurses in therapeutic relationships guided by psychological models (e.g. psychological flexibility or attachment theory). Clinical psychologists within healthcare systems could address power imbalances and effect systemic change by supporting meaningful service-user participation in service development.
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Social psychology paradigms could be used to explore reducing enacted stigma through protest, education or positive contact interventions in the wider population (Corrigan & Penn 1999)

Methodological Strengths and Limitations

To demonstrate commitment to quality and rigour, the researcher followed principles suggested by Yardley (2008). The researcher attended specialist teaching on qualitative methodology including IPA and consulted a range of literature. An audit trail is provided in order to provide a transparent account of the research process. A research supervisor with expertise in clinical health psychology and qualitative methods audited one transcript and agreed with the emergent and superordinate themes produced. One clinical psychologist familiar with the IPA method reviewed a transcript at the stage of producing emergent themes and another with expertise in the ACT model audited a transcript each. This was intended as a way of checking the coherence and credibility of the theme structures rather than accessing alternative interpretations of the data (Angen, 2000). It would, however, have been appropriate to offer a summary of the themes to participants and invite feedback to provide further validation of the interpretation. The researcher’s motivations, assumptions and values are acknowledged within a statement of reflexivity as shaping the research process, therefore acknowledging the possibility of alternative interpretations (Elliot et al., 1999; Yardley, 2008).
The varying settings of the interviews may have impacted on the quality of data gathered: it took time for one participant to feel at ease and engage in a deeper discussion of the issues within the clinic setting. Telephone interviews may have impacted on the rapport building process (positively or negatively) and participants may have responded more or less openly than during face-to-face interaction.

The sample size and method utilised mean that findings are intended to provide insight and increase understanding rather than make broad generalizations. Although the small number of participants may be viewed as a limitation, this enabled closer analysis of the accounts in the spirit of IPA (Smith et al., 2009). The participants were all of white, British ethnicity. As such, this study may provide a foundation for future work in the area, including the engagement of participants from a variety of cultural backgrounds.

The data provided a rich account of participant experiences and additional, clinically relevant themes were produced. It was unfeasible to include them all within current study; however, they could be included in an additional clinically focussed paper. For these reasons and also due to the novice status of the researcher to IPA, it may have been more appropriate to conduct an inductive thematic analysis given that the researcher would have been able to maintain an idiographic focus.

**Conclusion**

This study provides a contribution to understanding the adjustment experiences of individuals with a diagnosis of T2DM. An IPA cross-case analysis was used to develop an understanding of the issues presenting significant challenges to the interviewees and ways of coping were interpreted through the theoretical lens of the model of psychological (in)flexibility. The findings suggest that
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some of the underlying constructs (particularly experiential avoidance, self-as-context and defusion) may be a clinically useful way of understanding individual experiences of T2DM and that further research is warranted. Focussing on purely individual responses to adjustment neglects the relevance of the self, located in relation to social context, interpersonal relationships and comorbidity.
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Appendices

Appendix A: Glossary of Terms

**Functional Contextualism.** Psychological events are viewed as a set of ongoing interactions between whole organisms and their contexts, which are historically and situationally defined (Hayes et al., 1999). Therefore, ACT takes the view that cognitions aren’t inherently problematic in themselves, but depending on the context they occur in may function in a harmful way, i.e., work for or against attaining particular goals (Harris, 2009; Schoendorff, Webster & Polk, 2014). Rather than focussing on altering the form or frequency of specific private events, the functional contextualist perspective approaches psychological health from the position that how a person interacts with their life situations determines their behaviours and these behaviours are workable in moving them towards living in a valued direction (Schoendorff et al., 2014).

**Relational Frame Theory (RFT).** RFT follows on from Skinner’s attempts to provide a behavioural account of the development of language. Essentially, human behaviour is influenced by relational frames or verbal networks developed through socially learned associations and the human ability to make inferences from these associations. Relational framing is the process by which sensory experiences are transformed into mental events and become related to one another and also to other inner experiences such as thoughts, feelings and memories in multi-directional networks.

**Derived relational responding.** Constructing relational frames enables humans to learn without direct experience of “things” but also can result in “derived relational responding”. Schoendorff et al. (2014) use the following example in illustration,

For example, a five-senses experience of a charging bear naturally makes people run away. Through derived relational responding, the mere thought of a charging bear can make people run away or engage in other actions meant to move them away from that thought and the fear it elicits. (p21)

Due the nature of these networks, derived relational responding can become the basis for suffering: the use of avoidance strategies paradoxically entails that the strategy itself becomes associated with thing we are trying to avoid (i.e. it is brought into the frame). Attempts to control or modify these associations can have several consequences: reinforcement of the strength of the associations; and narrowing of

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20 Verbal refers to any mental symbol, e.g. images, words (Hayes et al., 1999)
the individual’s repertoire of behaviours consistent with long-term life goals (Bricker & Tollison, 2011). Attempts to control or modify associations are described by Hayes et al. (2012) as two major processes implicated in the overarching concept of “psychological inflexibility” - cognitive fusion and experiential avoidance and are seen as forming the basis for psychopathology.

Whilst derived relational responding can result in a narrowing of an individual’s repertoire, it is conversely viewed as the target for intervention. By increasing an individual’s willingness to experience rather than control or modify these private events, the relational frame is weakened and the individual is more able to focus on behaviours that guide them towards “appetitives” or values (Bricker & Tollison, 2011; Schoendorff et al., 2014).
09 June 2014

Ms Sarah Balla
Trainee Clinical Psychologist
Taunton & Somerset NHS Foundation Trust
University of Exeter
Washington Singer Laboratories
Perry Road
EX4 4Q3

Dear Ms Balla

Study title: An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes.

REC reference: 14/SW/0068
Protocol number: N/A
IRAS project ID: 149732

Thank you for your letter of 12 May 2014, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC at a meeting held on 20th May 2014. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Georgina Castledine.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

A Research Ethics Committee established by the Health Research Authority
as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication tree).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

A Research Ethics Committee established by the Health Research Authority
If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

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</tr>
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<td>Research protocol or project proposal</td>
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<td>03 March 2014</td>
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<td>Response to Request for Further Information</td>
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<td>12 May 2014</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (CI)</td>
<td></td>
<td>03 March 2014</td>
</tr>
</tbody>
</table>

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

A Research Ethics Committee established by the Health Research Authority
After ethical review

Reporting requirements

The attached document ‘After ethical review – guidance for researchers’ gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

| 14/SW/0068 | Please quote this number on all correspondence |

With the Committee’s best wishes for the success of this project.

