Research Methods Two

A Participatory Action Research (PAR) into how the language and vocabulary of diabetes facilitates peoples' experience of living with diabetes: The Language in Diabetes Study (LIDAS)

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Abstract

There are 4.2 million people diagnosed with diabetes in the UK. It has been established that diabetes causes psychological strain for people with diabetes (PWD) both in increased mental health diagnoses and specific issues under the heading "diabetes distress" (DD). The language and vocabulary of diabetes has been implicated in DD as it may comprise of a restricted code/dialect with negative connotations. Suggestions have also been made to alter speech forms to avoid this utilising alternative vocabulary. A further question however, is why this phenomenon persists at all?

Aims: The purpose of the Language in Diabetes Action Study (LIDAS) was to explore how the language and vocabulary of diabetes facilitates peoples' experience of living with diabetes. As a long-term condition diabetes has a high burden of self-management practices by the patient. Language and vocabulary is seen as a mediating factor in PWD understanding the meaning and purpose of those practices and how they mitigate risks for future complications and promote health. A phenomenological and existential underpinning understands that language conveys meaning but also shapes meaning and this will influence a PWD way of being with diabetes. A thorough review of the literature comprises scientific diabetes-related literature, health psychology literature, existential and post-modernist literature and comparison with language and its significance in other long-term conditions.

Method: The method deployed was Participatory Action Research by forming a Cooperative Enquiry group of Co-researchers that participated through cycles of dialogue and reflection to provide a "slice through" rather than a "snapshot" of their lifeworld experience with diabetes. This was in order to move closer to research *with* PWD as opposed to *on* PWD. Challenges in study realisation were explored and how technology in terms of video conferencing and transcription assisted. Nine participants contributed in the PAR group to varying degrees, of which a core group of 4 committed Co-researchers provided substantiate involvement over eight months of cycles of reflection and dialogue on a weekly or fortnightly basis by consensus. Additionally, work peers from Diabetes UK volunteered involvement. Co-researchers and team peers provided 27 hours of transcribed material, 9000 words of dialectic

material from the DUK Forum, with a total number of participatory voices totalling 40 respondents. The gender of participants, including those from the DUK Forum was quite even (47% male, 53% female). However, female participants contributed more cycles of dialogue and reflection over time. The data then comprises closer to 75% of the transcribed data set. Participants' age ranged from 21 to 50 with a mean calculated age of 32. A hermeneutic developed for Co-researchers through cycles as they became more invested and involved; this was augmented using interpretive analysis in the manner of Foucauldian genealogy considering bio-power, regimes of truth and Heidegger's notion of entanglement explicated in his discussion in the question concerning technology. In addition to Co-researchers reflections each dialogue was transcribed and analysed for themes and made available to Co-researchers for further comment, so each cycle refined and reworked the thematic analysis.

Findings and Discussion: The LIDAS group findings strongly support the phenomenon of a restricted code/dialect in diabetes and the significance in the aetiology of DD. Furthermore, the findings explore the underlying beliefs implicated and the mechanisms that may open understanding to the root of this phenomenon and the route by which it sustains itself. This abstract, idealistic notion is a discourse that concerns an unreflected belief that a PWD attitude and personality is central to management, termed Capacity to Control. In this way a PWD is viewed as having to become highly motivated, disciplined, ascetic and compliant to a restricted regimen, subjected to measurement and assessment of their HbA1c targets. This is as opposed to attributing diabetes management to Skills, Knowledge and Tools that are contextually optimised for the individual PWD and contribute to their pursuit of lifeworld goals. This is epitomised in the exemplars of Structured Patient Education, Pump Therapy and Flash Glucose Monitoring. The discussion explores how this entangled discourse leads to an illusion of choice, an abstract rather than humanistic view of PWD, burnout and DD, moralism and stigma. The study further notes that tensions over targets, resources and cost produce consumerist healthcare and a notion of a patient's responsibility to be compliant and that these pressures are the root of Capacity to Control.

Synthesis of Findings: This section continues by drawing together the themes revealed in the findings with the current literature and the concepts of Heidegger and

Foucault. It also explicates the tensions and forces at play for PWD and HCP, drawing attention to Healthcare for long term conditions viewed in the light of consumerism and moralism. The involvement of counselling psychology and psychotherapy is explored and problems that arise in how referrals are made and what psychological care means for diabetes.

Conclusion: The study concludes by assessing study limitations and evaluating PAR as a means of generating data and what this means for the findings. It goes on to explore the gender bias and its possible significance for understanding the findings. An exploration of the possible uses of the findings in relation to HCP training and reflective practice, counselling and psychotherapy services for PWD, patient empowerment for PWD and possible future purposes for PAR in health and psychology. It also suggests possibilities for further research: the potential for using the LIDAS study themes to generate survey questions and establish the extent of applicability with wider participation or to address the gender bias. It also assess the possibility of developing LIDAS adapted patient education for clinical trial compared with current patient education.

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Chapter One: Introduction

The most recent estimate for the prevalence of diabetes in the UK population is 4.2 million people (Diabetes UK, 2015)

Medically, diabetes is characterised by dysregulation of blood glucose caused by an autoimmune reaction that destroys insulin producing cells in the pancreas (Type 1 diabetes or T1), or a combination of endocrine dysfunctions beginning with insulin resistance and progressing to include irregular insulin production, and regulatory hormone imbalance (Type 2 diabetes or T2). T1 diabetes can occur from infancy and throughout life but peak onset is 12 to 14 years and younger. Onset for T2 is commonly over the age of 40. Causes of T2 are broadly established as genetic, age and lifestyle related, with an emphasis from the public health perspective on the impact of obesity, poor diet and low physical activity. Other prodromal influences may include the effect of other medications (steroids, anti-depressants and anti-psychotic medication), pancreatitis and pancreatic cancer. T1 gradually progresses to complete dependence on insulin therapy delivered by subcutaneous injection while slower non-linear progression of functional glucose dysregulation in T2 necessitates extending therapy over time from lifestyle changes (healthy eating, activity and weight management) to a variety of oral medications and for some, insulin therapy (Diabetes Care, 2014).

Hyperglycaemia (higher than normal saturations of glucose in the blood) can cause the presence of recognisable symptoms. Tiredness and unaccountable weight loss (from the failure to optimise glucose exchange into the cells to provide energy); excessive thirst, dry mouth and frequent urination (as body hydration is used to flush excess glucose from the blood); blurred vision, skin irritation, dryness or deterioration in eczema or psoriasis, athletes foot, poor healing, itching genitalia and increased risk of thrush or urinary tract infection (caused by excessive glucose secretion in the tear ducts, skin and urine). Treatment at diagnosis is targeted to stabilise glucose regulation and mitigate hyperglycaemic symptoms (*ibid*).

In the long term mild to moderate hyperglycaemia can cause damage to blood vessels that lead to potentially devastating complications. Macro vascular damage increases the risk of Cardiovascular complications such as heart disease and stroke. Micro vascular changes can lead to damage of sensitive organs reliant on capillary health; the kidneys (nephropathy), the retina of the eye (retinopathy and macular oedema) and the nerves (neuropathy affecting the peripheral nerves in the feet and hands and/or autonomic nerves affecting the muscles and viscera). A combination of micro and macro vascular damage can lead to loss of sensation and poor circulation in the feet presenting the risk of ulceration, necrosis or bone deformity (Charcot foot), in turn causing septicaemia or gangrene necessitating amputation. Long-term prognosis can be improved by optimal blood glucose control above and beyond stable levels. This requires the patient to adhere to appropriate clinical treatment and maintain a healthy weight and lifestyle to control blood glucose levels (UKPDS 1998).

The brief medical explanation of diabetes above is not atypical with the more striking concomitant being the general consensus of the patient's treatment adherence and control in respect of medication and lifestyle being paramount (Weinger, et al 2005; Nash 2013).

Although recognition of the personal or psychological impact of having diabetes is long established (Lawrence 1926; Johnston 1994), health psychology only really increased the focus on the psychological dimensions of the condition from the 1980's (Snoek and Skinner 2005). Predominantly interest has settled largely on two broad areas: psychological problems associated with the condition such as the increased incidence of depression and anxiety among people with diabetes, needle phobia or unique pathologies like diabulimia (an eating disorder of T1); and psychological factors and determinants that limit, facilitate or maintain an individuals' prescribed positive health behaviours (Peyrot et al 1997; Zambanini 1997; Larrañaga 2011; Weinger et al 2005; Snoek and Skinner 2005).

An example of the latter is a common question asked by health care professionals of psychologists and therapists, "how can I get my patient to do what they should be doing?" The wider debate for general medicine is the dilemma of patient non-compliance versus patient empowerment (Chaterjee 2006) that belies the fact that ill health is a state or biophysical event that occurs in a person within a complex context (Anderson 1995). However, classic epidemiology historically conceptualises a patient adhering to medical treatment until they are cured, in remission or the amelioration of unpleasant symptoms. Chronic conditions like diabetes require lifelong adherence optimised above and beyond symptom management and failing to do so will be causing undetectable harm that may result in devastating consequences decades later. Post-diagnosis patients ideally attend an annual review led by the clinical professionals at GP surgery or secondary care diabetes clinic. The review comprises medical tests that establish the relative success of management, any necessary treatment adjustments and the detection of early signs of complications. It is estimated that this involvement equates with approximately 3-5% of the total required for optimal management; 95% of care involvement is conducted by the patient and/or family (Anderson 1995).

The aim of the research is to study the influence of vocabulary and language of diabetes on people's way of being with diabetes and to facilitate an inquiry space for people with diabetes to explore other meaningful language, expression and narrative of their experience. I framed my question as "how does the language and vocabulary of diabetes facilitate peoples' experience of living with diabetes?"

Chapter Two: Review of literature

This research enquires into the language and meanings of a health condition and how these relate to a lived experience. As such, it acknowledges that much of the "knowing" is derived from a bio-medical model of illness, and must attempt to understand something of how this knowing has come about. Studying lived experience by utilising existential-phenomenological ideas and in particular, to explore problems of living with a condition and its psychosocial implications, results in a situation where much of the literature is derived from very different disciplines. Following Kuhn's (1970) work on paradigms, we need to acknowledge that the different disciplines of bio-medical science, health psychology/sociology and existential-phenomenology of health and illness are prefaced by different underpinning philosophies, arguably not always made explicit. Each speaks from specialisations that stand on different ground. A Venn diagram of medical articles about diabetes and psychosocial implications derived from an existential-phenomenological perspective would provide very little vector in this very large corpus of data.

A strategy for conducting a systematic review for this study needs developing in order not to lose one's way. It occurs to me that my long standing relationship of working for Diabetes UK (DUK) provides me with a template strategy for reviewing the field. My role has been to support people with diabetes by having a thorough knowledge of the condition. However, the DUK Helpline began to see that science information officers and health care professionals that populated the original Helpline approach were potentially missing a central feature of support. Although people with diabetes rang with questions about their condition, the answers rarely addressed people's concerns adequately. The organisation began to recruit staff with a psychology/counselling background, the point at which I came to the Helpline. The process of recruiting and training was very different from its first incarnation. Information scientists and health care professionals came from a scientific or biomedical background, so the process of clinicians training scientists about diabetes that spoke from a shared language and underpinning philosophy was relatively speedy. Training people with a counselling or psychology background in which the primary familiarity and skill-set was to hear, understand and empathise with a person, in a knowledge of the science and medicine of diabetes was to straddle these worlds and philosophies. Some early recruitment resulted in staff moving on quickly, finding the collision of empathy and understanding with information and knowledge too uncomfortable, even jarring.

However, a psychological awareness of people's concerns and difficulties with the condition quickly highlighted that information alone didn't easily allow people to make informed choices or to feel equipped for life with diabetes. On the contrary, if the information delivered was abstract rather than explored within a person's particular context, it was capable of obscuring, confounding and obfuscating a path or route for the person to understanding. With colleagues on the team, regular supervision, and scientific clinical training, it became apparent that many people's struggles were based on narrow or distorted meanings of the illness implied by the media, other people with or without diabetes and sometimes clinicians themselves.

It became possible to discern a "flavour" of how this newly minted team (psychologically minded and trained staff given additional scientific information) operated in their encounters with people living with the condition:

1: It was possible to learn and retain a wealth of information from another theoretical discipline holding different values and underpinning philosophies from one's own training.
2: It was possible to evaluate scientific information and its veracity, reliability and validity in the light of how it spoke to people for whom the information felt vital, real and contextual.
3: It was possible to gather, amass and learn information – accounting for its evidence base – with particular reference to that which is applicable to points 1 and 2.

Many schools of counselling eschew the notion of an expert counsellor; one who knows, and strives to engage people with information without entering a dynamic of power that tramples on their sense of holding an equitable encounter with a person. However, using the above approach allowed the Helpline Counsellor and the caller to stand side by side and face the information and evaluate its relevance together, rather than the counsellor giving information. A context-rich formulation of the caller's concerns made, it possible to select what information might be explored in addressing those concerns. Notably call length increased on the Helpline but callers also reported greater satisfaction with the support offered.

I have incorporated some of these elements into a strategy for conducting a literature review. By keeping in mind that diabetes occurs only in a real person in a context with others it is possible to engage with biomedical information that tracks the developing narrative of treatment and management concepts and critiques its real world relevance.

The literature review is divided into section headings for diabetes-related literature and core research (which has had the biggest impact and influence on diabetic medicine), health psychology literature in relation to diabetes and existential-phenomenological literature that contributes an understanding to health or language and meaning.

2.1 Scientific diabetes-related literature

The diagnosis and classification of diabetes disorders historically has been complicated and confused, primarily due to the tensions in distinguishing between symptoms/treatment and pathology/aetiology (Herman et al 2010). Generally, medical science favours classification based on the pathology/aetiology of disease, describing the underlying physiology and progression from which symptoms and treatment follow while focus on symptoms/treatment hampers clarity as they may appear the same for widely divergent pathologies (Abduelkarem 2004). An attempt to classify distinct diabetes disorders was not even achieved until 1979 when diabetes mellitus became Insulin Dependent Diabetes Mellitus (DDM) and Non-Insulin Dependent Diabetes Mellitus (NIDDM), the focus of distinguishing diagnoses being treatment with insulin despite NIDDM patients also being treated with insulin in 30% of cases (*ibid*). The predominant measurable symptom was and still is hyperglycaemia (high blood glucose concentration) but there is vast heterogeneity in blood glucose levels and presence/absence of symptoms at diagnosis of NIDDM above the diagnostic criteria of >7mmol/l Fasting Plasma Glucose (*ibid*).

Although The World Health Organisation (WHO) acknowledged at the time that this distinction actually comprised a number of heterogeneous conditions characterised by hyperglycaemia the evidence base was not available to distinguish the differential pathologies, even after debate convened that DDM and NIDDM be re-classified as Type 1 diabetes (T1) and Type 2 diabetes (T2) to remove insulin treatment as a confusing distinguishing factor (RECDCD 2000).

In addition to classification and diagnostic criteria for T1 and T2 the increasing evidence base for rare but distinct nomenclature for diagnostic variations that have a bearing on symptoms and treatment as well as clinician and patient understanding continued from the turn of this century (*ibid*). Often these are described with reference to similarities to T1 and T2 with additional noted differences i.e. Gestational Diabetes (only occurs after the first trimester in pregnancy, commonly goes into remission after labour but is similar to T2 and carries increased risk of T2 later in life); Latent Autoimmune Diabetes in Adulthood (similar pathology to T1 but has features of T2 and often diagnosed later in life than T1); Maturity Onset Diabetes in the Young or MODY (T2 but in adolescence and commonly contingent on obesity) and Monogenic MODY (appears and often misdiagnosed as T1 but characterised with a specific genetic fault and is a particular endocrine deficit that doesn't require insulin) (*ibid;* WHO/IDF 2005).

The significance of these variations and complicating classifications is multitudinous. An example of the medical significance is rare Monogenic MODY. Fairly recently discovered, children with this genetic endocrine disorder were diagnosed with T1 requiring lifelong insulin use, struggling with suboptimal blood glucose management and the risk of life-limiting complications. However, it transpires the condition is caused by a faulty gene that damages enzyme messaging to healthy insulin producing beta cells and can be treated to the point of full remission with a small daily dose of oral sulphonylurea (Rubio-Cabezas 2014).

However, this is also of great significance for clinicians and their patients as this complexity of physiological and contextual variations gives rise to confusion in terminology that can detrimentally affect patients' outlook and progress (Parry 2004).

This includes a tradition of clinicians developing a vernacular to use with patients, instead of a recognised nomenclature. Such terminology may even pass into medical literature in the absence of consensus for a distinct nosology. Examples include:

Term	**Possible Meanings**
Sugar diabetes; a touch of sugar; borderline	T2 but not requiring medication at this stage
Borderline	Possible risk of T2 but no diagnosis
Borderline	Normal blood glucose at a range close to the threshold for non-clinical Impaired Glucose Regulation
Pre-diabetes	Standing in for non-clinical Impaired Glucose Regulation
Type 3 diabetes	Has been used to denote LADA, MODY, steroid induced diabetes or even diabetes related vascular dementia onset
Type 3c diabetes	Damage to the pancreas from pancreatitis or pancreatic cancer or surgery/radiotherapy/chemotherapy as treatment for cancer
Type 1.5 diabetes	T1 but diagnosed after the age of thirty or LADA or Insulin Dependent due to pancreatitis damage, pancreatic cancer or injury

(Abduelkarem et al 2004; Herman et al 2010; Valentina et al 2014).

Access to internet searches by patients commonly referred to as asking ‘Doctor Google’ has been shown to provide benefits to patients’ general knowledge and understanding (Wilson 2013). However, where this is based on a pluralism of terms in conjunction with a huge online market for costly cures and quick fixes generating unfounded and even bogus claims for herbs, supplements and fad diets, adds to confusion. Confusion in terminology can be costly to the patient clinician relationship and further confounded by the change in professional values in medicine between mature and newly trained clinicians (Southon et al 1998; Borgstrom 2010). This can be seriously detrimental to patient wellbeing, patient satisfaction, trust in clinicians (Bakar 2016) and even lead to issues of identity threat in which the patient feels disempowered, dehumanised and devalued (Coyle 1999a; Coyle 1999b) or experiencing a sense of abuse not identified through medical error (Brüggemann 2012). Pluralism of meanings leads to implicit messages, unintended or otherwise, that confound patients and obscure access to practical relevant approaches to day-to-day management.

