**Introduction**

Type-1 diabetes mellitus is usually an autoimmune disease which results in the human body producing no insulin. Insulin is essential to control blood sugar levels. Self-management is usually essential for good outcomes in diabetes [1]. The self-care behaviours required to avoid long-term complications include home glucose monitoring; adjustment of food intake, administration of insulin, foot care and attendance of healthcare appointments [2]. In the long-term, poor diabetes self-management can lead to secondary organ damage such as visual impairment, kidney failure, cardiovascular disease or limb-loss secondary to peripheral neuropathy or infection. Poor self-management of type-1 diabetes can also lead to rapid death from diabetic keto-acidosis (DKA). For most cases of DKA poor adherence to therapy is the likely cause [2]. Qualitative research has shown that patients appreciate advice adapted to suit their individual lifestyles [3], family and economic circumstances [4]. Conversely, when these factors are ignored patients may consider clinicians’ advice to be not relevant to them [4]. The prevalence of diabetes among individuals with mental health problems has been estimated as high as double the general population [5]. The prevalence of depression in people with diabetes has been estimated to be between 11% and 32% [6]. It could therefore be argued that consultations should elicit relevant information about how psychosocial factors impact on individual patients and identify mental-health problems in need of treatment. This pilot study was undertaken to determine the nature of psychosocial factors that can be revealed with a one-off holistic occupational therapy consultation.
Literature Review

Research has shown motivational, patient-centred consultations to be more effective than traditional, didactic approaches for facilitating lifestyle change and improved self-management of diabetes [7]. Hornsten et al. [1] interviewed 44 patients with type-2 diabetes in Sweden and found agreed goals, patient autonomy and feelings of self-worth to be features of satisfying consultations, while disagreement about goals and perception of being forced into submission were features of unsatisfying consultations. Patients wanted non-diabetic factors affecting their lifestyles to be taken into account. ‘Patient-centred communication’ has been defined as “communicating in a way that conveys sensitivity to the patient’s feelings and needs, encourages patient participation, seeks to include the patient’s perspective, and attempts to fully inform the patient” [7]. Features of patient-centred practice include a bio-psychosocial perspective, a therapeutic alliance based on sharing responsibility and power and a personal relationship between the patient and clinician [4]. Trust, rapport and communication success are associated with positive therapeutic alliance [8]. Patient-centred care may be patient-led or clinician-led [4]. Qualitative research has indicated that the holistic, patient-centred consultations given by alternative therapists may influence patients to select complementary therapies that lack scientific legitimacy. It has been argued that adoption of these features into conventional healthcare consultations could increase patient concordance [9].

Occupational therapists commonly treat people with organ damage secondary to poorly controlled diabetes [10], such as stroke, visual impairment or limb amputations. It has however been argued that occupational therapy should have a more pro-active, preventative role in facilitating diabetes self-management. Outpatient occupational therapy for diabetes is not a new concept [11]. The American Occupational Therapy Association [12] advocates occupational therapy for exercise, habituation of glucose monitoring, healthy-eating and self-medication, emotional regulation and compensations for secondary organ damage. This has been delivered by direct occupational therapy intervention, sign-posting to community resources [11] and setting up peer-support [13]. As a general trend over time, the focus of published occupational therapy diabetes literature developed from specific, prescribed input based primarily on medical needs, to broader, holistic input incorporating more individualised psychosocial factors. Early articles described multi-disciplinary interventions in which occupational therapists delivered sessions on specified subjects, the most common being exercise [11, 14, 15]. A programme with a much broader remit was described by Scott et al. [16], and was designed to incorporate diabetes management skill-building into everyday functioning; however the extent to which this programme was individually tailored to the user remains unclear.

When psychosocial issues were brought to the fore in more recent studies it was often through the occupational therapy researchers listening to the views of service-users. Hwang, Truax, Claire & Caytap [17] carried out a survey of a mixed type-1 and-2 diabetes population over the age of 55 in the USA. They found that subjects would value assistance in a number of areas which lend themselves to a more holistic, psychosocially-oriented frame of reference such as “improving relationships” and “help with fatigue management and pacing”. Interestingly, only 13.7% had ever seen an occupational therapist. Pyatak’s [18] qualitative study into young adults with type-1 diabetes produced similar results, with psychosocial issues very prominent in participants’ accounts. The young adults interviewed described peer-pressure, social events involving excessive eating or alcohol consumption and concerns about the attitude of others towards insulin injection as major barriers to effective diabetes self-management. Both articles highlighted the potential of occupational therapy’s psychosocial frame of reference to help address such issues. The idea that psychosocial interventions are needed in diabetes services, and that occupational therapists are well placed to deliver them, was further developed in a systematic review by Pyatak [19]. The theoretical trend over time towards a less medically prescribed role was identified within the review and the author suggested ‘Lifestyle Redesign’, an approach developed to address the psychosocial needs of elderly people, as one which could be adapted for use by occupational therapists in a diabetes service. She gave a detailed description of how this was achieved [20], focusing on her attempts to combine the consistency of a manualised intervention with the tailored individualisation of therapy demanded by the differing psychosocial needs of this client group.