Yours sincerely

Dr Joan Ramsay
Vice Chair

Email: nrescommittee.southwest-exeter@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

“After ethical review – guidance for researchers” [SL-AR2]

Copy to: Ms Gail Seymour
Mrs Margaret Younger, Poole Hospital NHS Foundation Trust
A Research Ethics Committee established by the Health Research Authority
16 December 2014

Ms Sarah Balla
Trainee Clinical Psychologist
Taunton & Somerset NHS Foundation Trust
University of Exeter
Washington Singer Laboratories
Perry Road
EX4 4QG

Dear Ms Balla

Study title: An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes.
REC reference: 14/SW/0068
Protocol number: N/A
Amendment number: 1
Amendment date: 12 November 2014
IRAS project ID: 149732

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The sub-committee reviewed the following amendment:
1. Recruiting clinic patients with type 2 diabetes with any standard of blood glucose control (as opposed to recruiting participants according to whether they have high average blood glucose or a low average). This will result in 1 PIS and wording will change to reflect this.
2. The inclusion of a question on the interview schedule exploring patients’ perceptions of their blood glucose control (rather than making this a criteria). This will also be reflected in the PIS.

A Research Ethics Committee established by the Health Research Authority
Approved documents

The documents reviewed and approved at the meeting were:

<table>
<thead>
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<th>Document</th>
<th>Version</th>
<th>Date</th>
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<tr>
<td>Covering letter on headed paper</td>
<td></td>
<td>19 November 2014</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants</td>
<td>1.2</td>
<td>12 November 2014</td>
</tr>
<tr>
<td>Notice of Substantial Amendment (non-CTIMP)</td>
<td>1</td>
<td>12 November 2014</td>
</tr>
<tr>
<td>Participant information sheet (PIS)</td>
<td>1.2</td>
<td>12 November 2014</td>
</tr>
<tr>
<td>Research protocol or project proposal</td>
<td>1.3</td>
<td>12 November 2014</td>
</tr>
</tbody>
</table>

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at [http://www.hra.nhs.uk/hra-training/](http://www.hra.nhs.uk/hra-training/)

14/SW/0068: Please quote this number on all correspondence

Yours sincerely

Dr Denise Sheehan
Chair

E-mail: nrescommittee.southwest-exeter@nhs.net

Enclosures:

List of names and professions of members who took part in the review

Copy to:

Mrs Margaret Younger, Poole Hospital NHS Foundation Trust
Ms Gail Seymour

A Research Ethics Committee established by the Health Research Authority
NRES Committee South West - Exeter

Attendance at Sub-Committee of the REC meeting in correspondence

Committee Members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Present</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joan Ramsay</td>
<td>Retired Associate Director of Nursing (Women and Children)</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Dr Denise Sheehan</td>
<td>Consultant Oncologist</td>
<td>Yes</td>
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Also in attendance:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position (or reason for attending)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miss Georgina Castledine</td>
<td>REC Assistant</td>
</tr>
</tbody>
</table>
16 June 2014

Sarah Balla
Poole Hospital NHS Foundation Trust

Dear Sarah

Re: An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes.
REC reference number: 14/SW/0068
Protocol Ref: 1.2

We are pleased to advise that the above named research project has been reviewed against the Research Governance Framework for Health and Social Care (2005 2nd edition) and NHS permission for research has been granted to undertake the proposed project at Poole Hospital NHS Foundation Trust.

Documents reviewed were in accordance with current versions listed in the favourable ethical opinion correspondence received from NRES Committee South West - Exeter dated 09 June 14.

Conditions under which this approval is granted can be found at http://dorsetresearch.org. Please notify the Research and Development Department if there are any changes in the above named study relating to these conditions.

Yours sincerely

[Signature]
Sarah Grasse
Head of Research, Innovation, NICE and Clinical Audit

Cc: Dr Coppini

Please send all correspondence relating to this study to:
Research & Innovation Dept
Poole Hospital NHS Trust
Longfleet Road
Poole, DORSET, BH15 2JB
Appendix B3: University of Exeter, School of Psychology Ethics Committee
Letter of Approval

21/04/2016

Your application for ethical approval (2014/619) has been accepted

apache@exeter.ac.uk on behalf of Ethics Approval System <D.M.Salway@exeter.ac.uk>
Fri 04/07/2014 16:33

To: Balla, Sarah <sb521@exeter.ac.uk>

Ethical Approval system

Your application (2014/619) entitled
An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes has been accepted

Please visit http://www.exeter.ac.uk/staff/ethicalapproval/

Please click on the link above and select the relevant application from the list.
Appendix C: Participant Pack

Appendix C1: Invitation Letter from Consultant on Behalf of the Researcher

Dear [Mr. / Ms. LAST NAME],

I am writing to tell you about a study being conducted by Sarah Balia, Trainee Clinical Psychologist at the University of Exeter. As a care provider, I am involved in treating my patients and promoting participation in research in order to understand and find better ways to treat diabetes and the problems associated with the condition.

My colleague Ms. Sarah Balia, is conducting an interview study at the Poole Hospital diabetes clinic aimed at understanding the experiences of individual psychological adjustment to a diagnosis of type 2 diabetes. I am contacting some of my patients who meet the criteria for the study to let them know about the research, in case they might be interested in learning more.

It is important to know that your decision to participate is entirely voluntary and your decision will have no effect whatsoever on your care in the Poole Hospital Diabetes Centre.

If you are interested in learning more about this study, please review the information pack from Sarah Balia, complete the enclosed form, and post it back to her in the stamped, addressed envelope or alternatively you can leave the form and envelope with the clinic reception. You can also contact the research team by telephone on 01302 724635 and/or by email on s0621@exeter.ac.uk.

You do not have to respond to this letter if you are not interested in this study and if you do not respond, no one will contact you, but you may receive another letter in the post which you can simply disregard.

Thank you for your kind consideration.

Yours sincerely,

Dr. David Coppini MD FRCP
Consultant Diabetologist
Appendix C2: Participant Information Sheet

Participant Information Sheet

My name is Sarah Balla, I am a trainee clinical psychologist at the University of Exeter and I would like to invite you to take part in the following research study:

An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes

Before you decide to take part it is important for you to understand why this research is being done and what it will involve;

- Please take some time to read the following information carefully and discuss it with others if you wish.
- Please ask if there is anything that is not clear or if you would like more information.
- Take time to decide whether or not you wish to take part.

Thank you for taking the time to read this information sheet and for your consideration of whether to take part in this study.