2.2 Core research literature

Several major health studies have contributed to influencing clinical care, outcomes and recommendations for significant biomarkers of successful diabetes management. The Diabetes Control and Complications Trial (DCCT) and the Epidemiology of Diabetes Interventions and Complications (EDIC) Study in Type 1 diabetes both established that significant reductions in complications correlated with optimal blood glucose management. The DCCT included nearly 1500 patients over a 10 year period in the USA and Canada, while the EDIC followed 97% of the same cohort from 11 to 20 years, with some further follow up at 30 years. Both studies have produced sufficient data for elaboration across clinical outcomes and tens of follow up clinical research articles. The central purpose of the studies was to compare intensive insulin therapy that attempts to optimise metabolic blood glucose, with standard insulin therapy designed to reduce the risk of symptoms of hyperglycaemia and hypoglycaemia.

Historically, Type 1 diabetes correlated with an increased risk of mortality and reduced life expectancy. Prior to the discovery of insulin, 50% of patients died within the first 20 months after diagnosis. After the discovery of insulin in 1922, patients with diabetes survived for longer but still had a 20-year reduction in life expectancy and the risk of secondary complications. During the second half of the 20th century and the beginning of the 21st century, advances have narrowed the survival gap to less than 4 years compared with the non-diabetic population (Wright 2015).

The DCCT and EDIC established an association of decreased risk for complications of diabetes and premature death with intensive insulin therapy that has been adopted worldwide. Essentially, metabolic control of <7%mg/l (58mmo/mol; HbA1c glycosylated haemoglobin test) has become the standard medical target for clinicians and patients. Intensive insulin therapy describes the use of a basal/bolas regimen of 1-2 long acting basal insulin and 3 fast acting bolus insulin doses at mealtimes with optional extra adjustment doses, all delivered by subcutaneous injection. The principle is to administer insulin to closely mimic pancreatic insulin production and achieve blood glucose profiles similar to people without diabetes and that this mitigates adverse outcomes and early death. The development of newer accurate home blood glucose monitoring technology, insulin types (such as analogues with more predictable absorption profiles and quicker fast acting insulin), insulin delivery technologies like insulin pens and continuous insulin infusion systems (insulin pumps) have been driven by this principle of ever more intensive therapy. One primary goal of the DCCT/EDIC was to test the hypothesis that hypoglycaemia was an adverse long-term outcome to be avoided. Increased intensity of insulin therapy has a correlation with more hypoglycaemia incidents and greater severity but these were shown not to contribute to poorer long-term outcomes such as cognitive impairment. Hypos were deemed unpleasant but not detrimental to long-term health, therefore intensive (sometimes also referred to as aggressive) therapy could be safely achieved.

However, the EDIC follow up studies showed that HbA1c between the two groups began to level out above 7%mg/l (58mmol/mol) as time went on past the original 7 years. This strongly suggested that participants found it very demanding to maintain intensive therapy regimens over the following two decades. Interestingly, the improvements in lower complication risk and total mortality at 27 years was quite modest, albeit statistically significant, and less than four years difference from the general population (Miller 2012; Wright 2015). It may be that improvements in insulin and monitoring coupled with greater awareness in patients and clinicians mean that targets in excess of those recommended but lower than overtly hyperglycaemic still equate with better total outcomes. There is also a possibility that other protective variables are at play in addition to the biomarkers measured. An example is diabetic heart disease in diabetes that has a specific metabolic problem of not switching to glucose metabolising during myocardial infarction increasing the risk fatality (Heather and Clarke 2011).

In Type 2 diabetes the primary cohort study that supported the principle of optimising metabolic glucose management mirroring the DCCT/EDIC was the United Kingdom Prospective Diabetes Study group (UKPDS 1999). This study involved 5,102 patients newly diagnosed as Type 2 with an average follow up of 10 years making it the largest study conducted worldwide in Diabetes. Broadly the UKPDS reported reductions in complications overall with the same HbA1c targets as the DCCT. However, improved outcomes varied between different complications with the greatest reduction for retinopathy (eye damage), some reduction for nephropathy (chronic kidney disease) and a probable significance for reduction in neuropathy (nerve damage). Cardiovascular outcomes barely showed any significant difference and in patients this demonstrated the significant variable was use of oral treatment metformin irrespective of HbA1c. Another issue raised concerning the UKPDS is relevant to similar clinical trials, namely that the stated outcome measures at the outset of the trial were reframed during the trial potentially weakening findings (McCormack and Greenhalgh 2000). It has even been suggested that these findings make a case for not aggressively targeting blood glucose levels in Type 2 (Ewart 2001).

Despite such reservations glycaemic targets of 6.5%mg/l (48mmol/mol) have become the standard recommendation for Type 2 management rising to 7%mg/l (58mmol.mol) for patients with Type 2 using insulin) (NICE 2013).

For many people with both types of diabetes these targets are very difficult to achieve for long periods across the life span of diabetes post-diagnosis and the concern produced by the desire for optimal glucose are highly demanding and burdensome for the individual (Anderson et al 1995; Polonsky et al 1995, 2005; Fisher et al 2007, 2008, 2010 and 2010a)

It has also been pointed out that data relating to metabolic targets derived from clinical trials may not accurately reflect real world achievements as patients in research may give more attention to treatment and lifestyle knowing they are part of a study. Indeed, some new evidence from the US suggests that people with Type 2 attain expected target levels only 50% of the time (Edelman and Polonsky 2017). There may be some reasons for this particular to the American health system. The UK estimate is that less than a quarter of people achieve target levels (Diabetes UK 2015).

In conjunction with the drive to meet target blood glucose (BG), blood pressure (BP) and cholesterol, lifestyle targets for people with diabetes are established to promote overall improved health and assist in achieving biomedical recommendations (*ibid*; NICE 2013). Generally accepted lifestyle recommendations include a healthy balanced diet, achieving target Body Mass Index (BMI) of 25 or less, physical activity (at least half an hour of moderate paced activity per day) and smoking cessation. There is a great wealth of research and literature in support of these lifestyle approaches to management and their benefit for physical outcomes (Povey and Clark-Carter 2007 for an overview). However there is equally a wealth of research data and discussion identifying barriers for PWD in achieving lifestyle goals (Rushforth et al 2016). Maintenance and sustainability of health behaviours is also an issue (Rise et al 2013). The example of literature outside diabetes pertaining to weight-loss and smoking cessation alone evidences the difficulties of achieving goals. This is too great an area to go into in depth but serves to demonstrate the complexity of the problem and to explain the poor success rates in accomplishing goals. It becomes apparent that the degree of problem and complexity in lifestyle goal achievement in diabetes becomes its own barrier. There is just too much to do and many people feel overwhelmed.

Another significant issue is accessing appropriate information. An immense amount of misinformation and myth is published in the media and online. This obviously generates confusion but more worryingly misrepresentations of near factual evidence is “sticky” requiring several solid debunks before individuals can address the confusion or bias (Lewandowsky et al 2012; Powell et al 2018). This phenomenon is not confined to the general public but HCP are also susceptible (*ibid*). Given that primary care is the point of diagnosis for the majority of people with T2 coupled with the fact that health nutrition is not part of GP standard training (Ball et al 2014) and that there are notable discrepancies in information recalled in health consultations between clinicians and patients (Parkin and Skinner 2003) there is a sense that early consultations in the life of a patients diabetes journey can produce unhelpful and/or erroneous messages that are hard to undo.

The establishment of Structured Patient Education (SPE) over the past 15 years has attempted to address this, however the problem of misinformation may also be evidenced by the success and improvements demonstrated by SPE (Hill et al 2006; Mansell 2012).

The other major cohort study of significance is the Diabetes Attitudes Wishes And Needs, DAWN and DAWN 2 (Funnell 2006; Peyrot et al 2013). This international large-scale survey of patients, family members and HCPs is discussed further in the section on health psychology literature because of the emphasis on psychosocial experiences of the condition.

2.3 Health psychology literature

Much of the endeavour of health psychology in relation to diabetes has been driven by the medical imperative of patients improving or reducing barriers to optimal self-management. Where the DCCT and UKPDS provided evidence that improved blood glucose reduced complication risk, health psychology sought to establish the significance of the psychosocial dimension of living with the condition (Snoek and Skinner 2005). Primarily, evidence has been sought to demonstrate increased prevalence and comorbidity of diabetes and psychological issues (Eiser, 1990; Kovacs 1995; de Groot et al 2001; Anderson et al 2001; Snoek and Skinner 2005; Broadbent et al 2011; Fisher et al 2007; Speight et al 2012).

Following the tradition of health psychology research into other health conditions, exploration of correlations between psychological factors and the impact on health behaviours and key physiological outcomes (Assal et al 1985; Peyrot et al 1997 and 1999; Zambanini 1997; Griva et al 2000; Weinger et al 2005; Hill et al 2006; Davies et al 2008; Harvey and Lawson 2008; Larrañaga 2011; Pouwer et al 2013; Chew et al 2014). From this a picture emerges of how the burden of living with diabetes increases the risk of psychological problems and these interfere with individuals' abilities to integrate healthy behaviours, leading to poorer physical health outcomes.

These streams of knowledge have developed into two broad strands: interventions to ameliorate the negative impact of distorted illness perceptions, lack of resourcefulness or unhealthy behaviours (Assal et al 1985; Griva et al 2000; Hill et al 2006; Rollnick et al 2007 and 2010; Davies et al 2008; Mansell 2012; Steinberg and Miller 2015); and psychological interventions for comorbid depression and anxiety (Ruben and Peyrot 1992; Harris and Lustman 1998; Glasgow et al 1999; Delameter et al 2001; Britneff and Winkley 2013; NICE Guidance 2013).

Since the turn of the century increasing focus from William Polonsky, Lawrence Fisher and colleagues has reassessed the concept of increased comorbidity of depression and anxiety in diabetes by distinguishing it from Diabetes Related Distress (DRD, also referred to as Diabetes Distress, DD). Work began developing measures and comparing features to establish psychological characteristics specific to the rigours and challenges faced by people with diabetes. The Problem Areas in Diabetes Scale and the Diabetes Distress Scale are self-reported survey measures used to assess the relative strength of psychosocial issues in relation to specific dimensions of diabetes. These include emotional burden, regimen distress, interpersonal distress and physician distress (Polonsky 1999; Polonsky et al 2005; Fisher et al 2007, 2012). Equally significant was to show that these measures detected an experience distinct from depression and anxiety but often confused with these clinical phenomena. Direct comparisons of DDS and standardised measures GAD7, PHQ9 were made (Gonzalez et al 2011; Fisher et al 2007, 2008, 2010a, 2014). Much of the perceived increases in depression and anxiety from earlier studies may now be described by DD (*ibid*).

A picture is emerging of DD that sometimes flows from depression and anxiety, is sometimes a precursor to, and/or displays greater prevalence of these conditions, and is a distinctly better predictor of poorer care outcomes (Polonsky 1999, Polonsky et al 1995, 2005; Fisher et al 2007, 2008, 2010, 2010a, 2012; an Bastelaar 2010; Gonzalez, Fisher and Polonsky 2011, 2014; Snoek et al 2015). Interestingly DD has been distinguished from depression and depressive symptoms in that psychologically addressing depressive symptoms alone does not correlate with improvements in physical and metabolic outcomes; whilst challenging DD directly does (Fisher et al 2010; Wardian and Sun 2015).

The measurable dimensions of DD are tantalisingly suggestive that meanings derived from language used in consultations with health care professionals and others with the condition, in other words the medically mediated discourse of the management and complications of diabetes, are potential antecedents of DD (Polonsky 1999; Speight 2012). This is in respect of those dimensions of the encounter in consultations where explicit or implied meanings diverge sharply from the patients experience or the evidence base e.g.

- moral rather than practical tone emerges “you ought to have better control”, “it’s not good for you” (Broom and Whittaker 2004)
- gross endpoint outcomes are related to one-off particular behaviours “well you can eat the cake if you don’t mind going blind” or
- patient concerns or experiences are diminished or invalidated - Patient: “I’m really struggling with injections” – Nurse: “I’ve known five year olds who cope perfectly well”

The language of diabetes is beginning to gain credence as a potential obstacle to understanding and management for people with diabetes and clinicians. Professor Jane Speight has been enthusiastically involved in research and comment concerning the impact of language on diabetes behaviours and dialogues in clinic. In 2006 Diabetes UK Helpline secured funding to pilot a two-day training for HCPs in language and communication skills in consultations with patients. The format for the first workshop was designed to explore skills in engaging with psychosocial dimensions of patients’ expressions in the consultation room. Common words and phrases used in diabetes, derived from discussion topics published in DUK’s Professional Members magazine, *Update* (Usher A, Mind Your Language) were unpacked with alternative ways of speaking offered and practiced. The second day involved reflective practice on the uses of communication skills developed and held a month from the first meeting to allow concrete professional experience to inform reflection. The third and fourth groups run were observed and evaluated qualitatively with the inclusion of participant interviews by Jane Speight and colleagues. The report identified perceived communication barriers and increased HCP understanding and confidence in addressing them and was subsequently published (Mosely, Aslam and Speight 2009).

In 2010, Speight moved to Deakin University Australia and was a founding member of The Australian Centre for Behavioural Research in Diabetes. In collaboration with Diabetes Australia a position statement was published highlighting the need for greater thoughtfulness about the meanings derived from commonly used language in diabetes care, research settings and publications (Diabetes Australia 2011). This closely reflected the concepts explored in the original Update articles but was presented cohesively within a single publication. Flowing from many other articles and seminars, the significance of language use and its facilitation of diabetes experience pollinated internationally (IDF 2015; Dickinson et al 2017) Six to eight years of research, debate and conference seminars that established the ways in which commonplace vernacular and language of diabetes contributes to a delimiting, negative experience of living with and treating the condition has produced a conceptualisation of a restrictive code/dialect of diabetes (Dunning et al 2017). Despite this the UK is only now following this trend publishing a statement with partners of NHS Diabetes (Lloyd et al 2018).

An interesting feature of research and articles in this area is the focus on identifying and offering replacements to key words and phrases in diabetes language for HCPs and diabetes educators. Although this makes sense on the face of it as these are individuals with early contact and potential influence for patients, it also belies that PWD are often considered and/or referred to as “lay”. This is problematic in terms of the underpinning relationship on the subject of language. If lay is to denote a non-expert, non-professional status of limited knowledge requiring education from professional clinicians and educators who nevertheless are unaware of the impact of language use on day-to-day living and coping that becomes apparent to many PWD, then the meaningfulness of the distinction dissolves somewhat. An example in one study illustrates this (Broom and Whittaker 2004). This method of the study utilised semi-structured interviews of PWD. They were referred to as diabetics and their conversations were termed lay. However, in the body of the text it was revealed that participant PWD included two nurses, a pharmacist and a lawyer. Other participants included people with a family history of diabetes so the combined knowledge and experience of diabetes outweighed that of the researchers. Moreover, the convention of using acronyms for people with diabetes and healthcare professionals were published as pwd and HCP: the capitalising of HCP but not PWD may reveal a further distinction between "lay" and Professional. It is worth noting that structured patient education does not currently include psychosocial aspects of the condition or discussion of language use and its implications.

Attempting to position a psychosocial perspective on living with diabetes clearly and squarely within the literature has been problematic, possibly due to its location in the rift between the objective/subjective epistemology and the underlying concerns of scientific method applied to quantitative and qualitative data capture. It speaks perhaps, to the privilege still granted, of scientific measurability as the route par excellence to truth that diabetes as an endocrine disorder (in a lab or test tube) trumps embodied experience; despite diabetes only being of relevance because it is relevant to a person with diabetes and those persons around them. One approach to addressing the dichotomy of knowledge production in this underlying debate is to provide undeniable credence from the perspective of either validity or reliability, two tenets of scientific method.

The Diabetes Attitudes, Wishes and Needs (DAWN and DAWN2) studies comprise the largest cohort of clinicians and PWD internationally, focusing primarily on the psychosocial experience of the condition and the barriers to self-management this presents. The first DAWN study began in 2001 and utilised structured interviews conducted in person or by telephone. Eleven regions were selected representing 13 countries; each region contacted 250 individuals per region per three stakeholder groups, PWD, generalist and specialist clinicians and nurses (totalling subjects n=5,104 PWD, n=2,705 physicians and n=1,122 nurses). Results were published in multiple research articles over several years (Funnell 2006) but the DAWN study group felt findings needed augmenting.

In 2011 DAWN2, using established principles, conducted a similar methodology, expanding its remit to 17 countries across four continents and to include family and friends of PWD. The final study population consisted of 15,438 participants, including 8,596 adults with diabetes, 2,057 adult family members of adults with diabetes and 4,785 providers of adult diabetes care (Peyrot et al 2013). The purpose was to address that despite some progress since the original DAWN study, it was felt that the psychosocial needs of patients were still not appropriately recognised. The primary stated objective was to further elucidate the barriers to optimal management and the key facilitators to better care. The findings of the combined studies have been reported across numerous ongoing papers, conferences and web resources establishing an interdisciplinary community of professionals and advocates. These establish that PWD experience a negative impact on wellbeing (45%) with some sufficiently burdened to receive a diagnosis of depression or anxiety (14%). Family, friends and peers also were likely to feel emotional strain (45%), leisure and financial burdens (31%, 35%) and their own physical health (27%). Significantly, people close to someone with diabetes report wanting to help them with their feelings regarding diabetes (45%) but did not know how to do this (37%). In relation to HCP engagement, PWD diabetes reported receiving physically tests for diabetes (HbA1c, cholesterol etc 73%) but only asked if they were anxious, depressed or stressed 32% of the time. HCPs identified a greater need for psychosocial support (63%) but only 20%) had received any training in identifying or supporting the psychosocial needs of pwd. However, HCPs also identified their patients needed to improve lifestyle changes (60%) particularly physical activity (93%), healthy eating (91%) and weight loss (90%) (Holt 2013).

The DAWN Study group attempts to recommend actions to support improvements and people-centred care. People-centred, Patient-centred, and Client-centred are terms and concepts that have been widely used and debated belying an underlying tension in the patient-clinician relationship. Stewart (2001) points out some misunderstandings that she feels limit the potential of advancing the clinical relationship. One is that many definitions attempt to make the implied notion of patient choice explicit and this tends to oversimplify. Another is a widespread belief by clinicians and researchers that some patients may not prefer a patient-centred approach meaning it would be unwise to adopt this universally. Stewart argues that this suggests all clinical decisions should be made with the patient collaboratively and this misses the point that the patient’s concerns, experiences and responses are accounted for in consultation. It is not a matter of asking the patient which medication they want to use in every case but their experience, understanding and concerns about medications per se. Finally, Stewart identifies that definitions of patient-centred care comprise several components such as exploring the patient concerns and need for information; an integrated understanding of the patients world, emotional needs, and life issues; common agreement on the problem and its management; enhancing prevention and the patient-clinician relationship. Stewart feels this compartmentalisation is convenient for teaching and research but does not properly reflect the holistic relatedness of this in practice: a patient-centred approach cannot be “done” to patients in bits and pieces, as patient-centredness utilises all parts holistically in a unique way in each interaction (*ibid*).

