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Understanding the occupation of diabetes self management using the Model of Human Occupation

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Manuscript Type:	Research Paper
Key Areas:	Research Methods and Methodology, Professional Development
Keywords:	Model of Human Occupation, diabetes self-management, occupational forms, occupational therapy
Abstract:	<p>Introduction Over 400 million people worldwide are living with diabetes. Research suggests that people struggle to manage their diabetes and an in-depth understanding of the lived experience of diabetes is required to inform and promote occupational therapy practice. This article reports on one part of a PhD study into the role of occupational therapy in diabetes self management.</p> <p>Method Semi-structured interviews using an intuitive inquiry methodology were conducted with 22 people with diabetes in three separate studies. Analysis of the lived experience of all participants was drawn together to explore the understanding of diabetes self management from an occupational perspective using the Model of Human Occupation.</p> <p>Findings The occupation of diabetes self management was conceptualised with seven inter-related occupational forms. Challenges were related to occupational identity, volition, habituation, performance capacity and the context in which these took place.</p> <p>Conclusion This study, embedded in the experiences of those with diabetes, suggests that occupational therapy has a distinct role in diabetes self-management, through seeing this self-management as an occupation. The use of the Model of Human Occupation enables a focus on the characteristics of the occupational forms and how these might be adapted for successful occupational engagement.</p>

Introduction and background literature

The rising number of cases of all types of diabetes worldwide is a concern for public health policy (World Health Organisation (WHO) 2016) and the personal impact on the individual with diabetes is considerable. Approaches to diabetes self management that can help people to manage this condition and prevent further complications in terms of the context of their own lives appear to be the way forward (Nagelkerk et al 2006).

This research article focuses on one aspect of a PhD study into the role of occupational therapy in diabetes self management (DSM). The three aims of the PhD study were to explore the lived experience of diabetes, explore the use of metaphor to understand that experience, and to explore the role of occupational therapy in relation to DSM. A previous article described the lived experience of diabetes (Youngson et al 2015) and the focus of this article is a consideration of the use of the Model of Human Occupation (MOHO) (Kielhofner 2008) to conceptualise diabetes self management as a distinct occupation. Within this, the occupational forms and the impact of volition, habituation, performance capacity and the environment will be considered.

Diabetes

Over 400 million people worldwide are living with diabetes but it can also result in premature death and disability (WHO 2016). There are three main types of diabetes: type 1, type 2, and gestational diabetes (WHO 2016). Prediabetes is a borderline condition, where blood glucose levels are higher than normal and where it is considered that people are at risk of developing type 2 diabetes (Mainous III et al 2014). Type 1 is characterised by the body's inability to produce insulin, while in type 2 either not enough insulin is produced or the insulin does not work properly (WHO 2016). Gestational diabetes is a temporary condition which develops in pregnancy where the mother develops resistance to insulin (WHO 2016). Insulin is required to help glucose enter the cells from the blood stream, where it is used as fuel. Lack of, or resistance to, insulin results in high blood glucose levels which can lead to macrovascular complications such as cardiovascular events and stroke (particularly when combined with high blood pressure and cholesterol levels), and/or microvascular conditions such as kidney, eye and nerve damage (WHO 2016). Poorly controlled diabetes is also linked to depression, anxiety, phobias and eating disorders (Diabetes UK 2016). Type 1 diabetes is not preventable and is treated with insulin therapy. Type 2 is the most common form of diabetes and may need medication to lower blood sugar levels. In the long term insulin therapy may be required. It is overall recommended that lifestyle changes are made to diet and exercise to control blood sugar levels to manage and prevent type 2 (WHO 2016).

Diabetes self management

Traditionally DSM is viewed from the medical perspective of monitoring of blood glucose levels (HbA_{1c}), blood pressure and cholesterol, collectively known as metabolic control (NICE 2015). Additionally people with diabetes are encouraged to make lifestyle changes to pursue a healthy diet, take more exercise and comply with medical recommendations (WHO 2016). However, this tends to simplify exactly what is involved in the complexity of DSM. This includes managing medication and testing (Montez and Karner 2005), engaging in healthcare appointments (Thorne and Paterson 2001; Watts et al 2011) incorporating diabetes education (Lutfey 2005), plus lifestyle changes such as alterations to diet (Brackenridge and Swenson 2004), and incorporating exercise (Nagelkerk et al 2006). Evidence suggests that, despite educational programmes and healthcare guidance, many people with diabetes struggle to adhere to advice on self management and experience barriers to successfully incorporating this into individual lifestyles (Mulvaney 2009, Nagelkerk et al 2008). Indeed Ingadottir and Halldorsdottir (2008) conclude that managing diabetes is a constant balance between trying to follow recommendations and the well-being of living a normal life.