Aim of This Study

This is an interview-based research study with the purpose of gaining more understanding about the experiences of people with a diagnosis of type 2 diabetes and managing lifestyle changes. Most research in this area focuses on methods using questionnaires. However, it is also important that people’s individual lived experiences are considered; for example it can help professionals to understand some of the barriers people with type 2 diabetes might face when adjusting to a diagnosis.

There are different psychological explanations for how people cope with long-term health conditions. Acceptance and Commitment Therapy (ACT) is an evidence-based psychological therapy used to understand and help with emotional distress; including distress experienced in association with adjusting to long-term health conditions. “Psychological flexibility” is at the heart of this psychological model and
describes a practical skill of moving towards a valued way of living, in spite of a natural human tendency to avoid painful thoughts and feelings. I am interested in whether the concept of “psychological flexibility” is relevant to the way people with a diagnosis of type 2 diabetes describe their experiences of adjusting to the condition.

A second aim of the study is to explore the differences in people’s experiences of adjustment in relation to their perceptions of how well they manage their blood glucose (for example whether they perceive that they have good control of their blood glucose levels or difficulties in its management).

**Why Have I Been Chosen?**
As an individual with a diagnosis of type 2 your experiences are important to me in order to gain more of an understanding of the difficulties people face with emotions and routines when they are diagnosed with a long-term health condition.

I aim to recruit 16 people into the study and to meet this target I will be inviting approximately 45 people to participate.

**What Will I Need to Do?**
You will be asked to engage in an interview about experiences of managing diabetes: this interview will be audio-taped at a confidential setting within the diabetes centre in Poole Hospital or in your home if you are unable to travel to the centre.

The interview process will take approximately 1hr 30 minutes: the interview itself will take approximately 45-60 minutes and will involve me asking you about your experiences of adjusting to your diagnosis and your perceptions of your blood glucose management.

Additional time will be required for you to sign the consent form and to ask any questions you may have about the research. At the end of the interview, I will ask for your feedback and this may be used to improve the interview experience for future participants.

Parking or travel expenses will be reimbursed to the value of £3.00.

Participant Information Sheet V1.2 - Date: 12.11.2014
Do I have to take part?
You do not have to take part in this study if you do not wish to do so.

Your routine care will not be adversely affected should you decide not to participate; neither will you receive any benefits to your care in return for taking part.

You can state at any time during the study that you wish to withdraw your participation and you will not be required to give a reason (your routine care will not be affected). This includes stopping the interview at any point or choosing to refuse to answer any of the interview questions.

How could my participation help?
Participation in this study could help inform the treatment approaches psychologists use with individuals with type 2 diabetes and who are experiencing difficulty. It may also give healthcare professionals a valuable insight into the lived experience of individuals with the diagnosis and an understanding of barriers to managing the condition.

What Could Go Wrong?
The main risk associated with the interviews is possible discomfort when answering some of the personal questions. Due to the nature of the difficulties that can arise as a result of type 2 diabetes, some of the experiences we may discuss could be upsetting. You are encouraged to participate only if you feel comfortable with discussing these experiences.

If you wish, a letter can be written to your GP informing them of your participation in this study.

If after the interview, you find that you are experiencing distress there are several ways you can access some support.

- Contact the Poole Hospital diabetes centre on 01202 448063 and inform the clinic that you have taken part in this study and as a result are experiencing distress which requires some support. Your details will be given to the team's healthcare professionals and you will be contacted at the earliest opportunity in order for you to discuss your needs.

- Alternatively you can contact your General Practitioner who will be able to refer you to local sources of psychological support.
- If you feel that the interview has raised some issues requiring non-clinical self-care support, "My Health My Way" is a free web-based coaching service for people living in Dorset whose daily lives are affected by a health condition. The site can be accessed at http://www.myhealthdorset.org.uk

No other risks are known to the investigator at this time, however if you have any concerns as a result of taking part in this study you are encouraged to contact the primary research supervisor Dr. Phil Yates (consultant clinical psychologist) on 01392 724635, in the first instance.

The University of Exeter adheres to a strict code of ethics when conducting research, if you would like to make a formal complaint about any aspect of this research study please contact Dr C. Burgess, The Chair of the Ethics Committee, School of Psychology, University of Exeter (Tel. 01392 724627).

What will happen next?

You will be asked to sign a consent form stating that you have understood the information given to you about the study and that you have the right to withdraw at any time. The contact details for the researcher are on the form, should you have any questions or concerns about participation. When the interview is complete you will have the opportunity to discuss your experience of the interview with the researcher.

After the interview, the audio tapes will be transcribed and the researcher will look at the manuscripts and try to identify themes in your described experiences. The research supervisor may also look at the anonymised transcripts in order to check the analysis.

What Will You Do With My Information?
The information you give which is recorded will be kept strictly confidential, except as may be required by the law or professional guidelines for psychologists.

- All information will be identified by an alias, not your name.

- Any form that requires your name (e.g., the consent form) will be stored separately from other material. I will not have any access to your medical records.

- All information will be kept either within a paper file in a locked filing cabinet or on a password protected electronic database on a secure computer.

Participant Information Sheet V1.2 - Date: 12.11.2014
• Audio files will be used solely for the purposes above in accordance with the ethical standards of confidentiality that govern psychologists. The digital files will be deleted once typed transcripts have been made although you retain the right to request they be deleted at any point in the study.

• In accordance with the University of Exeter Open Research Exeter policy, the anonymised transcript data will be given a code, securely stored and might be made available to other researchers if deemed appropriate by the research supervisor. The data will be stored for up to 10 years from the last point a request is made to have access the data.

• Your name or other identifying information will never be associated with any research reports or publications that use the results from this study: this includes any direct quotes that are used from your interview.

• You will receive a copy of the information sheet and signed consent form for you to keep.

I've Changed My Mind......
Your participation in this study is voluntary, and you may discontinue at any time, without it affecting your care. If you decide that you no longer wish to participate after giving consent, then you can request that your interview data be withheld from the study.

I have more questions before I take part........
If you have any further queries about this study, please ask any questions before you sign the consent form. You can contact me before the interview on sb521@exeter.ac.uk or 07903334513.

What Will Happen to the Findings of the Study?
This piece of research will be submitted as part of a clinical psychology professional qualification as a thesis and in accordance with University of Exeter Open Research Exeter policy, it will be made available online on the Exeter University Open Access database (ORE). I also aim to publish the work in an academic journal and will make an information leaflet with the study findings available to anyone taking part. If you would like to receive a leaflet please complete the request form included with this information sheet. Your name and details will not be used in any publication.
This is study is not funded and is sponsored by the University of Exeter as part of a professional training programme, as such the researcher is not receiving payment to conduct the study. It has been reviewed by an independent group (a Research Ethics Committee) to protect your rights and safeguard your wellbeing. The study has been reviewed and given a favourable opinion by the NRES Committee South West – Exeter.