It is likely there is a more subtle and complex relationship between living with diabetes, language and impact on wellbeing than simply being another phenomena that “happens” to people.

2.4 Comparative review of literature and the significance of language and meaning in other long-term health conditions

Studies of language related to other long-term conditions (such as chronic substance abuse or HIV) and in consultation skills in general, tend to focus on more blatant abuses of language (Dans 2002; Broyles et al 2015, Fix et al 2018, Pugatch and Gordon 2015). These identify pejorative terms that lead to (or reveal) stigma, often by association with socially negative behaviours deemed morally degenerate (drug use, homosexuality, sexual promiscuity) which themselves belie the complexity of these situations. These approaches often focus on specific conditions. Nyblade (2019) conducted a review across a differing conditions and settings, to provide some consistency of stigmatising medical language across varied health and mental health conditions.

One area that stands out is in the form of obesity and language. In 1997 the World Health Organisation published a paper setting out the challenges of the obesity epidemic and clearly identified obesity as a non-communicable disease and the American Medical Association followed suit in 2013 (Frellick 2013). Research focus has been on the impact of complex obesogenic factors and the language used by HCP and the media on the experience of obese people. Terminology and the autonomy of people with obesity to choose their vocabulary to improve care provision and intervention has been roundly debated, with politicised action groups reclaiming the term “fat” but attempting to distance it from its pejorative connotations, and also “first person” language and vocabulary (Dutton et al 2010, Brochu and Esses 2011, Meadows and Daníelsdóttir 2016). There would appear to be a subtext to these approaches: researchers and experts exploring the most appropriate use of language in consultation and collaborating with patients to give them choice over terminology they prefer. The issue, however, is that all these approaches begin with problematising excess weight from a health perspective that in itself tends to narrow definitions of bio-markers for health. Intriguingly, this also is not necessarily supported by the evidence. Cernelič-Bizjak and Jenko-Pražnikar (2014) found that negative cognitions concerning body image impacted negatively on inflammatory health status despite BMI. Blake et al (2013) measured weight satisfaction in patients across BMI in excess of 25 and found it to be a better predictor of health behaviours and biomarkers (blood pressure and cholesterol) than BMI. In other words, positive self-perception improved health status regardless of BMI.

The tendency of these research narratives is to specify particular vocabulary and explore alternatives that are hopefully less loaded as we have seen in regard to diabetes. However, a more nuanced picture emerges where studies exploring language do so in conjunction with considering consultation approaches. This is within the ongoing debate of comparing person-centred/patient centred consultation approaches with traditional, authoritarian, medical expert approaches. Bourdieu (1989) interviewed HCP working with obesity, diabetes and COPD and found a tendency to profess using person centredness whilst actually practising as an authoritarian, medical expert. The tensions and contradictions were not apparent to HCP. Fix et al (2018) studied how a moral discourse crept into consultations among HIV HCP providers and noted that when lifestyle interventions were considered the patient's responsibility, nonadherence is viewed as a moral failing. A systematic review of literature conducted by Franklin et al (2018) found that collaborative and person-centred approaches to consultations were hampered by dominance of a traditional model of care, encompassing the provision of generic information, exclusion of the psychosocial and temporal nature of interactions. They also found higher levels of self-blame and guilt among patients and poorer health outcomes. In studies where health provision was delivered by a multidisciplinary team collaborative patient approaches improved (*ibid*).

Long-term health conditions of their nature include a degree of self-management for the patient. It appears this provides HCP with a challenge in conceptualising the patients' approach to this particularly when information is generic and narrow.

2.5 Existential and post modernist literature

There are numerous possibilities for the use of existential ideas and phenomenology for a richer understanding of diabetes. This claim is made on the basis that diabetes, or aspects of the endocrine function or dysfunction that may be studied at the level of cells, enzymes and hormones, nevertheless only appears as a medical condition in a person. Diabetes does not spontaneously appear in a test-tube or a petri dish; the medium of its appearance is always in a person-within-a-world/context-with-others. This being the case, it is understood that the contribution a philosophy such as existential-phenomenology may bring forth aspires to the kind of holism that resists isolating phenomena for convenient study. Broadly speaking such an endeavour is lifeworld led; it seeks its understanding as it emerges in the inseparable dimensions of embodied-being-in-the-world-with-others that is always situated in a time and place that gives it its meaning.

What follows in the review of literature in this section is an examination of sources from an existential-phenomenological basis or modern attempts to make use of these approaches. It is not meant to be exhaustive or comprehensive but seeks to participate in a wider dialogue exploring the benefits and limitations of such an approach in health, medicine and the lives of people with diabetes in the current study.

As described in the opening introduction, two epistemological traditions are apparent in this review requiring something like the two lenses of a pair of binoculars.
In this case, one lens is bio-psycho-social-(spiritual) [the parenthesis denotes a degree of ambivalence in this perspective for inclusion evinced by positivist atheists like Richard Dawkins (2006) where seeking greater meaning or spiritual belief is at best a bias to be overcome and at worst, delusion] . The other lens is lifeworld-led. By bio-psycho-social-(spiritual) I mean here the medical models' tradition of privileging an objective biological knowledge whilst attempting to include, or invite to the debate, a psychological or social or spiritual knowledge. These other dimensions and researches are invariably conducted by disciplines seen as auxiliary or allied to the medical model but are evaluated by criteria that is primarily for validating objective knowledge (Suls and Rothman 2004). This is in contrast to the existential concept of the four worlds model (van Duerzen 1997, 2002) that superficially appears similar in proposing a physical world (including the body), a personal world (psychological), a with-world (social) and a spiritual world (meaning, values and ideals), but differs markedly on closer inspection by not privileging one dimension over another, significantly because all four worlds dwell within each other as equally real aspects of being-in-the-world. Unlike the bio-psycho-social-spiritual approaches that are so

often written about discretely by different disciplines with the biological commonly trumping others with greater claims to scientific method and truth, the four worlds are so indivisibly interwoven in given experience that “it is merely a matter of clarification to try to distinguish these different forms of world relation in the first place” (van Duerzen 1997; p100).

The four worlds model is therefore a lifeworld perspective, the other lens in the binocular metaphor. Furthermore, the dioptre is the “closer inspection” that reveals the significant and meaningful distinction between the bio-psycho-social-spiritual and the four worlds perspectives despite cursory similarities. The dioptre also allows an attitude that attempts to focus both in and out, bringing one or other lens into figure and the other into ground. One lens may blur as the dioptre is adjusted and the other is clearly delineated. This occurs when the meanings of the two perspectives diverge greatly. Also, both lenses may focus and an optimal focal length is achieved so that a greater proportion of both perspectives are configured.

The lifeworld approach also calls in other themes of existentialism and phenomenology under the same lens, the term being derived from Husserl (1978) and philosophers influenced by his work. Notable themes include intentionality (consciousness is always conscious of something in the world), embodiment, existence as an experience being aware of non-existence or death, concealed or pre-reflective consciousness, historicity, language and meaning making.

An exemplar of literature that features a call to both lenses and demands greater focus is Merleau-Ponty’s phenomenological research and conceptualisation of embodied being (Merleau-Ponty 1945/2002). This is because he directly addresses the corporeal body (that appeals to the meanings derived from a bio-medical lens and is body as object) and the body as lived (embodied-being-in-the-world as subject). Husserl first describes the experience of one hand touching another to highlight features of subjective consciousness in its relation to the body (1978). Merleau-Ponty extends his examination (*ibid*) to elucidate the relationship between the objective (corporeal) body and subjective (lived) body. They are inseparable but distinct; the corporeal body is a feature of the physical world that both apprehends and is apprehended in the lived body. The body is the medium, the interface for being having a world. This is of particular importance in relation to a significant characteristic of consciousness, intentionality. Husserl inherited the term from his lecturer Brentano and notes that consciousness is always conscious of something, that all mental phenomena have content and are directed into the world. Merleau-Ponty demonstrates that intentionality is also embodied in his description of motility and skill acquisition. It is not that consciousnesses intentionality produces the words I am writing here but inseparably the intentionality of my fingers that tap the keyboard with a degree of skill and awareness that does not require conscious direction. I perceive the words I intend to write but eyes, fingers, the sound of the tapping on the keyboard, the taste of coffee in my mouth and the chill in my toes are all there too, although the figure of my conscious attention is writing about Merleau-Ponty.

Furthermore, intentionality of the body is not given in bits and pieces in that at a pre-reflective level bodily perceptions are meaningfully coordinated into an experience of world and self that is fluent, tacit and perceptually smooth. This he calls the intentional arc. This is the tacit grip on the world where horizons of body perceptions and our history, values and meanings, in a given situation are where being and existence take place. This allows for a movement away from notions of an indivisible mind/soul "housed' within a divisible corporeal body that is the hallmark of the Cartesian positivist worldview from which science, biology and medicine arise.

The concept of embodiment for Merleau-Ponty in The Phenomenology of Perception (2002) is the precursor to his later concept in The Visible and the Invisible (1968) "The Intertwining – The Chiasm" and the ontology of the flesh. Merleau-Ponty addresses the paradox of "perceptual faith", the shared sense of embodied experience as a sensible perceptual world being given as it actually is whilst being mediated subjectively by the senses. This presents no problem in the everyday until one attempts to reflect, to form theses and propositions about the world or draw essences, as they cancel one another out and dissolve into confusion. He argues that natural science, which does not acknowledge that relies on perceptual faith for a world to be there at all whilst constructing a reality that rules out the very possibility of its existence, and so cannot account clearly for this paradox. Nor can reflective philosophy (for instance Plato, Descartes and Kant) for it relegates the perceived world to an idea, an abstract, and equates being with thought in a way that shuts it off from the world forcing the experience of other sentient beings to a merely inferred notion. This paradoxical polarising is the Chiasm. Merleau-Ponty acknowledges that fellow phenomenologists move some way closer but points out Sartre's arrangement of being (for itself) and nothing (in itself) acknowledges the *thisness* (haecceity) of the objective world presented to subjective consciousness, their relationship is oppositional and ambivalent. Husserl presents lived experience as a conversion of the world of things into essences before a pure spectator but Merleau-Ponty points out that essences can never be detached from the sensible world and are only referents that differentiate objects of the world in perception. Here Merleau-Ponty returns to Husserl's illustration of one hand touching another, both hands experience touching and being touched but perceptually this is non-simultaneous, distinct but bi-directional, both obverse and inverse. The sensible and the sentient, the seer and the visible, are not one but neither are they two, instead "there is reciprocal insertion and intertwining of one in the other" (*ibid* pp138). The term "flesh" Merleau-Ponty uses in a far more literal sense even than embodiment, as in the order of a primordial element like the classical earth, wind and fire, and the tangible and sentient share a kinship:

"Between the exploration and what it will teach me, between my movements and what I touch, there must exist some relationship by principle, some kinship, according to which they are not only, like the pseudopods of the amoeba, vague and ephemeral deformations of the corporeal space, but the initiation to and the opening upon a tactile world" (*ibid* pp133).

A key feature of this thick fleshliness interwoven in a thick fleshly world is in the region of intersubjectivity (indeed, on reading Merleau-Ponty the term itself appears strangely inappropriate and echoes his dissatisfaction of subjective beings ever being able to meet across the objective divide precisely because each are subjects "in a" world, that cannot be). His reframing of object and subject as sensible and sentient becomes a new opening onto the world of others and their shared world, one that meets in the elemental ontology of flesh. Again, the seer and the visible and hand touching and being touched by hand are iridescent exemplars of *intercorporeity*. "If my left hand can touch my right hand while it palpates the tangibles, can touch it touching, can turn its palpation back upon it, why, when touching the hand of another, would I not touch in it the same power to espouse the things that I have touched in my own?" (*ibid* pp141).

In this statement I believe special interest should be derived from the word "palpate". A verb that belongs, in large part, to the medical practice of feeling/touching the body of another to ascertain the thickness, smoothness, swelling and possible inflammation of parts of the body that is a physicians knowing/diagnosis of possible disease. Merleau-Ponty uses this action/perception to refer to how the sentient being senses the world as real in general. So he can speak of seeing as palpating the visible, "The look, we said, envelops, palpates, espouses the visible things… I do not look at a chaos, but at things— so that finally one cannot say if it is the look or if it is the things that command" (*ibid* pp133). All actions of sentient consciousness fall within an intentional arc that is flesh, so a skill and a knowing, that requires no second order of knowing: abstracted (as in natural sciences) or subjective, felt, reality become meaningless unless subsumed at the level of flesh.

It is likely this is difficult to grasp, particularly in a modern world that is habituated in speaking of life as a set of neuro-biological components, but Merleau-Ponty is making precisely the point that flesh is not matter, not a summation or a compound of elements and there is no conceptual/linguistic corollary in science or philosophy with what he is conveying. Furthermore, when Merleau-Ponty turns to the dimension of ideas, meanings, and language, or the invisible in relation to the visible, he notes that "…they could not be given to us *as ideas* except in a carnal experience… they owe their authority, their fascinating, indestructible power, precisely to the fact that they are in transparency behind the sensible, or in its heart." (*ibid* pp150). It is not just that in fleshly experience we find the occasion to think ideas, as our hold on an idea is different from our hold on an object or the world, nor do ideas *come out of* or *come into us* from the tangible world or from a shadowy interior world of pure thinking. The visible and invisible are never synonymous, never quite aligned, but thoughts are not without flesh and exist "only through its commerce with the visible, to which they remain attached." (*ibid* pp150).

Another area of significance for the current study is language. My research question is founded on the observation discussed in the previous chapter that one commonplace use of the language of diabetes could well be involved in problematizing fruitful ways of being with diabetes. For this reason in reading Ricoeur and Derrida (Cohen 1982) I note that language is intrinsically bound to being in the world, shapes it as much, if not more, than expresses it. However, the degree of relativism in Ricoeur and Derrida's work presents difficulties and possible risks in relation to knowledge and experience of a health condition. Although it may be possible to admit varying practices for healthful living with diabetes it is not possible to suggest all practices are equal and relative to the needs and wishes of individuals or cultures with diabetes. Hermeneutic and moral/cultural relativism are not the same and one must maintain the notion that some practices are potentially harmful to health and should be treated with appropriate challenges in light of the prevailing evidence. An example of this is the desire for "natural" remedies as a viable alternative to pharmaceuticals in the management of blood glucose. Google searches will provide a plethora of claims for naturally occurring substances and/or practices that can treat or even cure diabetes with no evidence base. At Diabetes UK Helpline calls concerning such approaches can be handled by pointing out that it would be a category error to consider "natural" as synonymous with "benign" simply by exploring examples of the many natural poisons and toxins in nature. Indeed, organic farming includes a long list of naturally occurring toxins available legally for use with scarce research into benefits or dis-benefits, although noted consumers often assume no pesticides are used in organic agronomy (Mie et al 2017). In short, the kind of hermeneutic relativism that supports a person's notion to throw away medications and eat black kohosh or cinnamon instead is likely to be in peril. Whilst understanding that there is unlikely to be a definitive or absolute interpretation, not all interpretative claims can be considered equal where health is concerned and therefore cannot be supported. This review does not spend further time and space to evaluating the more extreme relativist approaches to language for this ethical reason.

It would appear therefore, that an assessment of language would also benefit from those thinkers that offer some hope that the entanglements of language and meaning may somehow be navigated, however tentatively. Furthermore, philosophers whose work have incorporated the significance of language to a greater degree in their writing display the degree of concern and gravity attributed to language and meaning.

Two approaches stand out as worthy of further attention in this respect. The later work of Heidegger arguably contains a centrality to an understanding of language and its implications for being with (and therefore being with diabetes) (Standish 2002). Foucault, in his broader sense of attending to the archaeology of scientific knowledge but also the inevitability of underlying power in discourse and regimes of truth may offer insights into the un-reflected purposes of ways of speaking about diabetes and also an approach to understanding the antecedents within a broader spectrum of modern dynamics. A benefit to both philosophers is that rather than offering an opposition to commonplace understandings of our modern world, they offer a potential method for understanding or navigating meaning, rather than an alternative to particular meanings.

The position of language in Heidegger's later work is not only central but key in his exploration of truth, thinking and the relationship to modern technology in enframing the meaning of Being for beings.

He begins this journey by noting there was a beginning to language and that this beginning brought about the Being of the first beings as beings of language (1959). Heidegger feels at this point language was close to Being, or to put it another way speaking was speaking of a world of being. Language's origin is mysterious and must have arisen out of the strange and terrible. To this extent language would have shared vigour with existence and this possibility is still present so language is a custodian that preserves Being. This is related to the notion that truth is a self-concealing/self-revealing Event in the disclosure of beings in his conceptualising of truth as *alethia* (1998). Alethia is a deeper sense of truth than in factual or correct. He uses the Greek root Lethe, which means to conceal or forget, so that alethia is to unconceal, reveal or realise, perhaps even an unforgetting. Heidegger argues this sense of truth has been covered up and that the earliest Greek Philosophers had a meaning for truth closer to the word disclosure. But, he says, the clearing of being is bound up with disclosure but also with concealment, insofar as disclosure is never so complete that being is fully illumined. So, the very access and appearance of beings closes off openness and is concealing. Heidegger is calling us to the nature of alethia that is unconcealing, not a finished job that is revealed, but that passes back to concealed and requires further disclosure.

The word or name, then, is implicated in the delimiting and permanence of things. Heidegger also notes that naming does not come afterward, providing a signifier or hallmark to things, but is the other way around… "…originally an act of violence that discloses being…" However, as with his notion of inauthenticity and idle talk… "the word sinks from its height to become a mere sign, and this sign proceeds to thrust itself before the [thing]" (1959, p. 172). The "thrusting itself before" also means for Heidegger that language is ahead of us and being is always lagging behind that which it ought to have overtaken. But even language as signs, as the jabber of the They, is still capable of preserving being, of being the custodian (or the house) of being, even if the They and idle talk are inadequate for the disclosure of being, and fall short.

Heidegger's central concern here is to highlight the meaning of language for being and its potential to conceal or obfuscate being whilst returning the mystery or the way to clearing contained within its origin. This basic entanglement is the platform from which his analyses explore attitudes and stances that reveal further entanglements and possible pathways to clearing.