The need for psychosocial interventions and the potential for occupational therapy to provide them were also explored by Haltiwanger [13] and Haltiwanger & Brutus [21]. These studies tested peer support overseen by an occupational therapist, in which Mexican-American participants were free to discuss any issues of importance to them. Once again, psychosocial issues were prominent in the concerns raised, including specific discussions of the difficulties diabetic Mexican-Americans had with cultural taboos against refusing food. The results of these preliminary studies suggested that the peer-support group, with its psychosocial focus, was more effective than a health educator-led
group. Overall it appears that psychosocial issues are an important area to address when providing diabetes management interventions, but that this area is often neglected within existing diabetes services. Occupational therapy’s biopsychosocial frame of reference may have the potential to address this deficit.

The Norwich Diabetes Occupational Satisfaction Questionnaire (NDOSQ, Appendix 1) was developed from a model first published in the Asian Journal of Occupational Therapy [22] to assess psychosocial factors impairing diabetes self-care and the impact of diabetes on patients’ lives from the patients’ perspectives. It encourages patients to identify and prioritise their own problems in the following categories: 1. Spiritual, 2. Self-actualisation through psycho-spiritual integration, 3. Expression and communication, 4. Compassion, 5. Personal power and social standing, 6. Hedonism, 7. Basic survival needs. The NDOSQ was used for this research to explore the two-way relationship between type-1 diabetes and occupation.

Research Methodology

Participants

53 patients aged 18 years or over with diabetes mellitus type-1 and adequate mental capacity to consent were invited to take part in this research by their diabetes consultant physician during routine outpatient clinic appointments at the Norfolk & Norwich University Hospital in England. Exclusion criteria were: previous inpatient psychiatric admissions, suspected or confirmed personality disorders and those taking part in other medical research at the time of recruitment. Each patient was given the NDOSQ and the ‘Do you want to get the most from life?’ leaflet produced by the College of Occupational Therapists [23] while the consultant explained that the research was to explore the potential for occupational therapy to improve quality of life for patients with type-1 diabetes. Patients were contacted by telephone at least 24 hours later, and asked whether they would like to take part in this research by their diabetes consultant physician during routine outpatient clinic appointments at the Norfolk & Norwich University Hospital. Exclusion criteria were: previous inpatient psychiatric admissions, suspected or confirmed personality disorders and those taking part in other medical research at the time of recruitment. Each patient was given the NDOSQ and the ‘Do you want to get the most from life?’ leaflet produced by the College of Occupational Therapists [23] while the consultant explained that the research was to explore the potential for occupational therapy to improve quality of life for patients with type-1 diabetes. Patients were contacted by telephone at least 24 hours later, and asked whether they would like to take part in this research.

Eight patients (5 males and 3 females aged 39–71) consented and were invited to outpatient occupational therapy appointments. One of these did not attend his occupational therapy appointment. Patients are identified by sex (M/F) and age in years only (M40, M55, M56, M63, F39, F59, F71) to preserve anonymity.

• F39 previously managed a career in healthcare despite problems with alcoholism. She later developed diabetes and was unable to continue work due to frequent emergency hospital admissions for DKA, compounded by agoraphobia. She lived alone but received some support from a substance-abuse mental health team.

• F59 was a healthcare professional, married with children. She had successfully managed her diabetes, and so had no significant secondary organ damage. She had caring responsibilities for family members with physical and mental health problems.

• F71 had retired, but had also successfully managed her diabetes, so her career had not been affected and she had no significant secondary organ damage.

• M40 was married. He was unable to work due to several health problems and was being treated with anti-depressant medication.

• M55 was previously a lorry driver but was unable to work due to complications of diabetes. He had a below-knee amputation and presented at the occupational therapy interview with a new ulcer on his amputation stump.