Contact for further information

If you would like some general advice about participating in research you can contact Consumers for Ethics in Research (CERES) - an organization that offers information and advice on research in the NHS.

CERES, PO Box 1365, London, N16 0BW

Email: info@ceres.org.uk

Visit: http://www.ceres.org.uk/about.htm
Appendix C3: Study Opt-In Form

Study Opt-In Form for Participants

Project Title: An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes

Study Reference No: 14/SW/0068

Name of Researcher: Sarah Balla, Trainee Clinical Psychologist

I am interested in taking part in the above study and agree for the researcher, Sarah Balla, to contact me in order to discuss the matter further. My contact details are:

Name: ..............................................................................................................................

Telephone Number: ........................................................................................................

Email: ..............................................................................................................................

I prefer to be contacted by (please circle preferred method): telephone email

Study Opt-In Form – Version 1.0 – Date: 03.03.2014
Help with research

Sarah Balla is also seeking participants with type 2 diabetes for her research study looking at ‘the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes’. As a participant in this study, you would be asked to take part in a 1.5 hour long interview (either face-to-face at your home or via telephone) about your experiences of adjusting to your diagnosis and your perceptions of your blood glucose management. Participants will receive a £5 book token in return for their time. To volunteer or for more information on the study please contact Sarah / 07762506628
Appendix C5: Recruitment Poster

Department of Psychology

PARTICIPANTS AGED 18+ NEEDED FOR RESEARCH INTO THE EXPERIENCES OF ADJUSTING TO A DIAGNOSIS OF TYPE 2 DIABETES

I am looking for volunteers with a diagnosis of Type 2 Diabetes, to take part in the following study:

An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes

This is an interview-based research study with the purpose of gaining more understanding about the experiences of people with a diagnosis of type 2 diabetes and managing lifestyle changes. Most research in this area focuses on methods using questionnaires. However, it is also important that people’s individual lived experiences are considered.

As a participant in this study, you would be asked to take part in a tape-recorded interview (either face-to-face at your home or via telephone). This will involve me asking you about your experiences of adjusting to your diagnosis and your perceptions of your blood glucose management.

Your participation would involve one appointment lasting approximately 1.5 hours.

In appreciation for your time, you will receive a book token to the value of £5.00

For more information about this study, or to volunteer please contact:

Sarah Balla
Trainee Clinical Psychologist, University of Exeter

Tel: 07762606628
Email: sb521@exeter.ac.uk

This study has been reviewed by, and received ethics clearance through the University of Exeter, Psychology Research Ethics Committee.
Appendix C6: Informed Consent Form

Participant Consent Form

I give my informed consent to participate in the study: An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes

Please initial as appropriate:

<table>
<thead>
<tr>
<th>I confirm that I have read and understood the information sheet for the above study.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand that relevant sections of my medical notes and data collected during the study may be shared with regulatory authorities or from the 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.</td>
</tr>
<tr>
<td>I understand that my personal details will be kept secure and no identifiable details will be used as part of the research results.</td>
</tr>
<tr>
<td>I understand that if I choose to take part in the interview, that this interview will be recorded and the recordings erased immediately after transcription of the interviews (unless I choose them to be destroyed at an earlier time).</td>
</tr>
<tr>
<td>I give my consent for the use of anonymised, verbatim quotations.</td>
</tr>
<tr>
<td>I understand that my participation is voluntary and that I am free to withdraw at anytime and without giving any reason.</td>
</tr>
<tr>
<td>I agree to take part in the study</td>
</tr>
<tr>
<td>I would like the researcher to inform my General Practitioner that I am taking part in this study.</td>
</tr>
</tbody>
</table>

Participant Consent Form – Version 1.1 – Date: 08.06.2014
Participant Name: 

Date: 

Signature: 

Reseacher Name: Sarah Balla

Date: 

Signature 

Questions or concerns about the study can be addressed to:

Dr C. Burgess, The Chair of the Ethics Committee, School of Psychology, University of Exeter (Tel. 01392 724627)
Dear [Insert General Practitioner name],

Patient name: [Insert patient’s name]
Patient DOB: [Insert patient’s date of birth]

I am writing to tell you that the above patient at your surgery has agreed to participate in the following study and requested that I inform you.

Title of Project: An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes

Name of Investigator: Ms. Sarah Balla (Trainee Clinical Psychologist)

Study Site: Poole Hospital Diabetes Centre

This is a qualitative interview-based study with the purpose of gaining more understanding about the experiences of people with a diagnosis of type 2 diabetes and managing lifestyle changes. A secondary aim of the study is to explore the differences in people’s experiences of adjustment when they have either good control of their blood glucose levels or difficulties in its management.

There are different psychological explanations for how people cope with long-term health conditions and much research focuses on methods using outcome measures. It is also important that people’s individual lived experiences are considered, for example it can help professionals to understand the some of the barriers people with type 2 diabetes might face when adjusting to a diagnosis. The research questions are based upon the framework of the psychological model used in Acceptance and Commitment Therapy, a therapeutic approach used in a variety of long-term health conditions including chronic pain and diabetes.

The research forms part of the training for the doctoral programme in clinical psychology at the University of Exeter and as such is sponsored by the university.

Your patient will attend a semi-structured interview lasting approximately one hour, during which time they will be asked a series of open-ended questions about their experiences.

GP Information Letter – Version 1.0 – Date: 03.03.2014
Your patient has given consent for us to inform you of their participation. I enclose a copy of the patient information sheet for your information. For more information about this research project or advice: contact the main researcher (Sarah Balla, sb521@exeter.ac.uk) or the academic supervisor (Dr. Phil Yates, Clinical Psychologist, 01392 724635).

Yours sincerely,

Sarah Balla  
Trainee Clinical Psychologist  
University of Exeter
Study Debrief Sheet

Thank you for taking part in the study:

"An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes"

Your participation in this research is much appreciated. If you have experienced distress as a result of taking part in this study, there are several ways you can access some support.

- Contact the Poole Hospital diabetes centre on 01202 448063 and inform the clinic that you have taken part in this study and as a result are experiencing distress which requires some support. Your details will be given to the team’s healthcare professionals and you will be contacted at the earliest opportunity in order for you to discuss your needs.