It is helpful to note at this point that Heidegger's later philosophy is presented across a number of essays, seminars and lectures in contrast to Being and Time (Heidegger 1962) as a central cohesive approach (Young 1997). This is likely connected to what Heidegger termed his 'turn' (Kehre, also meaning bend, loop, curve). Being and Time took human beings as a starting point for his exploration of Being and temporality as a significant feature. Heidegger's self-proclaimed turn was his discovery that this was a flawed approach but instead of developing a consistent alternative methodology he appears to have favoured exploring different themes from differing angles whilst maintaining that the truth of Being is the self-concealing/self-revealing Event or Occasion (Ereignis) of the disclosure of being. Here, one might also return to Heidegger's term "entanglement" as a poignant feature of his observations of beings thrownness, explicated in Being and Time. We come to a world that is already there and populated by beings that furnish us with language and meaning within a milieu, similar to Husserl's observation of historicity. We are situated, but there is the illusion that we could break free or transcend this, and this quietens the tension we might experience if faced, that we are now and here and for a time. This is dasein, being-there or this-is, concealing (illusion of ultimate transcendence and/or vapid chatter of the They) and/or noticing the entanglement and alienation from the aliveness of being that is concerned with being and the absence of being, one's ownmost or end of being… being me… my-being. Later Heidegger, explores themes after the turn from, or re-turn to human being as the starting point to themes of Being/beings 'entanglements' in situations or contexts such as language, technology and ontotheology (Young 1997). Heidegger, at this point in his life, is encouraging listeners/readers to step up to entanglements and mull them over, feel their way through the tensions and dwell within them, rather than attempt to transcend, disentangle or extricate themselves (Hodge 2015).

In the entanglement of language Heidegger examines art and poetry as possibilities for disclosure or clearing. This disclosure or clearing he terms after the Greek poeisis or bringing forth or revealing (Heidegger 1977). Heidegger sees visual art as a revealing of worlds and being, but is connected with language's sense of being ahead, it offers a clearing that has already happened in language. Heidegger reserves special interest for poeisis as poetry or poesy. This is because the poet tackles the entanglement of language directly and engages in a free act of language that stands at the crossroads of Being and Language. For Heidegger, poetry is not aesthetic but an act of ontological creativity. It is not "…merely an ornament accompanying existence, not merely a temporary enthusiasm or nothing but an interest and amusement" (1949 p283) indeed, its significance is so much greater that "…the essence of language must be understood through the essence of poetry (1949 p284). Poets and poetry are therefore positioned between Being and beings, intercepting intimations of Being and gifting them through the free act to dasein with which they maintain a deep attunement.

Heidegger turns his attention to the act of thinking (1966). He is at pains to distinguish his notion of thinking from the traditional Western interpretation of "technical-scientific calculation" (1966, p91). His mode of thinking has parallels with poeisis and poetry, they share the same neighbourhood, but the two must be differentiated from one another.

“We must discard the view that the neighbourhood of poetry and thinking is nothing more than a garrulous cloudy mixture of two kinds of saying in which each makes clumsy borrowings from the other.” (1971, p90).

Distinguishing thinking as such from calculative thinking and placing it in the neighbourhood of poetry (though parallel and distinct from it) allows Heidegger to position it as an alternative to modern notions of instrumental thinking that have become commonplace, a way to become independent from it. He calls this ‘meditative’ thinking that carries a particular characteristic of a special comportment he terms ‘releasement’. This feature of meditative thinking, its comportment in terms of releasement, allows it to maintain openness to the mystery (1966). It is a way, then, to discern meaning without the temptation to fix or concretise meaning in the fashion of technical thinking to which we have become so accustomed.

After the turn, Heidegger returns to two important themes emerging from Being and Time. The idea of the They and of Tradition, we now see re-emerging in his later philosophy in the entanglement of language and of instrumental thinking. Heidegger pursues this further in his critical analysis of Humanism and Technology. Here he develops a new notion for understanding how our stance toward being and knowing came about, in the shape of ontotheology (2002). This term Heidegger took up from Kant (Hodge 2015) combining ontology and theology. His argument runs that ontology, being, has been seen from classical Greek times as containing two strands: firstly, that of being having an origin or progenitor or original event or occasion of its coming about. This genesis has its referents in deity. But the second meaning came about for being in the most general sense, in that being, to be, is manifest in the world of things, animals and people. In that all metaphysical philosophies contain these two barely noticeable strands gives them an ontotheological underpinning. Heidegger is engaging in an archaeology of ontotheologies, as entanglements, that have given certain ways of thinking a sense of intelligibility in a given era. In Being and Time, one such ontotheology was that arising from Descartes form, in which being had to be extricated in order to reveal being as being-in-the-world.

Another, in later Heidegger, is that espoused by Humanism (1998). Heidegger traces the antecedents to the Roman appropriation of ‘culture’ (paideia) from Greek academies to form the basic conduct and scholarship of training the Roman elite that becomes the hallmark of civilisation in contrast to barbarism. Heidegger explains that for Romans human being was evidently a rational animal and rationality becomes the general measure of humanitas that distinguishes him from barbaric atavism. This is the restrictive, unexamined ontotheology applied to beings in the classical Roman era. He also finds ontotheologies imposing themselves on the meaning of being in Christianity (salvation of man) and Marxism (social man). All the entanglements of ontotheology produce systems, codes of conduct and means of education founded on unexamined truths of the meaning of being. These nuanced forms of humanism reach a particular point in Descartes and the enlightenment. As god is no longer the pivotal position of certainty of being, certainty is nevertheless required by ontotheology and Descartes supplies this in the form of Ego, I am. All values therefore, are values attributed by human beings onto the world and for Heidegger the trouble with humanism that centralises all existence around man and human valuing leads us to nihilism:

"… it is important finally to realize that precisely through characterization of something as "a value" what is so valued is robbed of its worth. That is to say, by the assessment of something as a value what is valued is admitted only as an object for human estimation. But what a thing is in its being is not exhausted by its being an object..." (1998, p. 265).

This perhaps reveals Heidegger's movement in his turn, namely, that his beginning with human beings as a means to explore Being is flawed because it cleaved too closely to humanism. Later Heidegger may be revealing a way to co-respond to the entanglement of humanism's potential to be too enamoured with subject and value becomes so relative it tips into nihilism. I am reminded, at this point, that Merleau-Ponty's analysis produces the notion of 'flesh' as elemental precisely to attest to a world shared that is not pure subject, that challenges the subjective reflective philosophies of Husserl and Sartre.

The final entanglement I wish to pursue for its potential relevance to the current project is Heidegger's encounter with the question concerning technology (1977). He identifies the root of our modern technological era with the ancient Greek word *techne*, entwined originally as a form of poeisis or bringing forth. A close translation is art or craft, and this announces to Heidegger that the early Greeks had an understanding and close connection with the materials and their origins that formed the basis of human produced objects. We are also returning to Heidegger's exploration of visual art and poetry as techne being a particular form of poeisis as an expression of aletheia.

Heidegger addresses these ways of being when he appraises the modern mode of techne. He believes that the classical Greek stance is all but lost outside of art and that modern technology, like humanism, pits the human valuation of nature against its existence. Instead of a careful, respectful opening to the presence of things, bringing forth of poeisis, the modern mode challenges forth. He calls this 'enframing' but it is not merely a structural hermeneutic to aspects of the world but an ontotheology that perceives the world only through its ordering as commodity. Like his discussion of humanism and its flaws, the technological reduces everything to its means and that is its meaning. All things are about their narrow purpose and function, calculated for this to the nth degree. The presiding quality of revealing things in enframing becomes what Heidegger calls 'standing reserve'. The types of examples he gives to illustrate this are the river's standing reserve in the potential for damming it for hydro-electric power and the refuelled plane on the runway as the means of conveyance. Everything is then challenged into this ordering, measured resource and purpose to be exploited, and this includes human being(s). Being is the ordering being and therefore is never fully subsumed in the ordering of its standing reserve, never completely enframed. But being submits to this ordering without awareness and this is the danger, and the shape of aletheia, in our modern age. Heidegger is asking of us if we can confront this entanglement by spotting ways in which we view ourselves, others and the world as standing reserve, in the enframing, and attend, or co-respond, to other possibilities of poeisis.

Michel Foucault presents a fairly consistent evolution and progression of ideas throughout his work, extending and refining his basic notions. One origin and primary question for Foucault comes in exploring Kant's epistemological innovation which philosophical critiques that reveal the limits of our knowing also reveal the necessary conditions of knowing – what might appear as contingencies (like space, time and finitude) are actually essential. Foucault reverses this to explore what appears to be evident as necessary truths to uncover those that are mere contingencies on maintaining a society's worldview shaped by historical forces. He terms a milieu's necessary truths (or regimes of truth) *epistemes*, unchallenged and self-evident norms of thinking and speaking that produce and maintain the dynamics of power. The position of language for Foucault is the language that speaks to maintain epistemes and reveal the dynamics in who speaks (with authority), about whom and to what purpose. This is *discourse*, the dominant means of power for maintaining epistemes, but also the language that attempts to frame revolutions or resistance to dominant power. Like Kuhn's and, more closely, Canguilhem's (1961) treatment of the history of science, Foucault notes that the development of modern thinking and society is not the linear progression of revealing truth it may appear to be but is made of fits and starts and pumps in the road, historical turns that unveil the points of tension and the dynamics of forces (Dreyfus and Rabinow 1983). In his histories, The History of Madness in the Classical Age (1961) and The Birth of the Clinic (1963) Foucault excavates the underlying power dynamics that forge the modern epistemes of psychiatry and medicine. The method he adopts to do this he terms *archaeology*. This is a process of attempting to understand the differences of one milieu to another, and of the meanings contained within each. However, archaeology could say nothing of the causes of transition from one milieu to another.

With *Discipline and Punish* (1975) Foucault looks to address this limitation of archaeology using his extensive reading of Nietzsche. His new approach builds on archaeology, via a hermeneutic narrative of the historical points in which the action of forces 'turn' one meaning to another. This he calls *genealogy*, after Nietzsche's genealogy of morals that discusses how the classical Greco-roman ideas of "Good/Bad" become the Judeo/Christian notion of "Good/Evil", where the former denotes the arrangement of strong and feeble and the latter meekness/power (Dreyfus and Rabinow 1983). For Foucault, genealogy is a process of 'fictioning', creating new plausible narratives from history and philosophy without laying claim to a universal truth but containing truthfulness that more closely tracks the discontinuous movement of ideas and meanings instead of the linear, progressive tendency displayed in modern discourse. In this way, one is not fooled into resisting power as this only leads to different power dynamics, but becomes aware of the shapes and forms, catching the epistemes and regimes of truth rather than being impelled by them. This fictioning also means genealogy does not have defined methodological rules or steps. In *Discipline and Punish*, Foucault tracks the movement of discursive power from the sovereign power of aristocracy and their control and responsibility of/for their people (even sanctioned torture and death) to an enlightenment power dynamic that examines and evaluates a persons behaviour, under the auspices of gentler, but really more efficient, power and control: the gaze. Foucault's exemplar is Bentham's idea of the Panopticon, a prison in which inmates cells are open to the gaze of guards but they do not know if and when observation is occurring, encouraging self-vigilance. Ultimately, there are three forces predominating in modern discourses: hierarchical observation, normalizing judgement, and the examination (*ibid*). The epitome of the modern episteme is to hand these forces or functions back to individuals who monitor themselves (examination) critically (judgement) from outside of themselves, or another way, to see themselves as objects to be controlled (hierarchical observation). With or without irony, this is the most efficient and cost effective means of discursive control, convincing and expedient, subtle to the point of invisible and out of awareness. At this point I will doubly note that Foucault does not attribute power to one or other individual, organization or class. His view is that all arrangements contain power, forces, views and speeches that predominate in any given period, unconsciously. Herein the relevance and the importance of generating genealogy as an expose: not as a means of resistance within the same discursive episteme but as awareness and understanding of the dynamics.

Foucault extends genealogy in A History of Sexuality, Volume 1 (1976-84) and reveals more about his development of power. He demonstrates the internalisation of norms by individuals who with self-scrutiny now feel obliged to tell all (about sexuality but also about health, bodies, personality, desire's and thoughts). This is characterised by the gradual secularisation of religious techniques of confession. Power, then becomes embodied and the operations of the forces in discursive power inscribe themselves upon bodies, to become the internal conditions of our identities. Foucault delineates this modern *biopower* from *sovereign power* in that the dynamic of biopower is to regulate and manipulate bodies as resources and to normalise and control certain practices in multiple loci – home, school, town, clinic, prison, bedroom etc. Where sovereign power was exerted by aristocracy, church and law courts, biopower is the power of experts and administrators that compel us to adopt the narrow and unexamined notions of body and self. They provide the categorizing and note taking, regulatory and controlling procedures that form the modern panoptic gaze, handed to self-scrutinising individuals as learning to be internalised and operated on themselves and each other but often marketed as liberation, freedom and rights, so long as these conform to the narrow notions of the current episteme.

One can see the potential applicability of considering Foucault's ideas in relation to health, long-term conditions and diabetes. Even simply to identify that research articles and medical recommendations frequently adopt a language that can reveal the norms to be internalised if we can see that treating diabetes is about *regulating* blood glucose to a *normative* guidance range by *self-monitoring* and following a lifestyle and treatment *regimen*. It may also help to explicate what is happening in the tendency for health psychology to be marshalled by medicine to develop theory and practice aimed at corrective behaviours for patients identified as having 'poor' control.

Discursive power and biopower, like Heidegger's entanglement of enframing, offer possibilities for problematising the restricting and narrowing possibilities for meaning in the modern milieu including that of health. Merleau-Ponty provides accessibility of thinking of health in a lifeworld sense and possibilities for understanding without recourse to dichotomies of mental/physical, symptom/disease as these are subsumed at the level of flesh.

This brings me to the modern 'cultivators' that have found their roots in the soil of the phenomenological-existential tradition with regards to the field of health and medicine.

Patricia Benner (1984; 1987; 1992; 2004; 2010) has been recognised for her career in nursing education and practice. She has been particularly explicit about the existential phenomenological philosophy underpinning her work and popularised phenomenology in nursing practice research and in nurses' perceptions of patients and health. In particular Benner has widened awareness of Heidegger and Merleau-Ponty among the nursing profession by advocating for nursing to be considered a 'caring science’ and has studied nursing skill acquisition using Merlieu-Ponty theory of tacit motility and skill acquisition. However, most of the focus has lacked a cogent exploration of existential and phenomenological theory from the perspective of a person with a health condition, disease or illness. She has provided some preliminary explorations as part of this work, mainly in highlighting embodiment as a means for nurses to understand the experience of disease and illness from a patient perspective.

A greater focus from this angle comes from Toombs (1988) whose own experience of Multiple Sclerosis was informed by her knowledge of existential-phenomenological perspectives. Primarily she attempts to describe lived experience of illness and produce eidetic and essential themes in order to explicate how patient and physician inhabit different horizon’s of knowledge and understanding. This produces a decisive gap between the two that can only be breached by the physician adopting ways of understanding that include features of the patient’s phenomenological experience. These eidetic characteristics, that she claims are consistent regardless of the manifestations of any particular diagnosis are: “…the perception of loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world” (*ibid* p229). However, although the point taken reflects potential gaps between patient and physician valuing and meaning of the significance of illness (particularly soon after diagnosis and in discussions of prognosis), it does not account for patient’s potential adaptation to these changes that may adjust experience through newly acquired skills and learning. Furthermore, Toombs’ essential characteristics may be applied to very broad life changes other than illness, though not exclusively, and so may be said to encompass existential themes widely rather than specifically to illness.

Havi Carel (2016) explores similar ground as Toombs being a researcher who also has a lifelong health condition, Chronic Obstructive Pulmonary Disorder (COPD). In her book she sets out to address a balance in a twofold manner: that existential phenomenology can bring a fresh understanding to illness and disease and, noting the lack of philosophy’s interest in this area, exploring illness and disease can increase the scope of understanding this facet of human experience in existential philosophy. Having worked for some time in the field of clinical health psychology and personally experiencing ill health in my own family, Carel’s endeavour has, like Toombs, merit. Existential ideas have such parity with existence in relation to death and finiteness but these were often explored in an era when acute illness and war resulted in sudden death. Comparatively the thinkers of their time came before the modern increase of people living with chronic illness. Her use of existential concepts, again predominantly of Heidegger and Merleau-Ponty and context rich descriptions of illness and disease as experienced, are fluent and compelling. Notably, considering Merleau-Ponty, she describes the experience of losing one's tacit grip on embodied experience when illness symptoms dominate the foreground and how extensive this disrupted pre-reflective meaning for the body is in persistent chronic symptoms. Where the amelioration of symptoms in acute, treatable conditions may be experienced as a 'return' to health by degree, chronic health conditions present such a breach to a tacit embodied hold that reconfiguring and adapting demands a lengthy and painful renewal of acquiring this new, changed body.

This is a fascinating exploration, like Benner and Toombs, of the possibilities of existential-phenomenology applied to illness experience. However, Carel's understandable focus on symptoms of chronic illness like breathlessness and pain are of limited use in exploring diabetes. As previously noted, diabetes produces overt symptoms only in certain contexts: low blood glucose, high blood glucose and permanent long-term complications, for which in all cases, treatment and management are designed to mitigate. In a purely symptomological sense, therefore, diabetes is physically absent from the body in a corporeal sense – blood glucose levels in target treatment range are those of anyone else without diabetes broadly speaking.

A question then remains as to what other purposes existential-phenomenology can have for revealing features of a condition that, in Merleau-Ponty's vernacular, is equally about the invisible as the visible and tensions in the intertwining experience of positioning the two in their appearances?

Karin Dahlberg, her research supervisees and colleagues have focused their research intentions on health from a Lifeworld perspective (2001, 2006, 2009). She has been consistent in exploring Lifeworld phenomena in nursing education (Bengtsson 2013), patient experience (Dahlberg and et al 2001, 2006) and perspectives on health care delivery (2009).

This last is worthy of note as Dahlberg and colleagues question the current implied/explicit epistemology of Nordic and UK understandings of patient and healthcare systems. Notably that the common approach is to view the patient from the perspective of consumer/citizen and how this limits attitudes in relating to modern healthcare. She is explicit in challenging notions of patients' consumption of health services and of the rights and responsibilities of accessing healthcare as a citizen, producing an approach that privileges concepts of value for money (consumer) on the one hand and accessing stakeholder (citizen) on the other. Neither of which encompasses the scope of wellbeing in illness as they ignore central features of the patient achieving movement and peace (as a cornerstone of 'vitality'). One might be tempted to also say this arrangement (entanglement and/or discourse) suggests the patient is open to other potential meanings as a litigator, hoarder or waster of resources (consumerist) and a litigator, protagonist, rebel or even terrorist (citizen). Are these possibilities for understanding the commonplace phenomena amongst health care professionals of the 'heart sink' patient?

Chapter Three: Research Methods – Participatory Action Research (PAR) and Cooperative Enquiry Literature

PAR comprises a variety of action research methodologies founded on an attempt to equalise the balance of power between researchers and participants. Particularly it proposes a fundamental questioning of ownership in the hermeneutic task and its traditional placement squarely in the hands of the researcher. Where other qualitative research methods have equally focused on the significant problems of interpretation, developing rigorous approaches to the handling of data elicited from participants (triangulation, peer scrutiny, phenomenology, thematic analysis to name a few) action researchers have noted that however rigorous, the interpretive function belongs solely to the researcher.