Occupational therapy

Although it would appear that lifestyle change might be a key skill of occupational therapy, a review of the literature reveals that research into occupational therapy in diabetes care is sparse, particularly in relation to managing diabetes in the context of everyday life (Pyatak 2011). It is only recently that occupational therapists have started to consider an occupational perspective. Fritz (2014) examined the influence of daily routines on diabetes self management while Thompson (2014) considered the need to develop appropriate habits and routines to support self management. Similarly Pyatak et al (2015) emphasise the need to integrate self management behaviours into everyday occupations and routines. Interestingly, it is research in the nursing profession where examples can be found of where participants have discussed how certain occupations are affected by sugar levels or how medication impacts on routines and habits (Thorne and Paterson 2001). The use of occupational therapy models could allow an occupational perspective in contrast to a medically based 'impairment' focus (Scott et al 2017).

Model of Human Occupation (MOHO)

One of the most commonly used models in practice and in research is the Model of Human Occupation (Lee et al, 2012). The Model of Human Occupation (MOHO) enables us to understand people as occupational beings and to view them as being situated within dynamic complex systems. The MOHO concepts to explain this complexity include: motivation for occupation (volition); routine patterning of occupational behaviour (habituation); nature of skilled performance (performance capacity); and the dynamic influence of the physical and social context (environment) (Kielhofner 2008). Use of MOHO enables occupational therapists to have a conceptual framework which focuses on understanding occupation (Kielhofner 2008).

Volition involves a person's values, their interests and their beliefs in how effective they perceive they are at doing (Kielhofner 2008). Habituation relates to how a person organises their patterns of behaviour, which are guided by their roles, habits and routines (Kielhofner 2008). The environment includes immediate, local and global influences as well as corresponding social and cultural impacts (Kielhofner 2008).

The theoretical perspective of MOHO and its application to diabetes self management is the focus of this research article

Method

The Ethics Committee of the University of Cumbria consented to ethical approval for this study. A qualitative methodology and intuitive inquiry (Anderson 2004) research design were chosen in order to enable a reflexive and considered exploration of the issues. Intuitive inquiry is described as a qualitative hermeneutical approach which combines intuition with "intellectual precision" and includes creativity and deep reflection (Anderson 2004, p307). It provides a cohesive structure for the methodological aspects of heuristic phenomenology, interpretative phenomenological analysis, metaphor analysis, discourse analysis, creativity and mixed media artwork

There were three studies:

1. Diabetes Lived Experience
2. Occupational therapists with diabetes
3. Diabetes in Relation to the Potential Occupational Therapy Role.

For each study a purposive, convenience sample of people was sought. This ensured that participants had the particular characteristics required, of living with diabetes, to enable exploration

of the themes (Ritchie et al 2003). The convenience sample was chosen for ease of access. In order to reduce potential bias (Ritchie et al 2003), a range of ages, types of diabetes and time with the condition were selected. All participants were over the age of 18. Study 1 and study 3 participants were recruited from the general population while study 2 participants were recruited from the occupational therapy profession in the United Kingdom (and one from the USA). Participants were provided with an information sheet and written consent was sought prior to participation in the study. Data was collected in all 3 studies using digitally recorded individual, semi-structured interviews of 60-90 minutes duration by the first author. In study 1 participants were asked to describe what it was like to live with diabetes with subsequent questions for further exploration or explanation (Legard et al 2003). Fuller details of the method from Study 1 are reported in Youngson et al (2015). Study 2 participants were invited to use their own metaphors (Gauntlett 2007) to describe their experiences of diabetes. This gave an opportunity to further understand the realities of living with diabetes and explore the use of metaphor. Participants were also invited to discuss how they might have used occupational therapy concepts in their own self-management and how it might be applied to others with diabetes, thus enabling an exploration of an occupational therapy perspective. Study 3 participants were also invited to describe what it was like to live with diabetes through creation of their own metaphors, and to consider what kind of diabetes service would help with self-management. Although these studies each had a different focus, the overall findings gave a comprehensive perspective on living with diabetes and thus the data from the three studies was pooled for the purpose of considering the occupation of DSM.

Interviews were transcribed in full and sent to participants for checking. Thematic analysis of the data began with an initial immersion of reading and re-reading the transcripts. A line by line active coding in line with phenomenological principles followed from which broad categories were developed (Finlay 2011). As in the perspective of intuitive inquiry, a number of different strategies including the use of a fieldwork diary, reflection through creative mixed-media artwork and moments of intuition were employed alongside the coding to ensure a comprehensive representation of the perspectives of the participants. In each study an analysis of the findings were sent in a report to participants for review and comment. Participants who responded confirmed their agreement and some provided extra feedback in response to the reports. This included further detailed description of their diabetes experiences which was incorporated into the findings. A further deductive analysis of the data from all three studies was conducted using the concepts and definitions from the Model of Human Occupation (Kielhofner 2008) to focus on this theoretical perspective.

Findings

Seven participants were recruited to study 1, ten occupational therapists were recruited to study 2 and five participants to study 3. Demographics of the participants are shown in table 1 and pseudonyms are used throughout.