- Alternatively you can contact your General Practitioner who will be able to refer you to local sources of psychological support.

If you feel that the interview has raised some issues requiring non-clinical self-care support, “My Health My Way” is a free web-based coaching service for people living in Dorset whose daily lives are affected by a health condition. The site can be accessed at http://www.myhealthdorset.org.uk

If you would like to make a complaint about any aspect of this study, please contact the primary research supervisor Dr. Phil Yates at the University of Exeter on 01392 724635.

Study Debrief Sheet – Version 1.0 – Date: 03.03.2014
Appendix C9: Results Request Form

Request Form for Study Findings Leaflet

Project Title: An Exploratory Study of the Experiences of Adjustment and Psychological Flexibility in Patients with Type 2 Diabetes

Name of Researcher: Sarah Balla, Trainee Clinical Psychologist

I would like a leaflet describing the findings of the above study and would prefer this to be sent to my email/home address (please circle preferred method and give details as appropriate).

My contact details are:

Name: ........................................................................................................................................

Email: ........................................................................................................................................

Address: ........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
Appendix D: Extension to the Method

Appendix D1: Participant interview schedule

1. How long have you had a diagnosis of type 2 diabetes?

2. Could you tell me how it was for you when you were given the diagnosis?  
   Prompts: How did things change for you?  
   What have you had to do differently?  
   How did you feel about it?

3. What kinds of thoughts about managing your diabetes do you experience most often?  
   i. How does this impact on your life?  
      Prompt: What do you find yourself doing/not doing?

4. Healthcare professionals often talk about diabetes management in terms of blood glucose control, how well do you feel that you manage this aspect of your diabetes?

5. What kind of advice have you received about managing your diabetes?  
   i. What helps/get in the way of following advice?  
      Prompt: Thoughts, feelings, behaviours, situations

6. How much time do you spend time thinking about managing your diabetes?  
   i. Can you tell me a little more about this?

7. What is important to you in life since you got a diagnosis?  
   Prompt: Values/what you want to stand for/want life to be about  
   i. Can you tell me about how this has changed?

8. How do you remember yourself before you were diagnosed with diabetes?  
   Prompt: Were you any different to how you are now?  
   i. How do you see yourself now?

9. What kind of activities do you do (or not do) that as a diabetic you are aware might not be helpful (or helpful) in the future?  
   Prompt: Ways of thinking, actions etc.

10. Does anything help with difficult feelings about diabetes?  
    Prompt: Ways of thinking/activities/behaviours/people
Appendix D2: Extended Summary of Participant Demographic Information

Table D2

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<th>Pseudonym</th>
<th>Gender</th>
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<th>Occupation</th>
<th>Ethnicity</th>
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<th>Blood Glucose Control²</th>
<th>Treatment</th>
<th>Complications</th>
<th>Co-morbid health conditions</th>
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<td>Depression</td>
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<td>23</td>
<td>Poor</td>
<td>Insulin</td>
<td>Neuropathy</td>
<td>Renal</td>
</tr>
<tr>
<td>Frank</td>
<td>Male</td>
<td>50s</td>
<td>Retired</td>
<td>White, British</td>
<td>15</td>
<td>Good</td>
<td>Insulin</td>
<td>Erectile Dysfunction</td>
<td>Renal</td>
</tr>
<tr>
<td>Jack</td>
<td>Male</td>
<td>80s</td>
<td>Retired</td>
<td>White, British</td>
<td>2</td>
<td>Good</td>
<td>Insulin</td>
<td>Neuropathy</td>
<td>Cancer</td>
</tr>
<tr>
<td>Josephine</td>
<td>Female</td>
<td>60s</td>
<td>Retired</td>
<td>White, British</td>
<td>14</td>
<td>Good</td>
<td>Medication/diet</td>
<td>Muscular-Skeletal Cancer</td>
<td></td>
</tr>
<tr>
<td>Norma</td>
<td>Female</td>
<td>70s</td>
<td>Employed</td>
<td>White, British</td>
<td>12</td>
<td>Good</td>
<td>Insulin</td>
<td>Renal</td>
<td>ME</td>
</tr>
<tr>
<td>Paula</td>
<td>Female</td>
<td>40s</td>
<td>Employed</td>
<td>White, British</td>
<td>7</td>
<td>Good</td>
<td>Medication/diet</td>
<td>Renal failure</td>
<td>Muscular-Skeletal</td>
</tr>
<tr>
<td>Robert</td>
<td>Male</td>
<td>60s</td>
<td>Employed</td>
<td>White, British</td>
<td>14</td>
<td>Poor</td>
<td>Insulin</td>
<td>Erectile Dysfunction</td>
<td>Cardiovascular</td>
</tr>
</tbody>
</table>

¹ Mean duration of diagnosis = 14.6 years
² Participants' self-described control
Appendix D3: Reflective Statement and Excerpts from Reflective Diary

I’m a white, British female clinical psychology trainee, living in a multicultural area of a relatively ethnically homogenous town. I came to training later in my working life and have had varied life experiences up until this point, including living in another European country. During my life I have had close personal relationships with several people diagnosed with diabetes. I have witnessed their struggle with accepting the diagnosis, their successes and failures in maintaining control. I have also witnessed some of the distressing complications which could have been prevented. I have received several sessions on the ACT model of psychotherapy during my clinical training and have used the approach with at least one client per placement. I prefer an integrated approach to working therapeutically and am also interested in schema therapy and systemic approaches. I am a novice in the IPA method although I have conducted a thematic analysis for a previous academic assignment.
Excerpts from Reflective Diary

September 2013

I’ve received an email from the T2DM support group that I contacted regarding a meeting to investigate views and opinions on my research topic. Unfortunately they have declined to participate, this is the second group that I have approached that have declined. This surprises me due to the increased media interest in T2DM at present.

November 2014

I’m having difficulties recruiting from the clinic. I’m finding this challenging as at the moment I feel that my professional qualification depends on me completing the interviews. I’m beginning to understand the challenges of recruiting from within the NHS and having to rely on others for recruitment. I’m considering recruiting through the university as per my contingency planning. I feel frustrated with this as I’d really hope I could gain an entirely clinical sample. I think this is located in the dominant discourses of what constitutes excellent research which has connected with my personal drive for high standards.

December 2014

I’ve just finished my first interview and although I feel it went fairly well, I found it quite difficult for several reasons. Firstly I found it hard to maintain the position of researcher as opposed to therapist as I might normally find myself in when engaging in sessions of similar length in a clinical setting. However, I found that my clinical skills were helpful when the participant became distressed towards the end of the interview. I also found it hard when the participant talked about multiple miscarriages. I’m a few weeks from having my twelve-week scan and found this upsetting due to the uncertainty of early pregnancy.