The shaping of the hermeneutic task is there at the outset as it is the researchers' interest and topic that carves the structure of the invitation of participants, the questions used in surveys or semi-structured interviews and the direction of the researchers supplementary questioning.

It is also evident in the researcher's relationships with academic establishments, supervisors, the learning that influences the becoming of a researcher. The researcher therefore belongs, in some degree, to the academic language and environment from which they conduct their research. There is a limit to how likely this language and culture will resonate with the people who participate (with the exception perhaps of participants from the same academic discipline or students), but also what it means to be a participant will be influenced by the researcher's acculturation (Gaventa 2006).

This is also true for the moment transcribed interviews or survey materials are collated and the researcher moves from encounter with participant to the solitary process of handling data. The very nature of being out of the interpersonal setting and becoming individually analytical toward material garnered in relationship is at a remove. Participants provide the data, their experience as they express it, but the researcher ascribes the meaning. This, albeit whilst honouring and respecting participants' experience, is research on people. Action research and PAR approaches endeavour to conduct research with people (Heron 1995, 1996; Heron and Reason 1997, 2001).

Interviewing a person's experience may capture as much of the received discourse and meanings as the life-world experience itself. Liberating heurism to participants offers the possibility of critically researching their meanings to reveal what matters for them and any hitherto concealed incongruence with customary ways of thinking.

Paolo Freire highlighted the subtle mechanisms by which people are inculcated into beliefs and meanings that upheld the dominant discourse, thereby becoming oppressed (Freire 1996). This was not necessarily propagated by knowing oppressors but simply by other people who were equally acculturated but derived greater benefit from the current discourse. Oppression, for him, was the absence of means to contribute to or affect the discourse thereby invalidating aspects of their experience. Friere argued that to simply produce a change in power by revolution did not guarantee liberation from the discourse but only maintained the discourse in new hands or devolved it to a new but equally oppressive oppositional narrative. Equally, standing up for the oppressed would focus on the unfairness of the power disparity but not necessarily evolve into a genuine voice, since advocates were still under the thrall of discourse, albeit of it’s negative connotations. He believed that an answer was to encourage the oppressed and oppressors into participatory dialogue. Initially this would simply paraphrase, parrot or parody the dominant discourse in all directions, but as participants are human beings there may emerge greater expression of their experiences, individual and shared. A growing awareness blossoming from this examination, re-examination and research into one’s own oppressed living transcends the currency of conventional discourse and opens the way to what truly matters for the person that has hitherto been silenced and invalidated. Friere’s concept is redolent with the existential interest in meaningfulness, with-world and agency and this participatory process of raising consciousness and conscience he termed conscenciatisation.

“… women and men learn that through learning they can make and remake themselves, because women and men are able to take responsibility for themselves as beings capable of knowing—of knowing that they know and knowing that they don't" Freire, P. (2004). Pedagogy of Indignation. Boulder: Colorado, Paradigm. p 15

Fals Borda in his discussion of the experience of his participatory rural appraisal groups explores Husserl’s concepts of Lifeworld (Lebenswelt) and Experience (Erfahrung) as a means to understand the epistemological foundations of action research as a form of phenomenology. The process by which a group’s awareness and capacity to think and learn emerge within participatory settings he calls Vivencia, evoking the sense of vivid aliveness participants experience in search of what matters to them (Fals Borda 2006).

I should note comparatively with Interpretive Phenomenological Analysis (IPA) at this point. IPA is a distinctive qualitative research method that explores the subjectivity of a persons’ lived experience (Smith 1996). It is a highly structured approach that draws on three main theoretical/philosophical strands: phenomenology, hermeneutics and idiography (Smith et al 2009; Shinebourne 2011). IPA makes claim to being phenomenological in both its philosophical sense and its methodology, focusing on the exploration of experience as lived and the sense people make of this and incorporating the stages of phenomenological reductions. IPA is hermeneutic in that the focus of interest is the researcher’s process of interpreting the sense making and meaning processes that the participant uses in understanding experienced phenomena, referred to as double hermeneutics (Smith 2004). The idiographic strand in IPA aims at producing close, detailed description and examination of particular phenomena. This is evinced in the detailed verbatim transcripts from interviews with participants for interpretation and also in the purposive selection of participants that have direct experience of the phenomena under question (Shinebourne 2011). These factors, along with the clarity in the protocol for performing IPA research, have contributed to its popularity in many fields including health psychology (Brocki & Weardon 2006; Samson 2006; Paton et al 2014; Hobday et al 2015; Ryninks et al 2015; McKenzie et al 2016).

The knowledge derived from IPA is as close to the subjective experience of participants as possible but emerges from a single dialogue with the researcher in a semi-structured interview. With multiple participants, each interview, transcript and analysis are conducted independently with the researcher attempting to mitigate the influence of knowledge gleaned from previous analyses when working on the next. Only towards the end is a synthesis of the correspondences and differences in emergent themes conducted. The hermeneutic function is conducted by the researcher and may be tested with follow up comments by participants.

With participants in PAR their subjective experience is expressed within the group, reflected on with the interpretive tools provided and returned to many times between cycles of expression and reflection effectively producing their own living triangulation in an unfolding process. The hermeneutic function belongs to the individual participant reflector and to the group in dialogue.

In contrast, Heuristic research (Moustakas 1990) is a phenomenological approach to inquiry that uses the self as a research tool, applying rigorous and demanding processes to a deeply felt question to explicate self-knowledge of the researchers experiencing of the topic. The question is in-dwelling within the researchers internal frame of reference. The basic premise is that conscious, reflective knowledge and experience is deeply connected and influenced by an implicit, ineffable dimension of understanding – tacit knowing – and the processes and phases of heuristic inquiry seek to illicit the influence of tacit knowledge on reflective consciousness to illuminate deeper meanings. It is a highly thorough approach to a passionately creative methodology. However, it is a very demanding process that requires a high degree of commitment to deep immersion in the subject on the part of the researcher and being intuitive and creative does not conform to timelines and protocols. It has been noted that its similarities to contemplative, philosophical and spiritual practices of self-knowledge historically mean heurism is likely the oldest method of psychological inquiry (Hiles 2001).

I would also add that many features of heurism would be familiar to individuals that consider their work to be vocational. This is perhaps why heuristic inquiry has received attention in garnering knowledge and understanding amongst professionals in healthcare (Finlay 2009; Martin 2011) and education (Wong 2010; Hays and Singh 2012).

Although it is acknowledged that heuristic inquiry involves the researcher at times in dialogue with others the unique point of reference for the unfolding of understanding is the researchers' own internal point of reference and transformation in understanding belongs to the researcher alone. Although it is hoped that the dissemination of knowledge shared may speak to and illuminate others it is not a prerequisite of good heuristic method (Hiles 2001).

Participatory approaches could be said to involve an attempt to hand heurism to the participants and devolve the hermeneutic function to their individual and shared processes. Its difference lies in its attempt to evoke participants' vivid experience of lifeworld and withworld. As attractive as this might be PAR cannot compete with the meticulous idiographic detail of IPA or the consistency of the hermeneutic analysis. Nor can it expect the depth of commitment to immersion of heuristic inquiry. In short, it does not demand that participants become researchers to the level anticipated of academic endeavor nor reward them with a postgraduate qualification or professional career in recognition of their participation.

However, the payoff with PAR is the possibility for hermeneutic synthesis, learning, illumination and transformation to be democratized.

Action research approaches devolving power to the convening research participants in an evolving process of unfolding, shared awareness can be a time consuming and confusing. The epistemological desire to free up those involved goes far beyond a structured focus group and entails participants learning to do research, developing a means of consensus as well as processes of agreement, wading through dilemmas to reach not only a topic(s) for a research question but a methodology and a means of disseminating knowledge gained.

Heron and Reason's approach in developing Cooperative Enquiry (Heron 1995) attempts to provide some understanding to the process of participatory action research. By identifying that engagement in enquiry as a group will necessarily involve periods of individual reflection and group engagement, he has sought to anticipate how a group will pass through cycles of clarity and uncertainty and define the roles of participant, reflector and convener and the functions of the group as they pass back and forth between relative clarity and uncertainty.

3.1 Action research and cooperative inquiry literature

Significant reading in this area primarily to deepen the methodological and epistemological underpinnings of participatory approaches to research (Heron 1995; Heron and Reason 1997; Friere 1996, 2003; Fals Borda 2006; Gaventa and Cornwall 2006; McNiff and Whitehead 2011).

Participatory methods of research in relation to exploring health issues are less common than expected. A far greater body of research exists in social studies, environmental and rural appraisal, education and professional work settings.

Participatory Action Research studies that have focused on health are predominantly concerned with patients involvement in healthcare implementation (Lloyd and Carson 2005; Leykum et al 2009; Seekins and White 2013; Waterman et al 2015; Voigt et al 2014; Chaowalaksakun et al 2016) or work based inquiry into health care professional practice (Hummelvoll and Severinsson 2005; Stevenson 2005; Tee et al 2007; Manley et al 2008; Stuckey 2009; Priest et al 2015). It is also notable that there is great variance in the type, combination and degree of participation from group survey and interview to mixed methodology and full participatory training tools.

I could find only anecdotal evidence of Cooperative Inquiry research specific to diabetes in a chapter by Peter Reason (1994) but no reference, suggesting a group may have convened but no published material followed.

3.2 Qualitative, experiential and heuristic research tools literature

The primary literature resources for helping the group to develop their individual and conjoined skills for exploration will come from three key areas: heuristic research (Moustakis 1990), reflexivity and reflection (Etherington 2004; Schon 1983) and the model of critical friendship (Costa and Kallick 1993; Kember et al 1997). These concepts will form the didactic phases of the groups learning to research their experience.

Chapter Four: Methodology

4.1 Ethical consideration, limitations, potential difficulties in study realisation and recruitment of participants

The discourse - what can be said, how it can be said and by whom – historically flows from Health Care Practitioners, medical research and more recently, health psychology. That people with diabetes also talk about or publish accounts of their experience does not alter that the underpinning philosophy, vocabulary and focus is predominantly patterned on the implicit requirements of a consistent medical understanding.

I anticipated that a cooperative enquiry had the potential to encourage conscenciatisation and manifest vivencia, in which new themes and language significant to Co-researchers with diabetes emerged.

Deeper consideration was given to recruitment and inclusion criteria for participants in the project. Initially it may seem reasonable to utilize standardised nomenclature and diagnosis of diabetes as a benchmark i.e. the distinction between Type 1 and Type 2 diabetes, newly diagnosed, patient age and so on.

However, distinctions like Type 1 and Type 2 for instance belie a huge heterogeneity within each condition and further belie homogeneity across the two conditions. For instance, the notion that Type 1 is more likely to develop in childhood or adolescence is challenged by the risk of onset being the same up to the age of forty and decreases only minimally after forty. People can be diagnosed with Type 1 at any stage of life, half of all diagnosis is in adulthood and the majority of people with Type 1 are working age adults (Chiang et al 2014). Post eighteen years diagnosis is commonly managed in Primary care and under eighteens treated in Secondary care Paediatric Diabetes Services and this has led to adult Type 1 diagnosis erroneously being interpreted as distinct from childhood onset Type 1, sometimes given different non-clinical terms (i.e. Type 1.5, Type 3, or Latent Autoimmune Diabetes in Adults or LADA). Antibody and C-peptide tests often confirm these patients have adult onset

Type 1, but often with a slower progression to being fully insulin dependent than in childhood (Abduelkarem et al 2004).

Another distinction in Type 1 and Type 2 is the association of insulin treatment with Type 1 and oral medication for Type 2. However, insulin treatment in Type 2 diabetes has increased over the past 20 years so there a more Type 2 patients on insulin therapy than there are patients with Type 1 (Holden et al 2014). This also includes an increase in basal bolus insulin regimens amongst Type 2 patients making day-to-day management almost indistinguishable from adult Type 1 diabetes management (Nathan et al 2006; Berganstal et al 2008; Hamaty 2011; Inzucchi et al 2012; Mosenzon and Raz 2013).

Another consideration was length of time since diagnosis. Newly diagnosed patients with either type may share a process of adaptation to the condition both practically in terms of regimen, treatment and acquiring knowledge as well as psychosocially although the pace and timing of progression through this varies widely and is influenced by many factors (Eiser 1990; Cohen 1998; Snoek and Skinner 2005; Davies et al 2008; Nash 2013; Chew et al 2014). It is likely that during this process knowledge acquisition, coming to terms, finding some understanding and acceptance may occur within 3 to 6 months or may progress over the first few years so ‘newly diagnosed’ may not have a consistent meaning in relation to time from diagnosis. Furthermore, participation in an inquiry group for people still processing their diagnosis may influence their development unpredictably.

People experiencing a sense of personal and social familiarity in living with diabetes, as well as an established sense of identity before and after diagnosis will have likely been diagnosed a number of years.

Another consideration was that people experiencing severe secondary complications such as foot ulcers, amputation, painful neuropathy or renal failure are likely to be experiencing particular focus on the complication rather than diabetes per se (de Groot et al 2001; Snoek and Skinner 2005; Neeru et al 2015).

Taken together the criteria for recruitment fell along the following:

Insulin treated diabetes (Type 1, Type 2, LADA or pancreatitis induced)
Age over 18 and up to 65
Diagnosed 5-10 years or more
Without concurrent severe complications (severe foot ulcers, amputation, chronic painful neuropathy or renal failure)

Participants were invited from Diabetes UK User Involvement Network. This is a repository of people with diabetes who have expressed an interest in being involved with diabetes related focus groups, comment and other projects and therefore already possess a desire and commitment for a greater say. Permission for contacting this network was gained by producing a proposal report to senior managers and interview with the Research Team Diabetes UK. This was evaluated on the basis of consistent ethics, data protection considerations and alignment with key objectives and values of Diabetes UK. Once consent was given a contact list was drawn up using search software of the User Involvement Network following the above criteria and London region given that participants would meet face-to-face. This generated a contact list of 348 individuals.

A two-phased plan was proposed for convening a PAR group. The first was an invitation to a half-day workshop on the topic of diabetes conversations that would include experiential exercises followed by a question and answer session of PAR and convening a group. Participants in the workshop would then be asked to consider whether they would be interested in convening a PAR group as Co-researchers. The workshop and subsequent group meetings would take place at Diabetes UK head office. Participant information and consent were obtained at both phases commensurate with the different commitments to involvement of each phase. Travel expenses were refundable.

Of the 348 people invited to the workshop 20 people signed up. However it also became apparent from other expressions of interest from people who felt it was too far to travel that the 348 people contacted were from across the South East of the UK rather than the Greater London area.

Of the 20 people that signed up to attend the workshop 4 people turned up on the day. Although this in itself was disappointing, the participants felt they had gained a great deal and expressed a desire to form a PAR group. In early cycles of dialogue in addition to sharing diabetes related conversations discussions focused on the practicalities of inviting more people or finding other ways for the group to access data. The first major decision from a Co-researcher suggestion was to move the group work to an entirely online platform. We trialled video conferencing and found it worked very well, removing the problem of travelling to meet up physically. This also meant we could resend invitations to people who had shown an interest but would have found travel restrictive. A limitation however, was this would privilege Co-researcher participation to those confident with using the relevant computer software. Indeed there were gains and losses as 2 original members withdrew from the study (their material was redacted) as others joined. Eventually 9 participants contributed in the PAR group to varying degrees of which a core group of 4 committed Co-researchers provided substantiate involvement over eight months of cycles of reflection and dialogue on a weekly or fortnightly basis by consensus.

Being aware of my role on the Helpline at Diabetes UK, the group were interested in what my colleagues' experience of talking to people with diabetes had to offer. Co-researchers discussed the possibility of their involvement. I expressed concerns about the dynamics of relationships at work - although these were peers with no other management or supervisory dimensions, I did not want colleagues to feel obliged to engage for my sake. The PAR group discussed this and formulated an open letter that described what the group were involved in and carefully worded invitations for expressions of interest to voluntarily engage in a presentation and individual open dialogue about the project. Three peers at Diabetes UK responded positively and gave consent for Co-researchers to examine and discuss the data from their transcribed dialogues.

One Co-researcher was aware of the publicly available Diabetes UK Online Forum. I looked into this with management at Diabetes UK and discovered there was a protocol for researchers to contact members of the forum for research purposes. This done, with participant information consent was agreed with a further 19 people who either provided links to their own relevant material on the forum or who responded freshly on the message board I opened.

With the exception of the DUK Forum that responded in text format that I have used without any spelling or grammar checks and presented as they were uploaded, Co-researchers and team peers provided 27 hours of transcribed material, 9000 words of material from the DUK Forum, with the total number of participatory voices totalling 40 respondents. The average length of time from diagnosis was eight years.

Early face-to-face and later video conference material was recorded using Otter.ai that generated near 90% accurate transcripts. These were shared with Co-researchers via a cloud-based folder using Sync.com (chosen for its high security credentials) and could be shared during reflective cycles and discussed in subsequent dialogue.

Themes emerged from reflection and dialogue naturalistically and a deepening of meaning and understanding about the impact of language use unfolded over cycles leading to new ways of identifying issues of concern and confidence in addressing these. The passionate commitment and interest of Co-researchers evinced both Friere’s conscenciatisation and Fals Borda’s vivencia.

The gender of participants, including those from the DUK Forum was fairly even (47% male, 53% female). However, female participants contributed more cycles of dialogue and reflection over time. The data then, from female dialogues, comprises closer to 75% of the transcribed data set. It is difficult to construe whether female Co-researcher investment in participation was due to the methodology being more attractive to female participants because of the small number of subjects involved.

Participants’ age ranged from 21 to 50 with a mean calculated age of 32 (this does not include participants from the DUK Forum because individual forum profiles do not include age).

4.2 Reflexive exploration of the process of moving from study aims to study realisation

The initial struggle to convene a group and the low number of participants was highly anxiety provoking. I worried about the breadth of voices and whether we could generate enough material to reach data saturation. This meant working very carefully to foster a sound relational cohesion with Co-researchers in the group building sessions of the early cycles and offer a good deal of freedom in their choice of what to bring and how to work together. I found being extremely explicit about my interests and gains and encouraging Co-researchers to follow their interest first and foremost helped achieve this. I had anticipated that in following their own hearts and minds in this that the PAR group may eventually drift away from my central theme and that I should not attempt to lead them back or exert my influence. However, I had not anticipated that Co-researchers would so thoroughly embrace my research question and so quickly resonate with its significance for them. It became apparent that Co-researchers' experiences were redolent with the force of language in the conversations they had with others and particularly with HCPs both currently and historically. Even with Co-researcher dialogues that explored other aspects of life with diabetes we could not but use language to convey these experiences and this itself was revealing.