• M56 was in the process of divorce, socially isolated and unable to work due to multiple health problems including generalised musculoskeletal pain. He had visual impairment likely to be secondary to poor glycemic control and cognitive impairments that may have been due to pseudo-dementia secondary to anxiety and depression, or micro-vascular disease secondary to poor glycaemic control.

• M63 had attended grammar school as a child but was distracted from his education by the diagnosis of diabetes. He was married and cared for his children who had multiple disabilities. Due to successful diabetes management he had no significant secondary organ damage.

Materials

Structured interviews based on the NDOSQ were conducted in the General Medical Outpatients Department of the Norfolk & Norwich University Hospital.

Procedure and Data analysis

Patients were asked to think about and complete the NDOSQ before attending their occupational therapy appointment. They were then assessed by an occupational therapist in a 45-minute outpatient clinic appointment during which any issues the patients raised on the NDOSQ were discussed. Three different occupational therapists took part in this study but each patient was seen by only one occupational therapist. The occupational therapists offered practical advice and signposting or referrals for appropriate follow-up. Patients’ responses to the NDOSQ and issues raised during the occupational therapy appointments were analysed for themes. This pilot study was approved by the South Central - Berkshire Research Ethics Committee in accordance with the ethical standards of the Helsinki Declaration.
Results and discussion

Spiritual domain

The NDOSQ is based on the assumption that spirituality is the core of being, on which everything else is constructed. Spiritual awareness is therefore assessed with the question “What is the most important thing to you in your life?” For most people, success in this domain is thought to depend on opportunities for altruistic actions that contribute to a sense of self-worth [22]. For people with antisocial personality disorder altruism may not be required for spiritual fulfilment, but people with personality disorder were excluded from this research. Capacity for altruistic action may depend on either self-sacrifice or success in the other domains. Of the 7 patients who took part in this pilot study only two identified altruism as the most important thing in their lives:

• F59’s career was based on altruism. The most important things to her were “being able to care for” her relatives with a stroke and mental health problems, while also staying in work. Diabetes had minimal or no impact on her occupational freedom. She stated however that the demands placed on her by her caring and work responsibilities made her vulnerable to hypoglycaemia.

• M63 stated his “wife and two children” were most important in his life. His children had “multiple disabilities” and his “diabetic control requirements” impaired his ability to care for them. “Sometimes my requirements take second place”.

Of the other 5 patients, one (F71) identified mindfulness as the most important thing in her life. This suggests a high capacity for psycho-spiritual integration. The other patients indicated that basic survival needs were most important. This reflects limited opportunities or capacity for spiritual fulfilment. Occupational therapy intervention for basic health and social needs may be necessary before altruism can be addressed.

Psycho-spiritual integration

This domain depends on self-actualisation despite social pressures that may discourage individuals from living spiritually authentic lives. The NDOSQ assesses this by asking “How is diabetes affecting your ambitions or goals?” This question is based on the assumption that people may not pursue their inner-callings due to fears or low expectations. F59, F71, M55 and M63 expressed no problems with this domain though M63 wondered whether his life ambitions would have been different if he did not have diabetes. F71 stated “Living the day” was the most important thing in her life, reflecting an attitude of mindfulness conducive to psycho-spiritual integration. This mindfulness had not however been mastered and F71 expressed uncertainties about the future, indicating that she was worried that she would not be able to manage her diabetes if she acquired cognitive impairments in the future. The other three patients’ capacities for self-actualisation were limited by more basic unfulfilled health or social needs.

• M40: “For over 40 years none with other health issues, not being able to achieve”

• M56: “Internet cut off. OU degree cancelled. No ambitions.”

• F39: “was high functioning initially despite alcoholism. Diabetes threw this balancing act”

Occupational therapy interventions for basic health and social needs, facilitated goal-planning or vocational rehabilitation could be useful for psycho-spiritual integration.

Expression and communication

Self-expression is assessed in the NDOSQ by the question “In life generally, do you feel able to express yourself and have your questions answered?” F39 described herself as “quite British and quite reserved” even when she became angry. This behavioural trait has been associated with poorer prognosis for patients with autoimmune diseases [24]. F39 complained that occasionally as an inpatient she thought the insulin doses she was being given were too high, but healthcare staff did not listen to her and she subsequently became hypoglycaemic. “I do not need a nurse telling me what to do.” This disempowering alienation may have been secondary to judgements made by clinical staff based on the frequency of F39’s DKA recurrences. F39 explained that DKA only occurred when her mental capacity was impaired by intoxication secondary to alcoholism, and she felt capable of self-care following detoxification in hospital. M56 believed that “people do not have the time” to listen to him. Use of the NDOSQ followed up by group occupational therapy may be a good start at addressing the alienation experienced by these patients.