January 2015

The participant I interviewed today was very nervous due to the clinical setting (this transpired during the course of the interview). I hadn’t really considered this as a potential area of difficulty for participants and will ensure in the future when making appointments that I remind participants that they have the choice of me visiting them at home.
February 2015

I completed my final interview today, it feels like it has been a long journey to reach this point but I have a sense of relief at managing to recruit enough participants. I’m experiencing a combination of excitement and dread at the analytic process ahead of me. I’m excited to go through the interviews and begin the initial commentary and see what emerges from the data, this is also a source of dread as I have been avoiding thinking about the size of the task that lies ahead.

March 2016

Reading some of the interviews, I’m struck by how much my style changed over the course of the interviewing period. At first I sound very hesitant, unsure and faltering, however during later interviews I seem much more able to ask questions that draw more from the interviewees (for example I initially asked some closed questions, or didn’t follow up interesting points). I wonder how this impacts on my data, and I’m very much aware of my impact on the research process.

January 2016

I’ve been surprised and pleased at how interesting I find my research on returning to it after maternity leave. It’s challenging familiarising myself with the theory, data and method but I feel very fortunate that it’s a really interesting subject to me. I’m also taken aback at how honest and generous the participants were with their disclosures.

I’ve used the word regime in association with medication, this feels suggestive of the power of diabetes (regimentation, regiment, soldiering, totalitarian states, fascim). So how does this relate to ACT, a very individualistic approach to therapy when the individual may feel very powerless with such a diagnosis. What might be the role of functional contextualism? How does the function of power operate in different contexts?

February 2016

As I am working through the emerging themes, I feel as though I am trying to make Brian's experiences fit within the ACT model. There is a sense that his experiences could be reduced infinitum to these processes. I also find myself procrastinating and moving about the house, making drinks etc. I’m feeling overwhelmed by the data and that the emerging themes could fit into multiple areas of the model. The sense that I don't know enough about ACT is enhanced.
March 2016

I’m rereading Robert's transcripts before finalising the theme tables and I'm struck by the sadness and fear within the script, I feel afraid for Robert and wonder if he's OK. Once again I'm moved to tears by these individuals’ experiences and feel privileged that they have shared their thoughts with me. I want to do my best to do justice to this. Perhaps that is why I am feeling overwhelmed. On another level, perhaps I am responding to the hopelessness in this particular narrative, how can I help Robert? What could psychology do? It can't fix his kidneys........
## Appendix E: Extension to the Analysis

### Appendix E1: Example of Transcript Coding

<table>
<thead>
<tr>
<th>Emergent Themes</th>
<th>Transcript</th>
<th>Exploratory Comments (Descriptive/Linguistic/Conceptual)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shock</td>
<td>R: The thing that really brought me to a stop was [Professor] at the [Hospital], who had done the second cancer surgery. And he came in the morning after the surgery and looked at me. I was not in a very good condition [laughter] and we had a long chat. And one of the things he said to me - I'll never forget it - he said, “You know you'll recover from this. You've got cancer, and you think it's the worse thing in the world and you feel dreadful now, but I can tell you that the diabetes you've got will kill you, this cancer won’t.”</td>
<td>Shock?</td>
</tr>
<tr>
<td>Cancer : distressing</td>
<td></td>
<td>Physical or mental condition? Both? She was distressed?</td>
</tr>
<tr>
<td>Cancer worse than diabetes</td>
<td></td>
<td>I'll never forget it – key moment in her narrative</td>
</tr>
<tr>
<td>Diabetes as a killer</td>
<td></td>
<td>She thought the cancer was the worst thing the world</td>
</tr>
<tr>
<td>Fear of dying</td>
<td></td>
<td>Certainty in medic that diabetes rather than cancer will kill her – diabetes viewed as hopeless cause?</td>
</tr>
<tr>
<td>I: Wow. What was it like hearing that?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

150
| Shocked into paying attention | R: Well, that was a big shock, really. And that's really what made me pay a lot more attention to... And after that, I was more careful with diet, because I understood what he was saying, really. | Shock experienced at this point of the narrative – cancer curable but diabetes not?  
Starting to pay attention because of the realisation diabetes could kill her? |
|---|---|---|
| I: What was it you understood from what he said? | Dawn can't hide the truth from the Dr – BG as revealing the truth about behaviour? Self-deception limited  
Responsibility for monitoring in the hands of the medic – does this say something about privileged knowledge and power?  
The Dr knows a truth about Dawn that she is unaware of or in denial of? |
| Denial  
Medics: responsibility for testing  
Diabetes blamed for cancer?  
Blood sugars reflect an objective truth  
Cancer = fear | R: Well, that if I ignored the diabetes... because he knew that I was... he was measuring blood sugars. I saw him quite often... This vile condition that leads to cancer meant I saw him every six weeks for maybe 10 years, and he measured blood sugar. So he knew the way I felt about the cancer and the way I felt about the diabetes [laughter]. So I think he just wanted me to... a) he wanted me to be less frightened about the cancer, and b) he wanted me to focus on the thing that probably would make more of a difference to my overall health long-term. | Vile condition – does she mean the diabetes or something else  
Long relationship with Dr  
Fear at cancer  
Dr wanted best for her? Care? |
I come from a family with weight problems, so because of the research that I did, I found out about opportunities that I don't sit down and eat complete chocolate cakes, you know like you see those people on Working at the university you are classed as disabled if you have diabetes, so you get a Open about diabetic status They really don't have the time to give to you that you actually need to be able That little bit of information can make such a huge difference to people's lives, he was measuring blood sugars. I saw him quite often… Well, they say to you it's kind of inevitable that that's what will happen. You can put water in your wine and just, you know, enjoy the evening anyway but not we are much better looked after now.

Superordinate theme | Sub-themes | Emerging Themes | Quotes
--- | --- | --- | ---
Empowering the individual from patient role and engenders a sense of hope | Hopefulness or hopelessness | Hope for a cure | Now you want to live, next time I can take you into the university and have your DNA analysed and that will tell you exactly what you need to do to deal with x, y, and z. I would do it like a shot. There's always hope that there's a cure around the corner.

Knowledge liberates the individual from patient role and engenders a sense of hope | Hopelessness in services | Why, they say to you it's kind of inevitable that that's what will happen.