An anticipated challenge was how Co-researchers would perceive my position in the group and whether they would be able to fully take charge of the process and responsibility for their contributions. Co-researchers understood that I had extensive knowledge of diabetes from my work and from the literature review for the study. Although they found this useful and would sometimes ask me questions about diabetes it was made very clear that they were aware I did not have diabetes myself and that the research would predominantly value their lived experience over my diabetes knowledge unless it contributed insights to living with diabetes. Consequently Co-researchers took control of what mattered to them and predominantly shared this. This shaped my position and responsibility to engage with Co-researchers' dialogues to listen and contribute information when they shared conversations that displayed what they had been told deviated from the scientific and medical literature and signpost/email the correct information. The other area of responsibility in my role was to share ideas about emerging themes and openly discuss the value of these meanings. Co-researchers began moving towards ideas of addressing issues raised from emergent themes.

A hoped for strength of using PAR compared to other qualitative methods, was that single interviews would produce snapshots of lifeworld working with the same Co-researchers over time and together produced a rich slice of lifeworld experience.

In our dialogues we included thinking of a name for our work. The group settled on the Language in Diabetes Action Study and referred to ourselves as the LIDAS group.

As themes and meanings became more clearly shaped they also had an impact on my professional work with people with diabetes. This had two consequences: 1) greater opportunities in identifying with callers and clients the possible underlying messages they received about diabetes and addressing this more explicitly; and 2) callers and clients further confirming to me that these themes were indeed pertinent to their experience and had been the basis of the types of conversations they had had.

A limitation of the study was the small number of Co-researchers that participated substantially enough to be a robust example of PAR. Ideally I would have liked the group to consist of 6-8 Co-researchers meeting consistently together to co-create the structure and scope of the study. This would have produced a greater group experience of withworld and multiplicity of voices. However, I was impressed with the way participants surmounted the challenges that fewer Co-researcher numbers posed creatively. The use of professional peers and the DUK Forum did allow for corroboration of the meanings the group were developing independently, in a similar fashion to my discovery at work. Thus an internal form of triangulation was mirrored with an external form of triangulation. In sharing this Co-researchers became more confident in reframing some of their experiences that had previously been puzzling.

Something of particular note in the findings is a passionately felt sense of injustice and stigma in relation to PWD. There are some very strong views expressed at times that could be construed as polemical towards people, including HCP, who adopt language use that reveals these underlying values. It must be remembered that this phenomena is not proposed as proof of a conscious prejudice used to knowingly oppress PWD, but an entangled sense of meanings and values that potentially influence us out of awareness.

Chapter Five: Findings and Discussion

It is customary in the write up of qualitative research to present data and then move to analysis and discussion under separate headings. I have chosen to present the data from dialogues alongside an ongoing discussion of meanings from the hermeneutic process. This is then followed by a summary discussion that synthesises the literature review and existential and postmodernist themes with the general analysis. I have chosen this approach for three main reasons.

1) Unlike many forms of qualitative research like IPA, there is much less separation between the functions of data gathering and analysis as Co-researchers visit and revisit periods of reflection with dialogue, building and revising their understanding together co-creating emerging meanings. This is in contrast to the customary format for much qualitative research which lends itself to separate data capture when interviews or survey results follow a clear three-step cycle of transcribing one off interviews, single researcher analysis and synthesis/discussion.

2) The lives of my Co-researchers with diabetes are highly technical in terms of health tasks, vocabulary and paraphernalia utilised for looking after themselves or supporting PWD. Despite including a glossary of technical terms and the common vernacular (appendix A) that sometimes replaces them, this "insider" speech may have been difficult for the reader to hold in mind clearly whilst negotiating a separate discussion after a lengthy immersion in Co-researchers diabetic worlds. Although Co-researchers' responses and reflections to their lifeworld and their diabetes was recognisably human, the language they have internalised and use may be a challenge to outsider readers. This I wanted to avoid.

3) My research question was set out thus: *how does the vocabulary and language associated with diabetes facilitate people with diabetes to respond to their experience?* Assessing the question through the action research process it became apparent that "vocabulary" (language), meanings conveyed (values and beliefs) and "experience" (lifeworld) were intertwined and inseparable. It became clear to me that in separating them the thesis felt artificial and driven only by convention.

The following themes are presented as potential tensions on an arc or spectrum. A reflected intention on my part is to formulate these as exemplars of Heideggerian "entanglements" in the manner of the problem of techne. They are also open to the possibility of being seen as epistemes or regimes of truth in a Foucauldian sense and viewed in near proximity to his explication of biopower.

5.1 Capacity to Control Vs Skills, Knowledge and Tools

Health psychology literature related to diabetes has had quite a lot to say about disease/illness control and health behaviours. I have mentioned a tendency (see literature review) to see health behaviours as contributors to control. However, another reading in Co-researchers' explorations revealed a different arrangement of tensions on a spectrum. Our exploratory efforts seemed to coalesce around an entangled axis in which language and meaning vied for corroboration.

"Capacity to Control" is a notion that relates to a person with diabetes relative ability to finely manipulate their body and environment (lifestyle and treatment) for the purpose of diabetes control itself – to *be* controlling, or in control. It is predominantly attitudinal and behavioural and may be seen as mediated by ideas of Intelligence and Personality as an innate tendency.

This stands in opposition to "Skills, Knowledge and Tools". By this I mean an interlocking blend of factors that arise out of an individual's contextual understanding of what is necessary, sufficient and achievable for diabetes management in both a particular situation (e.g. how much short acting insulin is optimal for this meal) and in general (e.g. an improvement in my HbA1c will be helpful in mitigating the risk of future complications or having my "five a day" will contribute to my overall health). "Skills, Knowledge and Tools" is demonstrated in the positive evidence for Structured Patient Education, self-education through online resources (e.g. Diabetes UK's online "Learning Zone") and peer support. The "Tools" aspect of this notion can be seen as any accompanying equipment that contextually supports a relative ease of management for a particular individual in their circumstances. A person with diabetes therefore has “paraphernalia” or “kit” to contend with that fits with their circumstantial requirements to a greater or lesser degree and is “handled” with “Skills and Knowledge” to a greater or lesser degree. Tools are not just the advancing “technology” of insulin injecting pens, blood glucose monitoring devices or continuous subcutaneous insulin infusion sets (or insulin pumps) but also items like diabetes medications, dosette boxes, hypo treatmenst (dextrose tablets, coke cola etc), carbohydrate counting books or apps, weighing scales, BMI calculators, sharps bins, refrigerators, cool-bags and wallets, fit-bits or pedometers and so on.

In contrast, Capacity to Control also carries an implication of a moral obligation on the part of the patient to carry out the treatment plan and attain target levels for blood glucose, blood pressure and cholesterol. Behaviour is then seen morally as “good” behaviour resulting in optimal target levels and “bad” behaviour resulting in suboptimal levels. Biomarkers may be seen as indicators of behaviour or the lack of Capacity to Control and this is problematic as it may engender suspicion on the part of a HCP that their patient is not accepting “bad” behaviour conducted or “good” behaviour eschewed. This stands against a concept of behaviour as praxis or actions where results are derived from the application of acquired Skills, Knowledge and Tools from an individual contextual process of learning and engaging in healthful tasks.

Another aspect of this tension arc is one of ownership. Fulfilling required behaviours in Capacity to Control seen as derived from the authority of the HCP means compliance with an agenda that has not been chosen. This is at the heart of “patient adherence” instead of seeing “Skills, Knowledge and Tools” derived from the person’s learning and consequent management decisions belonging to them.

As C, a twenty-one year old female diagnosed with Type 1 diabetes in childhood put it:

“So I'm that case of my mum, and my family controlled it for all the years and then suddenly it was my responsibility. When I started taking over... quite honestly I was rubbish with it... that's some of the language you can use… [laughs] My nurses’ terminology.”

This problematizes the capacity for improvement or growing skill in management. More than just a self-fulfilling prophecy, because “being rubbish” carries the implied message of an innate incapacity to functionally control diabetes as opposed to being currently sub-optimal in the skills, knowledge and tools that would help and/or the motivation for control as opposed to tasks. The former is potentially intractable or very hard to change and this fixates low expectations for improvement. The latter is more likely to produce a question – what might you need in order to improve? Further, the notion of a capacity to control implies a certain type of person rather than a certain set of skills and knowledge i.e. a person who is disciplined, committed, orderly, adherent/compliant etc. This in turn implies an opposite temperament or type of person who is undisciplined, careless, lazy/messy or rebellious and wilful. But this might imply that beneath the physical health condition is some sort of disorder of personality for which there is no diagnosis or treatment and with significantly poorer outcomes. If not a personality disorder then a person that chooses wilfully to be rebellious. Might there be a pre-reflective tendency to account for sub-optimal management of diabetes (commonly referred to with terms like non-compliant, difficult or “heart sink” patient, poorly controlled) as a patient who is either “mad” (disordered, lacking understanding or in denial) or “bad” (wilful and rebellious).

C is all too aware of the phenomena of being judged.

C: *“Take a massive dose of insulin. If you get away with it won't be on the radar of your team. Because I got away with it, and I'm the only one affected at the time. And, to be quite honest, I've done that on a number of occasions in the past. Yeah. Essentially, if you end up in hospital it's on the map. It always felt that no matter what was going on it was always assumed that I myself had made a massive poor decision. Or I neglected myself. And, you know, obviously those situations, if you're not careful, you can end up in hospital with DKA, but they won't listen to the fact that you were ill, which has led on to why you ended up there. It was “well obviously you've missed an injection, you've done something wrong that's caused this. You're not looking after yourself.” And obviously these things are very serious. If you're thinking that I either mistakenly or purposefully missed something vital shouldn't you stop pointing the finger at me and try to work out perhaps why and let's fix it. I struggle with* *depression. And some of those times where I would end up in DKA were because I was really struggling with it. And it was not at all helpful for me to go to such a state where, obviously, I'm really not well and end up in hospital. And all I get is this nagging and being told off."*

The consequences of Diabetic Keto Acidosis [DKA] can be very serious occasioning a hospital admission to A & E or intensive care and can be potentially lethal if not treated swiftly with intravenous fluids and insulin.

C: *"A lot of the time it's kind of them rushing around me and her [Mum]. Over the years, she's got knowledge of what happens in those scenarios, which I wish she didn't have, because that shows how many I've had. I still feel some of the guilt with my mom on just how that experience affects her. I have a lot of guilt over them, not only about her [Mum], but also about me. I'm reaching a point where it's… I feel guilty about purposely causing DKA, which I've not done. I haven't gone out one day and said you know what, I'm sick. I'm tired. I want to have a DKA. But I still have that idea because it's been… been almost beaten into me that I've done something wrong, that's caused it. And for some of them [HCPs] I know they do believe that is a very true element."*

There may be a widespread belief amongst clinicians that once diagnosed and on insulin DKA can only occur if the patient does something wrong. But C is pointing out that if there is a problem there ought to be a way to address it. Instead she experiences a scolding that further reveals the meaning of wrong is moral rather than misadventure or accident.

C: *"...I'd burnt out... um... completely, I was barely doing anything... Um... just... well within the last year, I've just… just kept myself out of hospital… that was the only... like... insulin I was giving was just to keep me out of hospital… keep me in work."*

The transition to taking responsibility did not work well for C. It is also notable that it seems keeping well enough to stay out of hospital and in work are not sufficient under the circumstances to be considered a degree of management given that many people experience spates of severe hypo or DKA that necessitate hospital admission. Some time later another common transition occurred in moving from paediatric diabetes clinic to adult clinic.

C: *"…so I've only... um... within the last couple years actually joined... the adult side of the hospital... Um... so all my nurses, my doctors, everything's changed now. And I've done a DAFNE course, which is about carb counting. And as of... about two three months ago... um... I've been put on an insulin pump. And actually just had one of those HbA1c things. And it has dropped significantly [emphasis]... since I've been put on this pump..."*

In C's case transition to adult clinic (later than 18) quickly brought opportunities for Structured Patient Education (Dose Adjustment for Normal Eating or DAFNE) and later, Continuous Subcutaneous Insulin Infusion (CSII or pump therapy). The criteria for pump therapy on the NHS stipulates six months of carbohydrate counting following education. This is taught as group education and indicates in C's story that both were part of a coordinated care plan with the swiftest opportunity to progress to pump therapy.

In this account C mentions being "put on the pump". In an earlier reflection C says: "it was sold to me" (and with slightly misleading benefits about less equipment to manage on the go). Both suggest a degree of encouragement if not a hard sell.

Despite this the benefits in relation to improved glucose levels were understood by C before starting: "So obviously, this is giving insulin continuously... giving me some continuously. So I really knew that my average counts were going to drop at that point." This was confirmed at next HbA1c.

C: *"Um, well... So it was... a bit... confusing for me. Because... um... where I've had it for so long, I've grown up with percentages… when I call my doctor and he told me what it was [HbA1c result], and I was like... Okay... I don't know what that means... But I looked it up… it was somewhere around 67. Um, when I looked it up, I think it was some that was something like eight or 9%."*

The actual conversion is 8.3% and is significantly improved compared to 9%.

C: *"And, um... I used... my percentage used to be about 12%."*

This is 108mmol/mol. This reduction reflects a fivefold decrease in the risk of complications (DCCT and UKPDS). HbA1c tests changed the unit reading from %mg/L to mmol/mol (IFFC). The meaning of levels in risk reduction and future safety is not always discussed except in the general sense of "the lower the better."

This change in management of glucose is dramatic and cannot be accounted for by C's "attitude" to treating diabetes, or her Capacity to Control, changing. Clearly C is not "rubbish" at diabetes once appropriate Skills, Knowledge and Tools became available.

C: *"She… she was saying… "Oh, that's really amazing. I'm really proud of you..." um... I'd also… I actually bumped into my childhood nurse… and told her about it. And she was completely gobsmacked [emphasis]... about it."*

C's HCP expressing "pride" in her results is encouraging for C to hear. However, being proud also carries an implication that behaviour or attitude is central to C's improved HbA1c when C's explanation is that the pump improves her ability to deliver insulin particularly the background basal dose.

The encounter with C's former PDN being "gobsmacked" reveals something about C's diabetes case history (known to both HCPs). "Pride" and "gobsmacked" somehow stand in relation to "rubbish at diabetes" that locates it within a general sense that formerly "wayward" behaviour has somehow been corrected as opposed to skills and technology being appropriate to affect a positive change.

For C at this point, utilising carbohydrate counting skills and pump therapy was also added "flash monitoring" with the "Freestyle Libre". This is a blood glucose monitoring device that uses a sensor attached to the back of the arm with Bluetooth connectivity that we will return to later.

C: *"But, I mean, when I've been looking at what I'm doing now compared to what I used to do. It's so much better. It's testing so much more I know more about what's actually going on. And during the day… even though it is a hassle. At times, it's like the pump, it's already proven to me that if, if I do keep up with actually doing the work, like what it needs to actually function, then it's so much better than the traditional injections. I'm still learning, obviously with the pump… and the app is so much better. Like how… the insulin works. And… and… in a way, justifying my decisions, it feels like."*

Discussions around very new technology are interesting in how they address certain problems. Seeing real time movements in blood glucose confirms a reality rarely shared with PWD about blood glucose fluctuations and the numerous factors that influence this. The Freestyle Libre's trend indicator is highly valuable to understanding. Initially it can produce a panicky feeling because it reveals that blood glucose movements do not conform to the commonplace meaning of controlled and stable, attributed to them. But the "new" understanding can be liberating at many levels. This is a primary example of a "tool" that supports the notion of "Skills, Knowledge and Tools" as highly contextual and flexible that challenges the implied meaning of control in Capacity to Control and the rigidity of adherence.

C: *"I would be potentially having a, maybe a high carb meal. And my count might be fine. But I would be giving slightly more insulin than I normally would give straight away… because I would be having, like Coca Cola, or something that I know is a very focused… is a faster acting element of the meal."*

Fine tune discrimination of different carbohydrate, Glycaemic Impact (the relative speed at which carbohydrates are broken down into glucose in the blood after eating) and dosing are possible because of greater insight from real world decision-making. This is another counter to Capacity to Control as it reveals the subtleties and nuances involved in blood glucose fluctuations and the action of insulin that throws doubt on any supposition of "control" per se. It becomes less tenable to believe it is possible to be within target ranges continuously.

C: *"In the past, I either overreacted and ended up with hypos or getting into difficulties or had to just take my hands off a bit and just, just give basal dosing, and a bit of bolas… when you felt that was appropriate. But avoid hypos."*

Attempting to achieve targets, and falling in with Capacity to Control, can lead to overreaction in chasing blood glucose with insulin or becoming frustrated and fed up. Over reaction and rigid adherence are also more likely to promote more hypoglycaemia and since the body's response is to release more glucose from the liver that interferes with and obscures the blood glucose range (low to very high readings) and becomes harder to accurately read insulin requirements. Further overcompensation can produce a confusing cycle of repeating highs and lows with a wide range. Frequently, stability is only achievable again once hypos are minimised. When a PWD falls into Capacity to Control and discovers it does not deliver day-to-day management but instead, increased burden, anxiety and frustration, despondency can follow.

C: *"…so every other technique that I've been told to try… over the years, and to help me be more compliant to what I've always been told to do, and within a few days… I've given up"*

C's experience of access to new tools increased her engagement in making decisions based on contextual familiarity with her skills and knowledge.

"At the very least, it would kind of almost balance… and make me more consistent throughout my day… for someone that had HbA1c of 12%... about a year ago... it's kind of nuts… it says it all. It's been two pieces of equipment that's making my life just so much easier."

Co-research M is a young mother with Type 1 diabetes who worked in the events team at Diabetes UK some years ago. She also has some background retinopathy (vision impairment) in one eye.

M: "*When I was a young person when I went into my clinics, I found a lot of consultants, that use language like, "you need to do this. Oh, that's not good* *enough." You know, it's just stuff that as a teenager made you feel like "finger pointing" at every single appointment. And then I used to just avoid going to all my appointments up until I was about 20."*

For M the experience of finger pointing denotes both the manner in which information is imparted as finger wagging about her behaviour and also the degree of focus on negative aspects. The result is that she stopped attending appointments to avoid the unpleasantness.