Compassion

The NDOSQ assesses this domain with the question “How is diabetes affecting your relationships?” Two patients (F39 and M63) said that aggressive behaviour secondary to hypoglycaemia impaired their relationships with other people such as family or healthcare staff. F59 stated her “husband gets annoyed by” her hypoglycaemic episodes if they are frequent, and expressed getting “stressed with juggling everything trying to keep everyone happy.” One patient’s intimate relationship had previously been affected by erectile dysfunction, but this had been remedied with a vacuum pump. M40 attended
with his wife. They both described how recent deteriorations of his physical health had emotionally strained them both despite a strong, loving relationship. M40 reported tearfulness and “being snappy at times” despite being treated with anti-depressant medication. M56 was “half-way through a divorce.” This may have been precipitated by his diabetes and multiple co-morbidities straining his relationship, but the stress of divorce was also impairing his diabetes self-care due to maladaptive coping strategies. Occupational therapy interventions to increase social support could reduce the strain on these patients’ personal relationships.

**Personal Power**

The NDOSQ uses career success as a crude measure of personal power and social standing. This is not an acute measure, as materially successful people can suffer acute losses of personal power during acute illness. F39 for example, felt that control was taken away from her during hospital admissions and “a patient should be allowed to manage” their own diabetes “if they have capacity.” Similarly M55 was trying to manage a painless pressure sore on his amputation stump himself without seeking medical attention. When the occupational therapist spotted this she referred him to the consultant physician for immediate review, who then referred him to a podiatrist for tissue viability care to prevent further limb loss. M55 expressed dissatisfaction with his autonomy being disrespected and described this intervention as “cheeky”. These examples of patients prioritising sense of personal power over diligent management of basic survival needs may be considered by healthcare professionals to be maladaptive behaviour. F39, M40 and M56 felt unable to work due to co-morbidities. F39 was worried she would be discriminated against due to diabetes and M40 stated “I feel that I have to prove I can do more than others to be the same.” M56 said he had “no career prospects” and was “unable to work.” These patients generally fared worst in all domains of the NDOSQ. Other patients had varying degrees of success. M55 felt that his mobility affected his glycaemic control. “I lost my class 1 heavy goods vehicle licence but do my best to stay in work.” M63 described himself as a successful grammar school student who lost his sense of ambition when he was diagnosed with diabetes. He wondered how his life may have differed if he had not developed diabetes in his youth. F59 said that hypoglycaemia occasionally affected her at work, but this had not affected her career. F71 believed that due to adjusting well to her diagnosis, her career had not been significantly affected. Occupational therapy for vocational rehabilitation or patient advocacy by occupational therapists could be used to reduce patient disempowerment.

**Hedonism**

Patients whose basic survival needs had been fulfilled were generally able to seek pleasure. Conversely F39 reported inability to have fun due to agoraphobia and alcoholism. M63 wanted to go abroad on holiday but was afraid to do so because of his diabetes, and therefore had not travelled. If younger patients had been recruited into the sample greater adverse effects of pleasure-seeking on diabetes self-care may have been revealed by the data. Speaking of his youth M63 said:

“Yeah it does stop you having fun … all your mates used to go out drinking, so you would as well, feel rough for a few days after but”

M56 reported frequently binge-drinking alcohol and consuming sugary foods as maladaptive coping strategies to deal with the stress of divorce and financial insecurity. These behaviours are likely to lead to secondary organ damage. M56 also stated “I don’t have fun.” F59 reported that what she most wanted was leisure time with her husband, but that caring for her relatives and her own diabetes management made this “impossible”. The occupational therapist signposted her to carers’ support and sources of funding for hired carers. Patients may benefit from occupational therapy to introduce less-harmful pleasurable behaviours and peer-supported group recreational activities.