Pseudonym	Age	Type of diabetes	Time since diagnosis
Study 1 – Diabetes Lived Experience			
Rosemary	50	Type 1	19 years
Simon	23	Type 1	14 years
Alan	64	Type 2	4 years
Anna	64	Type 2	12 years
Terry	41	Type 2	< 1 year
Albert	51	Pre-diabetes	< 1 year
Rachel	54	Pre-diabetes	5 years
Study 2 - Occupational Therapists with diabetes *			
Nancy	50s	Gestational	11 years

Helen	50s	Pre-diabetes	< 1 year
Martin	40s	Pre-diabetes	< 1 year
Frances	40s	Type 1	41 years
Jill	40s	Type 1	22 years
Karen	30s	Type 1	27 years
Susan	30s	Type 1	32 years
Carol	50s	Type 2	9 years
Jessica	50s	Type 2	10 years
Vanessa	50s	Type 2	< 1 year
Study 3- Diabetes in Relation to the Potential Occupational Therapy Role			
Frank	59	Type 2	10 years
Josephine	67	Type 2	4 years
Louise	66	Type 2	15 years
Margaret	64	Type 2	< 1 year
Marilyn	34	Type 2	< 1 year

* The age of the occupational therapists has been adjusted to their current decade to prevent possible identification.

Table 1: Study participants

Studies 1, 2 and 3 all revealed aspects of living with diabetes where participants described the realities of fitting the condition into their daily lives. As shown in figure 1, the findings are conceptualised, across all participants, into the occupation of diabetes self management (DSM). Aspects of management from type 1, type 2, gestational and pre-diabetes are described and collectively they summarise the experience of the participants into seven inter-related occupational forms. The thinking bubble in the middle indicates the self and the decisions all participants have to make about how, what, why and when they will organise self management. Starting from top right of Figure 1, and in the direction of the arrows, these seven occupational forms of DSM are summarised alphabetically as follows: managing appointments; managing diet; exercise; information and education; managing other illness; managing medication; and testing blood sugar.



Figure 1: The occupational forms of the occupation of diabetes self-management

The complexity of this occupation is further broken down into the components of MOHO as summarised in figure 2 and table 2. Figure 2 takes one aspect of DSM, blood sugar testing, showing the impact of volition, performance capacity, habituation and environment, using the words of the participants from all three studies.

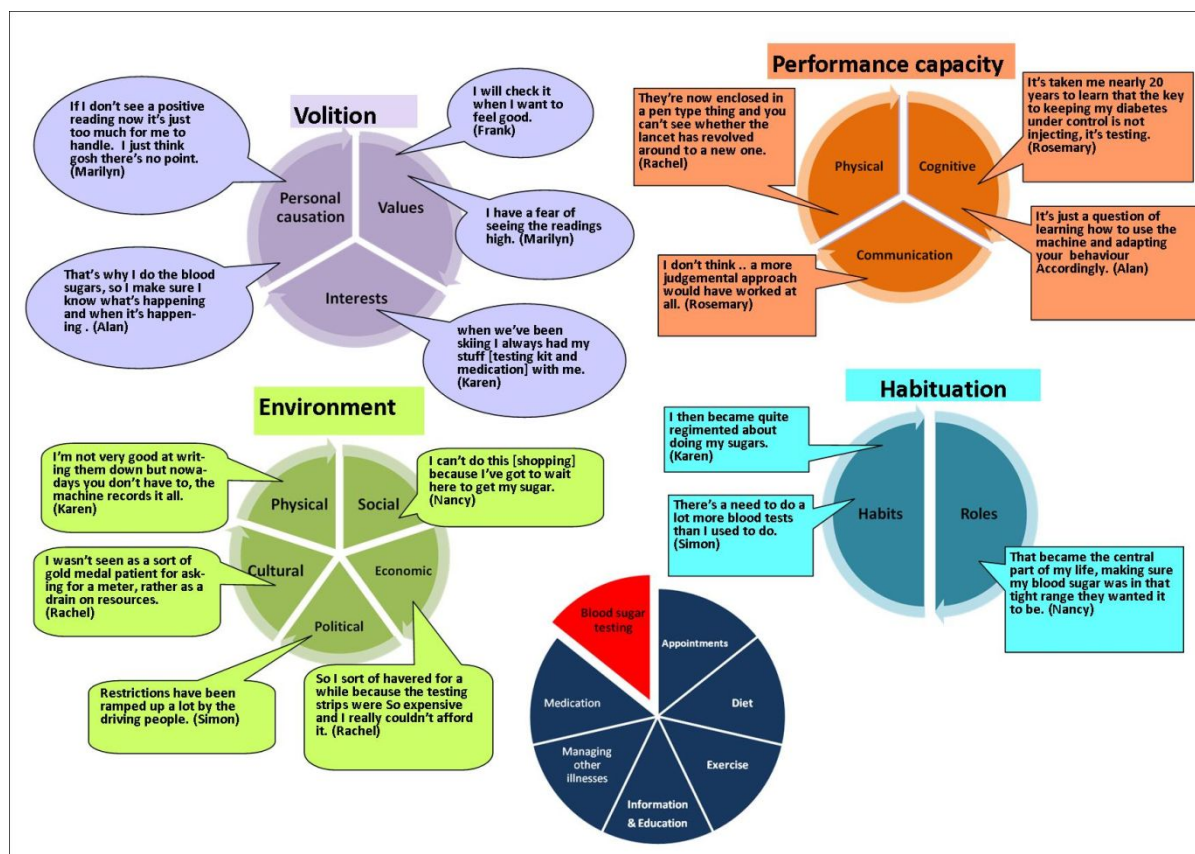


Figure 2: Using the Model of Human Occupation to illustrate blood sugar testing

As can be seen from the blood sugar testing example above, this is not merely a physical task, as might be understood from a medical perspective. The formation of new habits is required, it is impacted by job roles (such as the need to test before driving), requires learning, is value laden and is influenced by experience and beliefs.