The power of knowledge | Knowledge - self-efficacy | Taking active role | So because of the research that I did, I found out about opportunities that were there and I took those opportunities.

Taking responsibility impacts on outcome | Knowledge + empowerment | Taking an active role | So if you want to live, next time I can take you into the university and have your DNA analysed and that will tell you exactly what you need to do to deal with x, y, and z. I would do it like a shot.

Hope for a cure | Knowledge + empowerment | They really don't have the time to give to you that you actually need to be able to get better and help yourself.

Access to the right information | Knowledge + empowerment | Hopelessness - illness course | I was just something very small that she picked up on that made a dramatic difference to me in diabetes terms. They don't have any understanding of how to research information, they don't have access to any of the academic paper areas, which you do as an academic.

Superordinate theme | Sub-themes | Emerging Themes | Quotes
--- | --- | --- | ---
External vs internal focus of blame | Externalising blame | Externalising blame | So I had been diagnosed for 23 years. I had high glucose for 23 years. And along with high blood sugars go… I had retinopathy, feeling lousy sometimes. And if someone had come to the blood test that she did, they could have discovered the 25 years earlier, because this type of diabetes has been known for many, many years. So I thought, well, I've had 23 years of high blood sugars for no reason, and that rather upset me.

Self-blame | Blame - genes | Blame - genes | Some people came from a family with weight problems (laughs).

Self-blame for onset | Self-blame for onset | Self-blame for onset | Some people came from a family with weight problems (laughs). But I had a lot of anxiety.

Self-blame, regret | Self-blame - regret | Self-blame - regret | I felt a lot of anxiety at the research about diabetes at ages, if it had happened to do it then.

Managing the sense of difference to others | Feelings of difference | Feelings of difference | I can't go out sailing or walking or play tennis with them anymore, there isn't a huge risk, actually.

Different sub-types of diabetes | Different sub-types of diabetes | Different sub-types of diabetes | You can't do that to your wife and put her in the hospital because she's in a bit more of a risk… You can't phone your doctor and say, "Oh, I've got this, you know," and they don't think to tell you about it in the hospitals.

Different sub-type of diabetes | Different sub-type of diabetes | Different sub-type of diabetes | They looked at you, I suppose, in a bit more of a risk… there's a bit more of a risk there and they don't think to tell you about it in the hospitals.

Identified as a risk | Identified as a risk | Identified as a risk | There's always hope that there's a cure around the corner.

Externalising blame | Externalising blame | Externalising blame | So I had been diagnosed for 23 years. It high glucose for 23 years. And along with high blood sugars go… I had retinopathy, feeling lousy sometimes. And if someone had come to the blood test that she did, they could have discovered the 25 years earlier, because this type of diabetes has been known for many, many years. So I thought, well, I've had 23 years of high blood sugars for no reason, and that rather upset me.

Self-blame | Self-blame - genes | Self-blame - genes | Some people came from a family with weight problems (laughs).

Self-blame for onset | Self-blame for onset | Self-blame for onset | Some people came from a family with weight problems (laughs). But I had a lot of anxiety.

Self-blame, regret | Self-blame - regret | Self-blame - regret | I felt a lot of anxiety at the research about diabetes at ages, if it had happened to do it then.
So I thought, well, I've had 23 years of high blood sugars for no reason, evenings I didn't teach I tended to go out to theatre and to concerts. I can tell you that the diabetes you've got will kill you, this cancer won't.

I have, in the back of my mind, always thought what I intended to do when I came to retire. So my working life I decided that if I had diabetes it was stupid wandering about Africa. Well, because it's not worth is, is it? You have to get some enjoyment out of life. So if curing diabetes kills you, you have to do something else. That's really not worth the risk.

Because I was building the personal computer, which didn't exist when I started doing all that computer engineering. I mean, that was pretty much my life, so it was hard to give up. So it forced me to make a decision that I probably would have had to make any way.

And for the first couple of years I expected every time I went to have the blood sugar check done. It didn't go down. It went up. And you can imagine changing time zones and things like that. I just thought I need to have the blood sugars checked every time I flew. It was a once in a while I was working there. And the girl running the lab came out and was killed by these two guys.

And the guy who was my boss was killed by a car. So I was quite looking forward to a different way… while I was working there.

So there were compensations for my personal life. So I was following a fairly normal path way.

I thought it was a bit shocked when they first diagnosed. I mean, that was pretty much my life. It was fast food.

I mean, that was pretty much my life. It was fast food. So I didn't think much about the food that [Restaurant] has. I didn't go out w ith the wrong time. And you'd think about the food that [Restaurant] has.

I mean, that was pretty much my life. It was fast food. So I didn't think much about what I was eating. I mean, I'd have to change my life again. I would have had to leave that job, actually. There were a couple of sessions on diet, which is stuff I knew any way, and ignored.

And the girl running the lab came out and was killed by these two guys.

No, I wasn't much younger than I would have been forced to make that change. That's really not worth the risk.

So it forced me to make a decision that I probably would have had to make any way. Because I was building the personal computer, which didn't exist when I started doing all that computer engineering. I mean, that was pretty much my life.

And I wasn't much younger than I would have been forced to make that change. That's really not worth the risk.

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My working life I decided that if I had diabetes it was stupid wandering about Africa. Well, because it's not worth it. You have to get some enjoyment out of life. So if curing diabetes means that you don't enjoy life, then you have to do something else. That's really not worth the risk.

So I wasn't much younger than I would have been forced to make that change. That's really not worth the risk.

So it forced me to make a decision that I probably would have had to make any way. Because I was building the personal computer, which didn't exist when I started doing all that computer engineering. I mean, that was pretty much my life. It was fast food.

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And the girl running the lab came out and was killed by these two guys.