M: "*So "your blood sugar is like this, well you need to do this, or you need to do that, and you should be making more effort." And do you know, "do this, do that" rather than "why don't we explore this…" you know, the language that you should be using is quite an open conversation about things rather than finger pointing. GPs do that as well. They kind of don't have as much knowledge about diabetes, as you know, they're just a general practitioner. So they don't have as much knowledge as specific diabetes nurses. You often find that it's kind of the language that they use, is kind of "how often are you testing?" "How much did you inject today?" You know…"you inject morning, noon and night?" "No, I inject whenever I eat anything with carbohydrate in it." I kind of feel like sometimes you need to educate them a bit more."*

M identifies early on that she has learned a way of being in her consultations that resists buying into the restricted language of Capacity to Control. This suggests a degree of awareness and confidence that allows her to correct her HCPs' and even to educate them. C responds to this dialogue:

C: "Yes, I found it very similar at appointments. Except I'm still at that stage where I just, I either block it out, or I just wait until the appointment is over because a lot the time it feels like no matter what I say they use that sort of thing like "you should be doing this, you should be doing that"… a lot of the time. I understand there's an element of doctors… they don't know what it's like, on a day to day basis to actually live with the condition 24/7 for the rest of your life. So they see these guidelines, or how many tests or injections you should be doing a day. And they think "oh, well, why don't they do it?" And I'm also not at the stage where I feel that I can turn to a GP or something like say M, like you was saying about the injecting when you eat carbs. I *wouldn't turn around and say, "well I didn't eat that day. So why would I have injected anyway?"*

C confirms she has a similar experience concerning restrictive language but also notes explicitly that she suspects it is clinicians' lack of lived experience with diabetes that it stems from what M implied. Despite knowing this she doesn't feel the confidence to challenge this directly as M does.

M: *I especially find this with my eye. Like I said about the doctors letters I get from a doctor at the hospital saying "I told this woman she needs to keep control of her diabetes"… and it's like blame. That's what I feel when I read that last paragraph. And I'll think, "hang on, you didn't put it like that in the consultation." Every time I get a letter through, I go every two weeks, and every single time that letter comes through at the very bottom it'll say, "I've told this lady what she needs to do."*

I have also seen similar language in my patients' notes from some clinicians. It opens the possibility that even a clinician who engages more collaboratively with their patients may feel pressure to use Capacity to Control with other clinicians. Perhaps HCPs feel obliged to accept a responsibility for telling patients what to do.

Despite M's awareness she is also capable of expressing the insinuating nature of internalising the language of Capacity to Control.

M: *"I guess... it is a constant niggling pressure that you feel. I've actually talked about having diabetes as feeling that I constantly need to stay on track. I do feel like, "oh god if I don't look after myself." That's a constant sort of pressure, really, it is always just there, you know… I feel guilty if I've had one day where I've gone above 15 or something."*

TLC on the DUK Forum expresses succinctly the distinction between Capacity to Control in the process towards Skills, Knowledge and Tools:

"I had set myself unrealistic targets and was getting frustrated with the highs and lows of normal life with T1… which I was seeing as failures. A strategy I found very

helpful was to start to log events of hypers and hypos and to record the reason for these where possible, strategies available to overcome the problem another time, and to record whether this event was in my control, beyond my control or a combination of the two. It may sound simplistic, but I was amazed how many events I was beating myself up for which were beyond my control."

TLC discovers the very concept of control in diabetes produces unrealistic expectations that reflect adversely on one's sense of self. By adopting an approach of gathering real world data and trying to make sense of what real world factors influence fluctuations in blood glucose TLC is deepening his understanding of real world knowledge. The contextual variations in the events he logs teach him that on many occasions he has attributed control when there is none. The tools he deploys are his blood glucose testing kit and a logbook. The process of recording and reflecting seems "simplistic" and yet by treating his levels purely as data he gradually relinquishes "unrealistic targets" and "failures", dissolving the bias generated by Capacity to Control by growing Skills, Knowledge and Tools.

RM on DUK Forum: *"When I was a teenager, I went through a fairly extended period of not really testing. I think there are several factors that resulted in this, and I definitely take responsibility for not testing. Some of the reasons were that I was on mixtard at the time, and I'd never been shown how to adjust it. A big part of it was guilt - like one of the girls on the programme said, she'd test for a bit and then get depressed when she saw an high number and then stop. I know I definitely did that, because it would feel like I'd been 'bad' if my numbers were high (although I attribute at least some of that feeling to consultants who pretty much told me high numbers were my fault), and also there was nothing I could do about it. I couldn't change my insulin, and I didn't even possess any quick acting insulin, never mind understand about correction factors. I'd think "well, what's the point of testing?" and stop."*

The DUK Forum has also frequently posted a link to an article by Adam Brown on the American diabetes forum diabtribe.org. Like TLC Adam has been monitoring and logging factors that influence his blood glucose levels and has identified 42 across 6 dimensions: Food, Medication, Physical Activity, Biology, Environment, Behaviour and Decisions. He points out that any number of these factors may be at play in any given context. His stated purpose for researching and posting his article and blog is to directly expose the notion of blood glucose control being easily achievable:

“Ever heard someone explain diabetes with a frustrating level of simplicity? “You’ll have on-target blood sugars as long as you eat right, exercise, and take your medicine. If only it were that easy, and if only vague advice was all we needed to hear. One of our missions in diaTribe – and in this column – has been to debunk this myth.”

5.1.1 Capacity to Control, abstract knowledge and targets versus complex contextual lifeworld led goals

An aspect of the medical model is the tendency to privilege abstract knowledge over practical experience. The authority of abstract knowledge is its claim to truth but this also is reflected in the power dynamic of the educated professional with the “lay” patient.

C: *“Because it was almost... with some doctors, It was almost like, “oh, you're just a child, you don't know anything.” Then, “let's talk to the adult in the room about it.” As If I didn't have any say, or even any opinion of what was going on in my own life. Um... so that's always fun. It makes you cynical... "She doesn't know anything” because you don't have two degrees. Ha... what about a life degree?”*

In some ways the responsibility of the clinician to have patients attain abstract targets is often based on a knowledge that has little real world meaning for patients.

T: *“Like from their point... if I was them, and my only goal was keep this... this person's blood sugar as good as possible. If it's my only goal I wouldn't have to consider what I actually wanted... and that's the thing. And that's what my nurses, I think, would want me to do. It makes sense. But you have to understand that we're not robots... we are not blood sugar robots, we're human beings. I could definitely get my blood sugar to be under six all day but I’d have to eat seven times a day and with exactly the exact amount of carbohydrate in each meal. And not move much when I* *knew that I wouldn't go low. And I think that that is like... Yes... I can do it. Do I want to do it? No. Would anyone ever want to do that?"*

T neatly sums up what occurs when Capacity to Control abstracts lived experience into narrowly defined tasks and targets. The result is a feeling of having to become a "blood sugar robot" instead of a human being. The meaning is clear that lifeworld led goals are secondary to the performance of blood glucose control for its own sake. T also recognises that abstraction produces too narrow a meaning that does not account for complexities.

T: *"Take one look at someone else's schedule. And blood sugar's based on what they're doing to just know that everyone's so different. Really, obviously, you can't compare insulin doses of people."*

M: *I find a lot of the time healthcare professionals will make an assumption or they've not had the training probably to update them. That's what I massively found... "right, so you test before a meal you know, before breakfast, lunch and dinner… before bed, upon waking up, breakfast, lunch and dinner". I don't think they necessarily knew about post eating, you know, and other times."*

Assumptions and abstractions are unrealistic and diverge from the real world context of PWD lived experience. They can come across as simplistic aphorisms that are seductive because they are pithy and allay fears about uncertainty and complexity but are often hollow.

C: "…they [paediatric healthcare team] tried to make it seem as - especially when I was younger - that the idea was "you need to control your diabetes not let your diabetes control you"… and thought this is completely possible for someone 24/7, 365 days, for my entire life."

E: *"Okay, so some people though on the helpline... some people want that list, don't they, tell me the foods I can eat you know have you got a list of foods that I can eat so that's another kind of barrier to it. I'm sometimes talking to people who want something which is restrictive and very much telling you what to do."*

This is particularly difficult when it comes to conversations about complications.

C: *"The positives weren't ever mentioned. So, I don't think they ever really actually said to me about what would happen if I did actually fully engage and I've got all this stuff to do so I was, I was aiming for a goal that I didn't know what the achievement would be, the reward at the end."*

Me: So linking research data for HbA1c and relative complication risk was never discussed…

C: *"Not until I first met you. I've never seen that graph in my life [the plot graph of HbA1c against future complication risk]. I was only told this is what you're aiming for. You have to reach this number. And it's like, what does that mean to me?"*

T talks about what he has heard in relation to the average life expectancy for PWD.

T: *"Erm... I've been told... I just know the average, I think it's like nine [years]. But I've totally forgotten about it. Because I'm very into, you know, living while I am young. And just getting the most out of my time... not like partying all the time and stuff... but getting the most out of my music and like, you know, doing everything I want to do. If my normal expected age to die is 95... I'm not too fussed if I die at 85. I'm not going to do much between 85 and 95 anyway... as to how I am now mentally. Because obviously, when I was told... it struck me like "I'm not going to see that"... but I can see everything I want to see. You know, you can see grand kids grow up, things like that. But, you know, obviously... it increases with how worse your control is."*

T is interpreting what he has been told about diabetes and lifespan… and by implication, complications… in relation to his world. This results in having to project a long life so the implication of dying younger is mitigated.

Understanding the implications of future complications and lower life span is fraught with confusion and misinformation. A problem seems to be that some HCP on occasion feel it is appropriate to deliver messages that imply it is possible to predict an individual's personal outcomes. Clearly this is not scientifically possible as all data is average. However, it seems data used in this way belongs to "cautionary tales" to be told to patients, the purpose of which is not entirely apparent but could be to foster patient compliance, a belief that avoiding disaster is a positive motivation to management or driven by the desire to see a Capacity to Control. A further problem is not recognising that PWD diagnosed in the last few years will have improved outcomes on the basis that Skills, Knowledge and Tools have improved on generations diagnosed in the 70's, 80's and 90's. Again, motivated by control implies target bio-marker achievement is the primary purpose for a PWD in it's own right. This both denotes Capacity to Control that produces a good, compliant patient and re-affirms the notion that it is Capacity to Control that produces positive outcomes rather than optimising appropriate Skills, Knowledge and Tools. Once more, the evidence is strong that Skills, Knowledge and Tools and being motivated by lifeworld goals produce more positive outcomes on the whole: patient education, greater awareness, resistance to stigma, real-world contextual learning and appropriate technology.

Furthermore, updates to HCP awareness of risks for complications and early death are of their nature outdated. Because many people with diabetes live with a likelihood of devastating outcomes and early death over many decades the data supports a vision on the basis of the balance of probability that even in the least sophisticated treatment periods since 1927 and the discovery of administering insulin have never reached 100% probability of complications. Exceptional though it may be there are people that have survived with relatively high and risky levels for bio-markers, post diagnosis, 50, 60 and 70 years. Current data is always past oriented. A meta-analysis of end point outcomes can only speak of previous decades and generations that do not include our current understanding of what mitigates them. PWD and HCP are therefore always behind and past oriented unless they speak of future health in the most general sense and with caution.

The way in which complication risk and mortality are presented to people with diabetes does not often include that these are statistical averages and cannot be applied to individual risk.

T: *"And another thing which I was actually thinking about... if it makes sense... is like... Well, I got it when I was 14, 15, I think. I'm 19 now. By the time I'm 40 the effectiveness of the medication and ability to measure blood glucose is going to be far superior than to now. So Even if my blood sugars were total shite, like 10 years from now, by the time I'm 29. Like... I'm still young, you know... not even thirty... and think how far the medication would have come along in that time. So I guess they just think yes. If your management remained exactly the same from now, that's what'll happen, I guess that's why I look forward to a certain extent... things are going to change, things are going to get better."*

C: *"I've had a couple of eye tests before that have come back with the starting of it [retinopathy]. Which... um... that they will they always tell you when you've got the start, they start telling you all of the nitty-gritty details. I don't think they told me how many years but they said, "you're going to lose your sight".*

T: *"Ouch."*

C: *And at first they made it seem like that's it. You've done it to yourself sort of thing. And there's not really much you can do really, it's almost like you can put it off for a certain amount of time. But it almost came across like it was a definite. And then a couple years later, it came back and it was like "Oh, no, your eyes are fine".*

T: *"Yes. It reverses right?*

C: *"I mean, I don't know whether they do it with other people as almost like a scare tactic."*

T: *"I've had something like that…"*

C: *"Or if you're not playing ball with them, like "Oh, yeah, this proves that you're going to end up living this terrible life and you're gonna go blind, you're going to lose your feet and all those nightmares that they try to tell you."*

Me: Maybe even C, all at once on the same day?

C: “*Yeah…. Pictures I was shown…”*

T: *“Yeah, yeah, I've had that. A lot of the bad things I was told...”*

C: *“I don't really know what happened when it came to my eyes. Because to be quite honest I didn't change anything. In fact, I would say I had gotten worse. In my management or care, whatever you want to call it of my diabetes.” But I've almost become desensitised. Because it's been pushed on me so much. And it's kind of like, I'll think about that later. I'm not suffering from that now. If... if it's going to happen anyway. I'll deal with it when it does... erm... sort of thing.”*

An improvement in retinopathy during a period when management had not improved reveals to C that her life experience is not matching up with the narrative of complications. In relation to capacity for control this, once again displays a moral rather than rational scientific frame of reference. T spots this disparity:

T: *“Yeah, it's really interesting. For sure, you didn't change anything... like... it's chat room bullshit, really... try and make you change your blood sugar?”*

The complication narrative is not told in probabilities, averages or explicitly identified as abstract, but rather in individual predictions directly related to behaviour and is further evidence of a moral framework that borders on “moralising”. This may be what T’s reference to “chat room bullshit” is conveying.

Numbers in diabetes form a particular kind of language of their own. Blood glucose levels in frequent daily testing, HbA1c and percentages for risk profiles coalesce into meanings that have strong emotional corollaries. A high reading from a single test can occasion feelings of frustration, anxiety, despondency or guilt because of the overly strict association with harm. This might also be why PWD frequently use the vernacular of ups and downs, high and lows because they mirror the emotional vicissitudes of experiencing changes in blood glucose levels. However, it is not frequently discussed that the body responds to blood glucose levels that have become customary rather than the body being capable of “reading” the figures.

T: *"I remember when I... at the start I was running about 10mmols most of the time because I was trying to like... getting used to it. And as soon as I went down six, about 6mmols... which isn't unusual for me now, I felt super low. And then like, textbook 6.5. And being told it wasn't a hypo."*

Contextual experience in relation to BGs and experiencing symptoms of a hypo do not conform to the textbook. This is an example of abstract "facts" countermanding contextual experience. T was told, "that's not a hypo" because it didn't conform to <4 mmol/l. The real world context is that at diagnosis the range of glucose levels is higher and the body will not have experienced the normal range. Following targets too swiftly will mean hypos can and do occur when the body experiences unfamiliar levels that in the abstract textbook are considered normal.

T: *"So that's the other thing with the nurses... so funny... I've heard before... Like they, they always want to try and protect you from going too low with the hypo awareness, stuff like that."*

It is implied that highs are bad and lows are bad. The average described by an HbA1c also conforms to either a good target range or if not, is also implied as bad. If Capacity to Control linked with bio-markers is viewed as revealing good or bad diabetes management as acceptable or poor behaviour respectively, it is unsurprising that PWD may attempt to offset bad results by using unhealthy or risky means.

C: *"You just reminded me of something. This was some very bad practice that I did. I think I only ever really did it once and that was when I was in a very bad place. I knew that I was going up to the hospital to get my bloods done. I thought to myself, what I know about this test is that it takes the average of the last three months, of what your bloods been like. So what does my genius mind think to do to correct it? I've got an insulin pen with me. If some extra shots might bring myself down a bit [BGs down], you know, do that a few times. It'll put the average down, won't it? Which obviously is dangerous. Luckily, it never had serious implications for me. I'm very lucky. I haven't, I haven't been in a state where I've needed to be helped by people for a hypo."*

In the past one of C's lifeworld goals was to avoid awkward conversations about her HbA1c with her healthcare team and on one occasion this included the decision to overdose insulin to affect the averages.

Many peoples' gains in diabetes management are achieved by learning from actual experience and this is augmented in structured patient education like DAFNE.

T: *"So the language around... well... you're going to end up with this or this will happen, or you're going to end up with nine years less. None of that is actually predictable in any individual single case? Because I know some people who hear stuff like that, they suddenly become very obsessed with it, and it almost stops. And I noticed some people in my life would have potentially made themselves worse while trying to make themselves better. They would have decreased their happiness in their lives to live a little bit longer. So interesting."*

C: *"But well, what I saw of the books [on the DAFNE course] it was more like prompts, about things. Because it almost comes with a tagline of, "well you're going to have to work it out. See what happens to you when you do x y&z.""*

T: *"I'm sure most of us diabetics did exactly the same of, kind of... same sort of way. So, for myself, not listening to the doctors and nurses as to what you "should" be doing but what you know from experience and how you've lived."*

DAFNE and structured patient education (like "Kick Off" for young people and the X-pert Patient Programme) are examples of active experimentation to acquire Skills, Knowledge and Tools from a complex contextual real world experience.

Another example of Tools reinforcing Skills and Knowledge is the Freestyle Libre. This has only become more widely available in the last year. This device uses a sensor to detect blood glucose levels from interstitial fluid in the skin. A handheld reader or phone app can be scanned to the sensor in order to give a reading. However, the sensor also backs up with readings every ten minutes from the previous scan and information from this is displayed on a trend indicator that gives an impression of whether levels are stable, rising or dropping steadily or sharply. It is also possible to download a graph of blood glucose readings. Compare this to the traditional finger prick test where each test gives a static snapshot of blood glucose. As a result, the Libre device reveals the continual movement of blood glucose up and down in a way that was not readily available to PWD. Previously it was often implied that blood glucose levels were more or less stable if a PWD dosed the correct insulin. Now it is impossible to ignore that this abstraction was overly simplistic and often led to over reaction in dosing decisions that could promote far greater ups and downs and hypos.

M: *I don't think the numbers worry me as much now… I feel. I'm calm or calmer. Now, I get a bit stressed out, I mean I still get stressed out if my blood sugars are going that way. Yeah, because I've never been able to see it. Whereas this and actually until I got the Libre, I think I was always in those people that just injected when I saw a high blood sugar. I didn't wait for hours, you know, then I'd always have a hypo after. I used to over-inject because I couldn't see what was going on so that's why the numbers don't worry me as much because I can see what's happening. Now I've got this [Freestyle Libre], like you said, I can see the trend. I'm a lot less exhausted from chasing my ups and downs."*

Me: Yes.