Table 2 takes a wider perspective on DSM, summarising the MOHO components across the seven occupational forms. MOHO was applied to the findings to further describe the particular aspects of these occupational forms to aid understanding of what motivated participants, how the challenges might be explained in terms of performance capacity, changes to routine or the impact of the wider environment. These are explained in further detail below:

Applying the Model of Human Occupation to the Occupation of Diabetes Self Management

Volition

The components of volition – personal causation, values and interests – are interwoven and it is the relationship between these components which influences how people assess and manage themselves. For participants their ability to engage with the occupational forms of DSM was bound up with their beliefs about themselves and their trust in professionals. Managing the therapeutic relationship, especially where different professionals were encountered on each appointment, led

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3 some to insisting on seeing the same person as “*I was being given different advice by different*
4 *people everytime I went*” (Frances). For Frances dealing with this conflicting information not only
5 impacted on her sense of capacity to manage but was also at odds with her conviction that health
6 professionals should provide clear information to work with.
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For Peer Review

MOHO concept	APPOINTMENTS	DIET	EXERCISE	INFORMATION & EDUCATION	MANAGING OTHER ILLNESS	MEDICATION	BLOOD SUGAR TESTING
VOLITION Personal causation Values Interests	<ul style="list-style-type: none"> • Belief in advice • Fear of failure • Level of involvement • Wanting to please • Medicalisation 	<ul style="list-style-type: none"> • Will power • Choice • Deprivation • Guilt/anxiety • Enjoyment • Self discipline • Support 	<ul style="list-style-type: none"> • Liking / not liking • Use of apps • Impact on mood • Laziness / self discipline 	<ul style="list-style-type: none"> • Trust • Influence • Understanding • Sense of control • Compromising beliefs • Acceptance 	<ul style="list-style-type: none"> • Separating symptoms • Control over symptoms • Stress 	<ul style="list-style-type: none"> • Options • Empowerment (or lack) • Denial • Self discipline 	<ul style="list-style-type: none"> • Guilt • Fabricating results • Impact on mood • Maintaining tight control • Independence
HABITUATION Habits Roles Routines	<ul style="list-style-type: none"> • Organising around home and work routines • Frequency 	<ul style="list-style-type: none"> • Meal times • Eating habits • Discipline • Comfort eating and rewards • Socialisation 	<ul style="list-style-type: none"> • Use of apps • Adding to or changing routines • Planning ahead • Impact of roles 	<ul style="list-style-type: none"> • Impact on present/future roles • Ignoring advice • Impact on routines 	<ul style="list-style-type: none"> • Managing sick days • Increasing testing routines 	<ul style="list-style-type: none"> • Adding to routines • Changing routines eg meal times 	<ul style="list-style-type: none"> • Adding to routines • Changing routines • Impact of work roles
PERFORMANCE CAPACITY Physical Mental Lived Body	<ul style="list-style-type: none"> • Embodied experience of being a 'patient' 	<ul style="list-style-type: none"> • Embodied experience of food • Cognitive dissonance • Impact of potential complications • A life worth living 	<ul style="list-style-type: none"> • Embodied experience of sport • Working out insulin levels 	<ul style="list-style-type: none"> • At correct cognitive level • Knowing what correct action is • Having right mindset • Factoring in new information 	<ul style="list-style-type: none"> • Understanding symptoms • 'left field' symptoms • Celebrating 'wellness' • Stress 	<ul style="list-style-type: none"> • Lifespan development • Working out new rules • Competence with equipment • Remembering • Body image 	<ul style="list-style-type: none"> • Understanding results • Working out solutions to results • Deciding acceptable boundaries
ENVIRONMENT Global Local Immediate	<ul style="list-style-type: none"> • Dealing with different staff • Attitudes of staff • Impact of blame culture • Accessibility 	<ul style="list-style-type: none"> • Impact of seasons and festive events • Work & home temptations • Social & cultural rules • Choice – eating out & shopping • Cost • Cultural blame 	<ul style="list-style-type: none"> • Accessibility to facilities • Weather • Physical environment • Availability of 'buddies' • Putting others' needs first 	<ul style="list-style-type: none"> • Groups vs individual • Accessibility of education • Time available 	<ul style="list-style-type: none"> • Impact on others • Work / home impact 	<ul style="list-style-type: none"> • Using in public • Driving • Adapting to societal norms • Impact from work stress 	<ul style="list-style-type: none"> • Testing in public • Availability of testing kits • Cost • Availability of apps