**Basic survival needs**

Poorly controlled diabetes is a direct threat to survival. F71 had attended a Dose Adjustment For Normal Eating diabetes self-management course and was happy with her diabetes self-management at present despite feelings of insecurity regarding the future. She expressed clear indicators of success in every domain of the NDOSQ except spirituality. This specific deficit may reflect a weakness of the NDOSQ rather than an absence of spiritual awareness in the patient’s life. In contrast, the patients who expressed deficits in multiple other domains expressed underlying problems in this one. M63 felt he and his wife needed a “well overdue break” from taking care for their disabled children. Rest is a basic survival need; not a pleasure-seeking need. M40 worried about financial insecurity because both he and his wife were not working due to long-term illness. He said his resulting stress levels negatively impacted on his diabetes self-management. M56 stated he had “no money”, “stress”, a “bad diet” and fears about an undiagnosed cognitive impairment and said “I only feel safe when my mates pop in.” His function was also limited by chronic musculoskeletal pain, visual and cognitive impairment. All of these factors adversely impacted on his ability to attend to diabetes self-management. This patient would
benefit from further occupational therapy for in-depth cognitive testing and medical screening for dementia. He was therefore referred to community occupational therapy and his general medical practitioner.

M55 already had a below-knee amputation secondary to poor glycaemic control. His reluctance to report a new stump ulcer to medical staff put him at risk of further limb loss. Of all 7 patients, F39 had the most admissions for DKA and was at greatest risk of sudden loss of life due to poor diabetes self-management. F39 had not been seen by an occupational therapist before and was dissatisfied by her perceived lack of psychological support for alcoholism provided by the local substance misuse service. She was initially obsessive about glycaemic control and set an alarm to check her blood glucose level every 2 hours. This resulted in sleep disturbance. She described becoming “nonchalant” later in her disease course though she experiences continual anxiety regarding possible secondary organ damage such as blindness or amputation of her feet. Threats to F39’s basic survival had overwhelmed her to the extent that she is no longer able to pursue success in any of the other domains. F39 could benefit from intensive community occupational therapy to connect her with coping resources to fill every domain of the NDOSQ in addition to ongoing support from substance misuse services and psychiatric support for agoraphobia. Diabetes can also complicate the treatments of other medical problems. M63 for example said: “I had a hydrocortisone injection in my shoulder and it really did scupper me for a few days.”

This pilot study was limited by a small sample size of self-selected patients. It is possible that only the concordant patients with psychosocial problems would consent to an extra hospital appointment to try occupational therapy. It is important to gather data from patients who are non-concordant with diabetes care and do not attend their clinic appointments. No younger patients consented to take part in this research. It is possible that the hedonistic behaviours of teenage patients may increase their risk of DKA or secondary organ damage. It would therefore be useful to repeat this research with inpatients admitted with DKA. The NDOSQ is a crude, un-validated tool and cannot be used as a substitute for in-depth holistic occupational therapy interviews.

Summary and Conclusions

This small pilot study of 7 patients confirmed that type-1 diabetes can impact on patients’ self-awareness, interpersonal relationships, employment and career prospects, sense of autonomy and social standing, enjoyment, sexual function, mental health, physical health and sense of security. The patients’ responses also confirmed that co-morbidities, financial factors, pleasure-seeking and interpersonal relationships all impact on patients’ capacities for diabetes self-care. Many of these problems were occupationally mediated. Unless patients are provided with holistic treatment plans to help them manage their life problems, diabetes management is unlikely to be optimal. This pilot study has therefore revealed a role for occupational therapy in diabetes out-patient clinics.

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References:

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Appendix 1

Norwich Diabetes Occupational Satisfaction Questionnaire (Version 1)

How is diabetes affecting your life, and what can we do about it? Occupational therapy is to help people live happy, healthy lives. Please think about these questions while waiting for your appointment and write down any issues you would like to discuss. It may not be possible to discuss everything in one appointment, so the issues most important to you will be discussed first. Continue writing on the back of this page if necessary.

<table>
<thead>
<tr>
<th>Life area</th>
<th>Problems</th>
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| What is the most important thing to you in your life? | a) How is diabetes affecting this issue?  
b) How does this issue affect your diabetes? |
| How is diabetes affecting your ambitions or goals? | How are your ambitions and goals affecting your diabetes? |
| In life generally, do you feel able to express yourself and have your questions answered? | |
| How is diabetes affecting your relationships? | How are your relationships affecting your diabetes? |
| How is diabetes affecting your career prospects? | How does your career impact on your diabetes? |
| How is diabetes affecting your opportunities to have fun? | How are fun activities impacting on your diabetes? |
| Do you feel safe? | How does this affect your diabetes?  
How does your diabetes affect this? |