And the girl running the lab came out and was killed by these two guys.
Appendix E3: IPA Analysis - List of Superordinate Themes for Each Participant

Andrew
"We" not "I"
The struggle for "6"
Counterbalancing passive acceptance with asserting freewill
Coping with diabetes-related sexual dysfunction

Brian
Living for today: Fear and hope for the future
"It has not been in anyway a death sentence for me": vitality in the face of death
Process of developing awareness (BG level)
Managing self-concept in the face of negative diabetic stereotypes
"I'm aware of it and allow it to dictate some of my lifestyle."
Negotiating a balance between submission and resistance

Dawn
Coping with cancer in with diabetes in the background
External vs internal focus of blame
Knowledge liberates the individual from a patient role and engenders a sense of hope
Coping with the threat posed by diabetes using avoidance and denial
"I mean, that was pretty much my life. It was fast food": balancing self-fulfilment with self-sacrifice
Managing the sense of difference to others

Esther
Going to extremes to manage the fear of losing control: "a case of "just-in-case""
I fight long and hard to try and not to be like my mum.
"People automatically think….she's a junkie": coping with stigma
The self within the patient-provider power dynamic

**Frank**

Diabetes just another illness to cope with
Coping with negative stereotypes
Attachment to the patient role: patient and professionals
Male coping (rename)
Overcoming resistance to insulin

**Jack**

Coping with diabetes in older-adulthood
Cancer is the real problem

**Norma**

The fight for control
Problem-solving and avoidance as coping strategies following diagnosis
Changing the relationship with diabetes
I'm not like them

**Paula**

Diabetes threatens self- and social identity
Projecting shame for eating myself into diabetes onto others, but not always.
Connecting with an embodied sense of satiety
If I don’t have the emotion then I can’t see the point: The importance of monitoring for self-care
Conflict between work-role fulfilment and health
Self-empowerment in a climate of paternalistic care

**Robert**

“You don't feel like you are a man anymore”: the experience of sexual dysfunction
Sweet tooth: a powerful aspect of self, resistant to internal control

Coping as a couple

Destroyed from within: coping with the prospect of dialysis

The good boy and the old devil: the cycle of compliance and non-adherence

Anna

The impact of depression

Feeling supported by the healthcare system

Dangers of taking the diagnosis seriously and strategies for minimizing impact

Identifying with the rebel within

Josephine

Coping with prevalent negative social attitudes towards diabetes by distancing self from stereotypes and educating others

Impact of ageing on motivation and physical capacity for self-care

"It is a bit go-it-alone": Coping alone in the context of high-expectations of others
Appendix E4: IPA - Clustered Superordinate Themes and Master Themes for All Interviews

1. "Eating myself into diabetes"; managing the self in relation to perceived diabetes stigma

1.1 An unacceptable aspect of self

- Self-blame
- Judgements of others
- Shame
- Blame: self and others
- Difficult Emotions
- Stigmatizing social attitudes
- Negative stereotypes of diabetics
- Stigma
- Pervasive diabetic stereotypes
- Illness and slowing down are the natural order
- Diabetes more socially acceptable than depression

1.2 Difference to others emphasised

- Punished for having diabetes
- Feelings of difference
- Feeling isolated and misunderstood
- Made to feel different

1.3 Distancing the self from the diagnosis: bringing the self closer to normality.

- Conflicting needs
- Distancing self from a diabetic stereotype
- Distancing self from diabetic stereotype
- Distancing self from diabetic stereotypes
- Self-comparison to stereotype
- Distancing self from the diabetic stereotype
- Hiding diabetes in public

1.4 Confronting the stereotype: bringing others closer to the self.

- Coping with difficult emotions by confronting and avoiding negative reactions
- Educating others

2. My Other Illness is the Real Problem; diabetes minimised in the context of co-morbid diagnoses

2.1 “That's got nothing to do with diabetes”: Comparison of illness impact.

- "That's not the diabetes": Impact of chronic pain on quality of life
- Diabetes is nothing compared to ME.
- Cancer worse than diabetes
- Cancer experienced as more distressing
- Diabetes: one more illness
- Cognitive comparison of illness
Differing levels of psychological distress
Diabetes meaningless in context of depression

2.2 Impact on coping

2.2a Previous coping impacts positively on current
- Using previous coping strategies for diabetes
- Learning to cope with illness at an early age impacts on current coping
- I'm more aware of my own health
- Exercising for depression impacts on diabetes
- Impact of diabetes acceptance and denial on cancer recovery

2.2b Other illness depletes resources for diabetes self-care
- Impact on ability to exercise
- Cancer impact on ability to exercise
- Other health needs more immediate
- Impact on ability to exercise
- Physical ability for self-care
- Mental state affects diabetes self-care
- Nothing left for diabetes

3. Knowledge Reduces Attachment to the Patient-Role Self-Story

3.1 Attachment to “patient” as self-description.
- Power and expectations of others creates anxiety
- Paternalistic care
- The importance of the relationship with the GP
- Infantilised by services
- Power of professionals to shock
- Reduced to biology
- Distressed and disempowered by paternalistic approach
- Power of medics
- Not empowered to take control
- Always a patient
- Expected independence
- Powerlessness of the patient
- Risk poses a threat to being understood
- Paternalistic care perpetuates the patient role

3.2 Defusing from self-as-patient through developing self-knowledge
- Knowledge empowers to take responsibility for health
- Empowered by knowledge and understanding
- The power of knowledge
- Developing causal explanations
- Process of developing awareness (BG level)
- Developing an understanding of cause and effect
- Developing an understanding
Appendix F: Dissemination

Appendix F1: Dissemination Statement

The results of this study will be disseminated to interested parties through feedback, journal publication and presentation.

**Dissemination to participants and NHS services.**

The participant study packs included a “results request” form; all participants who completed this form will receive a leaflet detailing the findings using their chosen method of communication (email or post).

The staff at the Poole Hospital Diabetes Clinic will be sent a summary of the study findings and informed that the study is now complete. They will be offered the opportunity to attend a short presentation of the findings.

The National Research Ethics Service (Southwest Region) and Poole Hospital Foundation Trust Research and Development department will be sent a summary of the findings and informed that the study is now complete.

**Journal Publication**

It is expected that the study will be submitted for publication with the British Journal of Health Psychology (Impact Factor 2.776).

**Presentation**

On 13th June 2014, my research findings were presented for peer review as part of the University of Exeter, Doctorate in Clinical Psychology.
Appendix F2: Publication Guidelines for the British Journal of Health Psychology

**British Journal of Health Psychology**

© The British Psychological Society

Edited By: Alison Wearden and David French

Impact Factor: 2.776

ISI Journal Citation Reports © Ranking: 2014: 24/119 (Psychology Clinical)

Online ISSN: 2044-8287

**Author Guidelines**

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview (http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8287/homepage/Productinformation.html).

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. **Circulation**

   The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. **Length**
Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager (http://www.editorialmanager.com/hihp). The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission (BPS Journals Terms and Conditions of Submission.doc) and the declaration of competing interests (BPS Journals Declaration of Competing Interests.doc). You may also like to use the Submission Checklist (BJHP Submission Checklist.docx) to help you prepare your paper.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author’s contact details. A template can be downloaded from here (Sample Manuscript Title Page.doc).
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found here (http://www.addictionjournal.org/pages/writing-the-abstract).
- Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for ‘what does this study add?’ should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.
- The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:


• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

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