Table 2: Occupation of diabetes self management in relation to the Model of Human Occupation

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3 Appointments involved engaging with the scope of the intervention and managing the required
4 “checks and balances” (Carol) of eyes, feet, blood pressure, blood sugar levels, impact of medication;
5 dealing with information exchange; and managing the frequency of appointments eg too often or
6 not soon enough. Some participants felt that the frequency of appointments did not suit them and
7 the impact of their personal causation was explained in terms of wanting reassurance that they were
8 doing the right thing. Margaret, for example, reported that “they leave you, they let you flounder”.
9 Issues of trust, power and communication characterised the therapeutic relationship with some
10 participants describing that “it always felt like going to see the headmistress” (Jill) and only being
11 “given preconceived options” (Frances). Some participants approached appointments with
12 trepidation, concerned about being judged by professionals or wanting to please by adhering to
13 advice as far as possible. To meet this desire to please, Susan discussed making up blood sugar test
14 results stating that the healthcare staff “would look at the book that was completely fabricated” but
15 that would indicate that she was within the expected range. For all of these participants, the
16 content of appointments or attitudes of professionals had a direct influence on feelings of personal
17 capacity and self-efficacy, and challenged their values about what they considered to be the right
18 course of action.

21 Correspondingly changing behaviour as a result of education and information exchange appeared to
22 rely on whether participants trusted the information, or whether it actually compromised their
23 beliefs. Information and advice was often seen as negative “it’s very much about you can’t have, you
24 can’t be having this” (Carol). Others found that courses, such as Dose Adjusted for Normal Eating
25 (DAFNE) for type 1 diabetes, had a very positive impact allowing for more adaptability in diet which
26 meant, for Jill, that “I’m now a bit more flexible as to how I can control the diabetes”. Marilyn
27 reported that she wanted to manage her diabetes her way rather than follow the recommended
28 advice. However she concluded that “it was upsetting to see that there wasn’t anything natural I
29 could do and that I had to compromise my own kind of spiritual beliefs really to then treat this
30 condition”. Here the challenge related to a sense of obligation to acting on the advice. Where this
31 matched the participant’s beliefs and values, then there was the possibility for positive change but
32 where the advice was at odds with these, there was a likelihood of ignoring the information.

35 Making changes to diet and exercise was particularly bound up with values and interests – many
36 participants felt that they did not have the self discipline required to make changes, and described
37 their interests around socialising and food. Managing diet, for some, resulted in reduced food
38 choices and feelings of exclusion while shopping for food, and having to make efforts not to give in
39 to temptation. Participants discussed how their diabetes impacted on socialising with friends in
40 terms of trying to make healthy food choices while not inconveniencing dinner party hosts,
41 negotiating the refusal of food gifts, and of feeling a nuisance by spoiling others’ pleasure.

44 Personal causation was bound up with testing in terms of the emotional (either positive or negative)
45 impact of results. Carol reported her fear of becoming obsessed with testing and Louise stated that
46 she got “discouraged” by the results. Likewise Marilyn stopped herself testing because “if I know the
47 readings are going to be higher I don’t want to confirm it because I know that by confirming it my
48 morale drops”.

51 Overall getting into the right ‘headspace’, or positive personal causation, was seen as key. As Terry
52 reported “I’ve got to be in the right frame of mind because no amount of just telling me ‘if you
53 don’t do this your leg’s going to drop off’ is going to work.” While Anna similarly stated that “I think
54 you’ve got to be at a place where you think ‘I really do have to do something’”.

56 Habituation

57 The summary in table 2 indicates the impact of habits, routines and roles across all the occupational
58 forms and highlighted that some participants prioritised work and family life ahead of their own self
59 management. Some participants discussed the difficulty of fitting appointments around home and
60

work routines as well as the need to change routines around food, exercise, and testing. Participants had to learn to over-ride the habit to eat when stressed, change meal routines in relation to medication. Helen described changing habitual meal time routines with her family to ensure smaller portion sizes *"And the only way I could control them was to give them a smaller plate and then they got it better"*. Martin reported his habit of eating to control stress and to reward himself but stated that food had become his *"downfall"*.

Simon explained how his routines developed into a non-testing habit: *"I should worry more, I should do more blood tests and get everything under control more but I guess you know, having been for so long, maybe not getting there quite as quickly as I should have, maybe I've kind of got into that habit"*.

Routines required changing and sometimes careful planning. Jill described having to plan medication and sugar supplies to cover possibilities of hypoglycaemia, as *"it's quite hard to get things like blood sugars right on long [bicycle] rides"*.

Some found exercise had a very positive impact on their diabetes, such as Susan, who found sport to be *"my medicine"* but others found routines hard to sustain. Participants had to over-come exercise reluctance, such as Louise who stated *"I know I ought to do more exercise, I hate exercise"* and Margaret who said that it had been recommended to her that she join a fitness class but that this had not been part of her usual routine as *"I've never fancied gyms, I don't like them"*.

Performance Capacity

Performance capacity relates to the physical and cognitive components that enable people to perform occupations, as well as the subjective 'lived body' experience. As summarised in table 2, participants talked about the understanding of physical symptoms, the physical difficulties of using some testing equipment and the cognitive ability required to work out medical equipment and understand results. Medication management formed a major part of DSM for the participants. In terms of performance capacity this involved working out timing of medication, dealing with changes to medication and possible risk factors, incorporating new equipment, calibrating insulin amounts in relation to diet and exercise, making choices about where and when to inject. Jill struggled with *"phases where I just forget to take my insulin"*. This required participants to be aware of their safety limits and planning beforehand to ensure adequate supplies of medication or emergency glucose.

Performance capacity was of concern not just in the present, but also when considering the future. Carol and Terry reported that they did not think they could cope with the possibility of having to physically inject insulin in the future, while Frances reported *"I know I can never do an insulin pump"*.

Although diabetes education is seen as the cornerstone of prevention and treatment, participants described difficulties with courses being tailored to their own cognitive levels. Some, like Frank, found education patronising *"I found the level of information was quite low"* while others found it too complex.

Several participants discussed the difficulty of distinguishing between diabetes symptoms and the symptoms of other illnesses and how this impacted on medication or making adjustments to DSM. As Alan explained *"I only really check my blood glucose if I'm feeling unwell and I want to, by a process of elimination, work out that it's not my diabetes"*. Karen similarly stated that *"if I feel funny I will do more tests"* even when she attributed this to tiredness. Frances commented that hypos might well be due to *"a period or 90 million reasons and you can't control every one of them"*. Additionally participants felt the need to check out symptoms to ensure that complications of diabetes were not developing.

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3 The embodied experience of being a 'patient' was particularly pertinent here. As Frank stated "*I*
4 *don't want to be good at being a patient*" explaining that "*whilst I might be a patient outside this*
5 *office.... I'm not your patient, I'm my life*".
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8 Environment

9 The environment includes the physical, social, cultural, economic and political contexts that impact
10 on occupation. Figure 2 and table 2 give examples of the impact of positive and negative aspects of
11 the environment on DSM. One notable example of this was the impact of blame culture. Frank
12 reported that "*I think people blame you're a burden on the NHS*" while Jill commented that "*to*
13 *attach value judgements to food is a really dangerous place to be*". Louise discussed the difficulty of
14 "*constantly struggling with weight*" and how it was "*a curse especially in the age in which we live*
15 *where physical appearance is so criticised*".
16

17 The lack of available facilities in the physical environment constrained how well DSM was managed.
18 Jill commented that she did not always have access to somewhere to inject and that it had taken her
19 a long time to feel able to do this in public, being sensitive to the needs of others: "*I used to think*
20 *you couldn't inject in public because it might upset someone*". In the same way the local
21 environment in terms of the availability of leisure facilities, access to footpaths or difficulty of
22 managing hilly terrain all impacted on DSM.
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25 Discussion

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27 DSM needs to be accomplished in the context of the person's lifestyle, it being only one aspect of
28 the complexity of managing daily lives (Fritz, 2014; Gillibrand and Flynn, 2001). Conceptualising DSM
29 as an occupation with seven occupational forms allows further understanding of the many aspects
30 that require successful management. The occupational forms of the occupation of DSM change with
31 time, experience and other life events of the people concerned (Pyatak et al, 2015). Considering
32 diabetes from an occupational perspective differs from the traditional medical view of self
33 management tasks by taking into consideration the individual in the context of their own daily life.
34 Using MOHO further explains how the occupational identity of the person; their choices, beliefs,
35 values, and interests; their habits, roles and performance capacities; and the opportunities or
36 demands of the environment impact on that self management. This supports the findings of
37 Thompson (2014) who considered the need to develop appropriate habits and routines to support
38 self management. Pyatak et al (2015) similarly emphasised the need to integrate self management
39 into everyday occupations and routines.
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42 Although the diabetes literature highlights managing the therapeutic relationship (Thorne and
43 Paterson 2001), the importance of testing and recording (Ingadottir and Halldorsdottir 2008),
44 information exchange (Watts et al 2010), diet (Brackenridge and Swenson 2004), exercise (Nagelkerk
45 et al 2006) and medication (WHO 2016), it was clear from the participants that how successful they
46 were with these occupational forms was bound up in values and interests. Managing diet, for some,
47 resulted in reduced food choices and feelings of exclusion while shopping for food and having to
48 make efforts not to give in to temptation, as found by Wellard et al (2008). Amorim et al (2004)
49 describe the emotional impact of diabetes on identity and the participants here discussed how their
50 diabetes impacted on socialising with friends in terms of trying to make healthy food choices while
51 not inconveniencing dinner party hosts, negotiating the refusal of food gifts, and of feeling a
52 nuisance or spoiling others' pleasure.
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55 As stated in the findings, participants talked about the physical understanding of symptoms and the
56 cognitive ability required to work out medical equipment and understand results, highlighted by
57 Montez and Karner (2005), requiring participants to be aware of their safety limits and planning
58 beforehand to ensure adequate supplies of medication or emergency glucose. This was clearly
59 associated with roles and routines as well as personal causation.
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3 Overall dealing with the culture of blame across these occupational forms added another layer of
4 difficulty for the participants. Browne et al (2013) discuss the negative impact of stigma and how
5 negative or oversimplified views of diabetes can be experienced from friends, society in general, the
6 media and healthcare professionals. Participants described how unhelpful and demotivating this
7 culture of blame could be. Being censured by healthcare professionals for apparent lack of control
8 of blood sugars (Ingaddotir and Halldosdottir 2008) was not only seen as frustrating and
9 disempowering but also counter-productive.

10
11 As Gardener et al (2017) argue, successful DSM requires a complex skill set. They suggest that
12 occupational therapists have a role to play in enabling people to achieve mastery of DSM by
13 understanding the occupational performance elements. Conceptualising DSM as an occupation and
14 understanding the complex dynamic between the person, occupation and environment, using the
15 MOHO, could be one way of highlighting the unique occupational therapy perspective.

16 17 18 Limitations

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20 The sample size of 22 participants means that the findings cannot be generalised to the diabetes
21 population as a whole. However the study does give some insight into the complexity of managing
22 DSM and provides an occupational perspective that could complement existing services. Further
23 research will be required to investigate whether this theoretical perspective would work in practice
24 and how this might be used to design effective occupational therapy interventions.

25
26 The research is also limited in terms of its focus on the individual with diabetes. It is clear that DSM
27 also relies on effective policy in terms of access to healthcare, education and guidance in many
28 aspects of the occupational forms described, such as education and information, diet and physical
29 activity. Further research is required into the impact of public health and health promotion
30 opportunities on these occupational forms.

31 32 33 Conclusion

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35 People can live long and healthy lives if diabetes is well managed and type 2 diabetes can be
36 prevented with lifestyle changes to diet and exercise to control blood sugar levels (WHO 2016).
37 Within healthcare this is currently managed through medication, health education and follow up,
38 with a focus on the biomedical approach.

39
40 The purpose of this study was to understand the experience of diabetes self management and to
41 explore the potential role for occupational therapy. Within this the MOHO was considered as a way
42 of conceptualising and understanding the complexity of the occupation of DSM with its seven inter-
43 related occupational forms. This has highlighted the complexity of an individual managing DSM in
44 the context of their own lives and the multiple and complex systems that this entails, which goes
45 beyond the biomedical approach. This increases the knowledge base with specific reference to DSM
46 and occupation. This approach could strengthen an occupation based occupational therapy
47 intervention which is different to yet complements current medical practice in DSM.

48
49 This study, embedded in the experiences of those with diabetes, suggests that there is a role for
50 occupational therapy in DSM, and that occupational therapy has a distinct role through seeing this
51 self-management as an occupation.

52
53 WHO (2016 p53) concludes in its Global Report on Diabetes that “a range of health professionals is
54 required for the care and treatment of diabetes, including physicians, nurses, dieticians and
55 specialists such as obstetricians, ophthalmologists, vascular surgeons and physiotherapists”. It is
56 time that occupational therapists were added to this list.

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59 Key findings:
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- Diabetes self management can be conceptualised as an occupation
- Occupational therapy has a distinct role through seeing self-management as an occupation
- The Model of Human Occupation enables understanding of the occupational forms of diabetes self management

What the study has added:

Conceptualising diabetes self management as an occupation may enable occupational therapists to facilitate successful engagement in this occupation.

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For Peer Review

References

Amorim M, Ramos N, Brito, M and Gazzunelli M (2014) Identity Representations of People with Diabetes, *Qualitative Health Research*, 24 (7), 913-922.

Anderson R (2004) Intuitive Inquiry: An epistemology of the heart for scientific inquiry, *The Humanistic Psychologist*, 32 (4), 307-341

Brackenridge B and Swenson K (2004) Discovering diabetes: achieving target blood glucose control through a behavioural approach to insulin and food self-management, *Journal of Diabetes & Vascular Disease* 4 (2), 117-120.

Browne JL, Ventura A, Mosely K and Speight J (2013) 'I call it the blame and same disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes'. *BMJ Open* 3, e003384 doi:10.1136/bmjopen-2013-003384.

Diabetes UK (2016) *State of the Nation 2016. Time to take control of diabetes*. London: Diabetes UK

Finlay L (2011) *Phenomenology for therapists: researching the lived world*. Oxford: Wiley-Blackwell.

Fritz H (2014) The influence of daily routines on engaging in diabetes self-management, *Scandinavian Journal of Occupational Therapy*, 21 (3), 232-240.

Gardener L, Bourke-Taylor H and Ziviani J (2017) Occupational therapy: An untapped resource for children and adolescents with type 1 diabetes. *Australian Occupational Therapy Journal*, 64, 79-82.

Gauntlett D (2007) *Creative Explorations. New approaches to identities and audiences*. Abingdon: Routledge.

Gillibrand W and Flynn M (2001) Forced externalization of control in people with diabetes: a qualitative exploratory Study', *Journal of Advanced Nursing* 34(4), 501-510.

Ingadottir B and Halldorsdottir S (2008) To Discipline a "Dog": The Essential Structure of Mastering Diabetes, *Qualitative Health Research*, 18 (5), 606-619.

Kielhofner G (2008) *Model of Human Occupation*, 4th Ed. Philadelphia: Lippincott Williams and Wilkins.

Lee SW, Kielhofner G, Morley M, Heasman D, Garnham M, Willis S, Parkinson S, Forsyth, K, Melton J and Taylor R (2012) Impact of using the Model of Human Occupation: A survey of occupational therapy mental health practitioners' perceptions, *Scandinavian Journal of Occupational Therapy*, 19 (5) 450-456.

Legard R, Keegan K, and Ward K (2003) In-depth interviews, in Ritchie J and Lewis J (Eds.) *Qualitative Research Practice*. London: SAGE, 138-69.

Lutfey K (2005) On practices of 'good doctoring': reconsidering the relationship between provider roles and patient adherence, *Sociology of Health & Illness*, 27 (4), 421-447.

Mainous III AG, Tanner RJ, Baker R, Zaya CE and Harle CA (2014) Prevalence of prediabetes in England from 2003 to 2011: population-based, cross-sectional study', *BMJ Open*, 4, 1-8.

1
2
3 Montez JK and Karner TX (2005) Understanding the Diabetic Body-Self, *Qualitative Health Research*,
4 15 (8),1086-1104.

5
6 Mulvaney SA (2009) Improving patient problem solving to reduce barriers to diabetes self-
7 management, *Clinical Diabetes*, 27 (3), 99-104.

8
9
10 Nagelkerk J, Reick K and Meengs L (2006) Perceived barriers and effective strategies to diabetes self-
11 management, *Journal of Advanced Nursing*, 54 (2), 151-158.

12
13 National Institute for Health and Care Excellence (NICE) (2015) *Type 2 diabetes in adults:*
14 *management*, NG28. London: NICE.

15
16
17 Pyatak E A (2011) The role of occupational therapy in diabetes self-management interventions, *OTJR:*
18 *Occupation, Participation & Health*, 31 (2), 89-96

19
20 Pyatak EA, Carandang K and Davis S (2015) Developing a Manualized Occupational Therapy Diabetes
21 Management Intervention: Resilient, Empowered, Active Living With Diabetes', *OTJR: Occupation,*
22 *Participation and Health* 35 (3), 187-194.

23
24 Ritchie J, Lewis J, and Elam G (2003) Designing and Selecting Samples' in Ritchie J and Lewis J (Eds)
25 *Qualitative Research Practice. A Guide for Social Science Students and Researchers*. London: SAGE
26 Publications Ltd, 77-108.

27
28
29 Scott PJ, Cacich D, Fulk M, Michel K and Whiffen K (2017) Establishing Concurrent Validity of the Role
30 Checklist Version 2 with the OCAIRS in Measurement of Participation: A Pilot Study, *Occupational*
31 *Therapy International*, Article ID 6493472, 6 pages, <https://doi.org/10.1155/2017/6493472>

32
33 Thompson M (2014) Occupations, habits and routines: perspectives from persons with diabetes,
34 *Scandinavian Journal of Occupational Therapy*, 21, 153-160.

35
36 Thorne SE and Paterson BL (2001) Health care professional support for self-care management in
37 chronic illness: insights from diabetes research, *Patient Education and Counseling*, 42 (1), 1-90.

38
39 Watts S, O'Hara L and Trigg R (2010) Living with type 1 diabetes: a by-person qualitative exploration,
40 *Psychology & Health*, 25 (4), 491-506.

41
42
43 Wellard SJ, Rennie S and King R (2008) Perceptions of people with type 2 diabetes about self-
44 management and the efficacy of community based services, *Contemporary Nurse*, 29 (2), 218-226.

45
46 World Health Organisation (2016) *Global Report on Diabetes*. Geneva: World Health Organisation

47
48
49 Youngson A, Cole F, Wilby H, Cox D (2015) The lived experience of diabetes: conceptualisation using
50 a metaphor, *British Journal of Occupational Therapy*, 78 (1), 24-32.

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3 Table of minor amendments to BJOT article on diabetes
4

Source	Comment	Amendment	Location
Editor in Chief	List 3 studies at top of page 3 Identify which is Youngson et al (2015) Add that fuller details of method from study 1 reported in Youngson et al (2015)	As suggested, amendments made to all 3 – see highlighted text	Method section pp2,3
Editor in Chief	Change to acknowledgements so that authors do not also appear here.	Amended as suggested	Acknowledgements
Reviewer 1	Strengthen section on volition to clearly explain the links between occupational form and volition.	Sentences added to strengthen this section as suggested – see highlighted text	Volition section
Reviewer 2	Methodology – analysis related to MOHO not clear	Sentence added re deductive analysis in relation to MOHO	Analysis section

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26 Amendments are highlighted in yellow in the article. Thank you for the ongoing suggestions.
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