M: *"I don't know how I lived without it now, you know, I really don't especially after having my baby, feeling safe enough to sort of be on my own with her. When I first had her I didn't have the Libre. Oh god, I was just terrified of being on my own with her, I was quite anxious about hypos and things and like. It makes it easier. And she likes it now that she can get my machine and put it against my sensor, you know, I kind of quite like things like that. She knows that my kit is my kit and it's in a bag and she comes and gives it to me, you know. But yeah, it's made me not panic as much about things, because you don't need to as much."*

C: "*I've always been told off because I was constantly running high and I think that did cause a lot of my issues. Hmm… when I was following the instructions of my nurses and everything and testing however many times a day and everything, it would be constantly high. And then I'd go to the appointment, get told off for them being* *constantly high, and then be fed up. Stop doing everything, go to the next appointment, and then be told off the same amount for not doing it. And so for me it was kind of a case of, well, if I'm just going to be told off either way I'm going to save myself the stress of having to look at those numbers. So I wouldn't do it, which, quite frankly, landed me with DKAs on multiple occasions because I didn't know what was going on. But now that I've got this Libre I feel so much better. Since having the Libre I've only gone up to 20 once. And even then, when I haven't scanned but I can see from the chart that I've been quite high. Honestly, I don't care about it anymore".*

This gives a sense of C's caring about blood glucose levels before was in connection with an anticipated "telling off" in consultation. The real benefit is not the high and lows of blood glucose as with static finger prick testing but how it allows C to understand her blood glucose movements in acquiring new Skills, Knowledge and Tools.

C: *"Um, I definitely find the graph because, like, I mean I'm learning so much about my levels. I had no idea about during the night. That I'm technically hypoing during the night. And that's something that I never even thought it was doing. And even during the day. I knew my insulin took time to work. But I would do a finger test, and then it would be 20 or something. And I'd end up frustrated about it, thinking, well I've done what I'm supposed to do. I've corrected why isn't it doing anything? Whereas now it might come up as 20, but it will show that I'm about to shoot down or I'm trending down. So then I know, not to do anything else. Wait it out."*

Superior quality of blood glucose data has another benefit for C. Where there had been ambivalent consultations with healthcare team members the data removes doubt about her decision-making.

C: ***"****I find that this is almost a better way for me to justify my decisions... my daily life because I can, I can turn around to the doctor and say, "Yes, my count [HbA1c] might have been that. But look at what this [the Freestyle Libre data] is doing at the time. This is what I based my decision on, because of what was going on. So that's what I do, which I couldn't do before. And before even if I justified myself to the doctor it would be that they just didn't believe it, or I was making it up just to please* *them, where now I can be like, "Er no, there's actual scientific evidence that shows that I did the right thing."*

The Libre also reduces the risk of making snap judgements on snapshot evidence. It is possible to wait and see what the trends in glucose levels are doing as shown in the following dialogue.

C: *"I think now it's... where I have such a better understanding of how everything actually works. I feel a lot more comfortable and from experience that this going high is because of the way the pump works. I also need to not give all the insulin immediately because I've got a higher fat content or higher GI carbs. So typically when I'm going high now it's because I've just miscalculated that, which has been proven as I haven't over reacted to the high and I've come down without doing anything."*

Me: I think that that's something that sort of draws everything together in terms of, you know, these static points of making decisions because that's what you got from testing in the past. And becomes a kind of flow within the trends that opens up the possibility to respond rather than overreact.

C: *"Yeah, that's exactly what I think it is… I think I overreacted too much."*

Me: But where do you think, given the way that testing was presented to you and what it's meant to mean. Where do you think that sense of, I need to do something urgently came from?

M: "*From Health Care Professionals… probably "you need to have this you need to, it needs to be like this" then you panic. Yeah, because you never really saw anything else that was, you couldn't see patterns of what was going on. I don't think I had the knowledge about why. So then when I tested. I was just "I gotta get down as quick as possible because otherwise I'm gonna lose my feet". You know, so that I just inject as much as I could and then get really, really low and then go really high and then you're really, really low again."*

Abstraction also seems to imply a consistent, stable environment for controlling diabetes. The real world context where diabetes actually happens is in a person in a context and in environments like home, work, school and socialising.

C: *"If I'm having a hypo… what's the phrase "raiding the kitchen fridge". So the way that my house is designed is that the kitchen is on the bottom floor. And then there are three flights of stairs to my room. So a lot of the time if I was hypoing and if I wasn't smart enough to keep the stash in my room stocked up, then I've got to use that adrenaline you are talking about to not only get up, but then somehow make it down the flights of stairs without falling and killing myself probably. And then it's literally just grab the first things that I can find that I know are high in sugar. And then you wake up a couple of hours later just covered in wrappers. Like some secret eater?"*

M: *"We talked about the other day like the lovely big yellow hazard boxes that sit in the corner of where we have them. And it's not at all attractive hmmm. And these big boxes of medications that get delivered through the post, having to go constantly to a pharmacist, because doctors were only giving you a small amount of medication at a time, because it's so expensive."*

Sharps boxes for the safe disposal of needles and lancets are delivered and collection needs to be with the local council environmental services. Many people find this service is not smooth, leaving them with a stockpile of full sharps containers. Only a few years ago these were not easily available in many regions and PWD had to find alternative methods of dealing with the waste from kit.

M: *"So these sharps boxes are the first in my life. I used to put them in tin cans and put a piece of sellotape over them and chuck them in the bin… that was my mom's trick."*

M: *"So with the sharps bins I've got boxes and boxes. I had some friends visiting from London last weekend and I usually have my boxes lined up in my bathroom but they are just not very nice to look at with visitors so I put them in my wardrobe."*

M on the workplace setting: "*Yeah, I think the workplace is quite difficult. I think, you know, like my workplace at the moment it's not ideal. So I said to my manager at the beginning "oh yeah I'm type one" and they were like, "is that the good one or the bad one." I was like, God, "is it the good on or bad one." So I just said "it's the one where you inject", and I just left it that and I felt, "God I'm never going to talk about it ever again". Because I felt like I need to do a training session, honestly like, I think it was just a bit embarrassing."*

C describes going swimming when relatively new to insulin pump therapy:

C: *"…when I went away… and I was actually going to go swimming one day. Um... and even the morning of leaving, I was back and forth texting my nurse, like, "I don't know how to do this, what am I supposed to do?" So no. I don't know how to swim with this thing. Is the short answer?"*

Nevertheless C did manage swimming via a convoluted means of experimentation with cellophane and Sellotape. A person takes their diabetes with them everywhere and sometimes diabetes calls upon them spontaneously, as in this example during a Skype meeting:

C: *"Let's, let's try to get one a day. And then once you actually build that up, we'll try to build it up again and again… [beeping noise] And so having… Oh. So, I'm being told to change my pump set tonight."*

It also requires carrying kit and snacks to treat hypos everywhere.

C: *"You know it was well known in my school if you were hungry, you came to find me."*

It affects common ways of social engaging also.

T: *"So she asked when we were out "is everything okay?" there's an implication for her to say, like, to check if everything's okay. Because usually, things aren't always, you know, hundred percent perfect when we go out to eat, cos there's no way to* *completely know, what you're eating in terms of like, key carbohydrates. And, like, yeah, so I guess it's just kind of a given for her to ask that... which I resent obviously... cos it's happened in the past where.... you know, the choice you make is completely wrong because of different carbs."*

Quite a complex interaction in that practical issues of eating out require guess work rather than fine tuned decision making, leading to the possibility of error. However, eating out is also a socially shared activity related to bonding, intimacy, participating in pleasure and entertainment. That the question of blood glucose – and by implication – diabetes management should come up at this point creates a tension in which it might be inferred that all positives about eating out are subsumed by the potential impact on diabetes management. Furthermore, this may lead to an implicit question as to whether "eating out" is a wise move.

The notion that broader concerns for a PWD are consolidated into direct questions about diabete, defines the identity of wellbeing for a PWD as predominantly diabetes related for a person. This constriction or narrowing might reflect the narrowing in consultation to the disease model as if "this needs to be right first" and all other concerns are relegated.

T: *"And even though I know, it's like you said C... it's like your parents... um... dictating everything... So it is like there comes a moment when it's like... "Back off? I know what I'm doing..." And then it's like... "Oh no, no, no they're just caring about you". You just have to ignore it sort of thing."*

C explains the difference now that she is using pump therapy of no longer having to leave the table to inject.

C: *"It's especially easy now because obviously where I put the pump it's not so obvious so I don't always have to think about other people around me. With this I can just whip out the app and give myself some insulin. It's not that much difference from people just taking their phone out and texting at the dinner table, whatever. Whereas before I had this I'd have to run off to the bathroom and give like two units or whatever."*

Common life experiences that also carry an implication of being unwise can feel like being denied simple choices. In the following conversation C talks about getting her nails done and M about having a piercing.

C: *"Well, it started with me doing something that potentially. I might get a bit stuck for next week when I go see the doctor... which is, I got false nails put on."*

Me: And what's wrong with that.

C: *Well, I'd been in places before, and it specifically said that if you were a diabetic, that they would need a letter from your doctor. And I thought it was going to be, because I had to do the same thing when I got my ears pierced. Because it wasn't done before I was diagnosed. And then I thought, "you know what, I've gone most of my life without having my nails done". It's been a bit of a crap year. I want to do something nice for myself for Christmas, and something a bit weird. So actually, I looked it up, like the forums and that, and the only thing I could find was that people were saying their doctors were saying no, because if my nail breaks it's more prone to infection. And I kind of thought, that's a bit of a rubbish excuse.*

Me: I agree.

C: *"So I thought, forget that. I'm going to go do it."*

M: *"I definitely notice... I got my ears pierced about three months ago, and I swear as soon as I first had them pierced about... you know about 20 years ago. And I noticed as soon as my blood sugar's went over about 10, they started to get all gunky. And they took a lot longer to heal... not weeks, they actually took about three months to heal absolutely 100%. And because it's further up* [on her ear] *that I did notice the minute my blood sugar's went over certain, and I haven't noticed that before actually."*

If conversations and health consultations exclude the real world contextualised lives of PWD this can disaffect them by diverging from the true purpose of managing diabetes, that is, to engage in lifeworld projects. Capacity to Control and abstraction relegate real life as secondary to the job of diabetes control per se. To optimise Skills, Knowledge and Tools they must be applied not to blood glucose management but to their contribution to allowing the pursuit of life. When this happens abstraction decreases and the phrase “living with diabetes” has a chance to be more meaningfully about living with an acceptance of diabetes. This may even produce a sense of the benefits of life with a health condition as it raises awareness of the significance of one’s life.

T: *“It's just honestly like I'm... grateful for it in a way, because I wouldn't be doing a degree, especially in sports coaching, I probably wouldn't be weightlifting, I wouldn't be feeling good. I wouldn't be like wanting to actually... like... do quite well... Um... So... yeah... that's my view on it is that it kind of helped me to be honest.”*

Having to focus on health because of diabetes enables favourable comparison with people who are less health conscious.

T: *“...as a diabetic, I feel like I'm healthier than most people who aren't diabetic. In terms of my lifestyle.”*

T is exploring possible meanings to enhance understanding as we speak. This understanding confirms “correlations” and also reinforces possibilities for future experiment, not for better diabetes management per se but for better life goals; university, feeling good and weightlifting.

T: *“I felt my body's a lot more efficient now, which means that every... in every way.”*

The context T’s interest in sports science and growing knowledge from university increase his acumen for solving real world experiences related to his Lifeworld.

T: *“Obviously, as the [GP] said, they're only trained to tell you what they're... they know, kind of thing. Any time I'm asking them questions I... even with... even with my dietician, sometimes... I'm stuck.”*

However, he is also aware of the limitations of his health care team to engage with his life choices, that means he is stuck and has to solve issues by himself with active experimentation.

T: *"Even with their help, because they only know what they're taught. I mean... and the stuff I'm talking about is very specialised."*

Having made discoveries in order to fulfil lifeworld led goals T enhances his Skills, Knowledge and Tools to positive effect.

T: *I can actually start having a life without having worries now. Essentially, and without having other people constantly terrified when I leave the house.*

Safely going about the project of living opens PWD to the opportunities enjoyed by others without diabetes. Life choices can be compromised however, by an unreflected belief in Capacity to Control.

5.1.2 Capacity to Control and the "illusion of choice"

C: *"Yeah, I think... cos it's also, like, what you were saying last week about? What comes up… like the language that... like... nurses and doctors, use... it's very much always been a case of even when... er... I've done well, it's, "You've done well, but…" [emphasis]... "this still needs to be done." You're still so far off this target that they've got in their heads for you. That it's always been the case of... I have… I feel like I have to be defensive. Because I feel like I have to even kind of even say to them "Oh, yeah, I didn't, I didn't achieve this, but I've done this..." that there had been progress. So it's always been, that... way of thought. Like my current diabetes nurse is a lot better at not doing that. However… she's very conscious. She openly admits if she was a diabetic, she'd be absolutely rubbish at it, and everything. But there is still that little bit of an element of... I think it's more... it's more, it's more hidden... it's... is more like an undertone, rather than straight out, you should be doing this, you should be doing that. Because I am, I think I don't know whether it's I am an adult now. So they know they definitely can't be trying to push as much as when I was a child, cos* *they had that... almost authority over me because I was still a child. I wasn't an adult yet..."*

C experiences her current nurse as much better at not using deflection and acknowledging the demands and successes. However, she suspects that negative language has simply become more implicit, "more hidden" and an "undertone" and wonders if it was more explicit when she was younger and the authority in the relationship was more apparent.

C further explains how her transition to adult diabetes services was quite sudden and abrupt.

"Um... I mean, if my doctors and nurses had it their way it was... It would have been moved immediately when I was 18. I would have been... I did drag it out slightly. Because... I was still... very unsure I hadn't... because when I first met my new... all my new nurses and doctors... I'd recently had a lot of changes in the nursing team that I had previously. So I was a bit unsure about how much I really wanted another change... in um... all of that, and it was pretty much just said to me that "look, it's going to happen at some point, you might as well just get it over with" sort of attitude, like… "Go away. We're done with having your three massive folders in our, in our cupboards. We want rid of that now."

This left C with a sense of being "dismissed" from paediatric diabetes care.

"Well, I attempted to do that ["drag it out slightly" as above] it was a bit of... Looking back on it. Now it was a case of I wanted to… [stay] but I was told no, it's it, it's done. Just go... sort of thing. So it was the illusion of choice, right? I think I would probably say."

"The illusion of choice" is an intriguing phrase given the quantity of discussion in bioethics and best medical practice concerning collaborative patient choice and informed consent. This is embroiled within concepts of compliance and adherence. It is noteworthy that NHS training on Mental Capacity and Deprivation of Liberty is very explicit that a patient making an informed choice that may be deemed unwise is not evidence of a lack of mental capacity and does not justify forcing treatment or depriving a patient of their liberty. Deprivation liberty is often construed as physically detaining a patient in order to convince them to accept treatment and is unethical. However, to consider liberty in the broader sense of freedom or choice, a grey area emerges with long-term conditions that are obscure and pre-reflective. Unwise decisions by patients can be interpreted as a poor understanding of the consequences that ought to be convincing enough for the patient to comply with treatment even if the care plan is challenging, hard to maintain and continuously impactful on day-to-day life. This seems close to the aphorism "you have nothing if you don't have your health" with an expectation that sensible people would do anything to maintain their health. Under these circumstances success in interactions with PWD may be seen as putting their health first through capitulation and compliance. A problem arises from the patients' perspective: the experience of capitulating and complying is often likely to be felt as an abject loss of freedom and identity. Responsibility is less self-determined and owned, reinforcing capitulation to the authority of one's "care plan" that is experienced less as care and more as rigid adherence. In this, one's tacit hold on the experience of being responsible, free and self-determining, accepting challenges as problems to be addressed, is compromised, and real choice becomes "illusory".

T picks up the illusion of choice concept in this reflective discussion. It really seems to resonate with him.

T: *"Really interesting... I guess you really kinda don't... er... the illusion of choice is really big? Because if I ask my nurses to do... If I could do a certain thing I know what the answer would be... it would be… No. You know what I mean? And then, it's one of those things where they, they're like, "No, well, you can do whatever you want. But we're not going to help you" kind of thing."*

This might denote that choices that are challenge the maintenance of strict diabetes control are off the menu. This problematizes the notion of patient choice, patient collaboration and patient empowerment. Often, not enough information or support is forthcoming for a patient to make an informed choice, but clinicians are under pressure to make it appear that they are being collaborative. I have heard newly diagnosed patients that know very little about diabetes being asked by their clinician "what medication would you like to try?" The patient confesses they don't know anything about medication for diabetes so the clinician will often follow "ok so let's try this one".

T: *"Um... a lot of it was... diet related... and basically I had to ignore them in short... there was no choice for me to get support. Like... because… So... um... you know I said I like... I have to eat a lot of food sometimes it's literally the only way you can gain weight is to eat more calories... and I was told this by my dietician at the… at the clinic. Um... because… only that my blood sugar was fine. My… my BMI... which was like... well, it's a stupid measurement anyway just weight and height. And it works the same for a child as a six foot four rugby player or boxer... There was this person online who was a body builder. And he was… I think his body fat was 5%. So the average range for a male is still in between 12 and 18%... usually… bang in the middle average male... he was just 5%. He was told he was overweight by his clinic. And he had no fat on him whatsoever. Literally none… but 5% body fat. And all the muscle… the muscle weighs a lot more than fat."*

T has to actively ignore some aspects of consultations because there was no support to think through the choices he wanted to make. T feels he was dissuaded from attempting to gain muscle mass through his interest in sports science because it might compromise his blood glucose levels and that from an abstract point of BMI measurement of greater than 25 he would be deemed overweight. This is also reflected in the development of runsweet.com, an online forum developed for semi-professional and professional sports people who are also insulin users. This was started by Steve Redgrave and his consultant endocrinologist Ian Galen in response to Redgrave's desire to enter the 2012 Olympics post diagnosis of diabetes. The site offered a forum for discussing how sports people had addressed challenges faced by managing diabetes and high performance training and sport. It grew very quickly, reflecting stories people interested in sport who had experienced being dissuaded on the grounds of their diabetes. The flourishing of this platform and the nuanced discoveries shared for different aspects of physical activity supports the acquisition of Skills, Knowledge and Tools for complex contextual circumstances. It is surprising that support and encouragement in mainstream diabetes care has been slow to develop for diabetes in sports, given that a wealth of evidence exists for the health benefits of physical activity in diabetes.

T experienced dissuasion in relation to weight training, but this can equally be found in other life choices like travel.

SP on the DUK Forum: *"My son wishes to go to Canada for a gap year but was told at a recent clinic quite categorically that his continuing care, i.e. prescriptions and pump essentials, would not be funded by the local NHS trust. This does seem discriminatory, denying a young person opportunities that others can enjoy."*

EG on the DUK Forum: *"As an ex travel agent, I have heard enough [diabetes] travel horror stories to put me off travelling ever again! But it hasn't and has made me very OCD about it. I think, no I'm absolutely certain, that all is in place (I hope!) thanks for the advice though."*

The DUK Forum offers people an opportunity to discuss plausible solutions to these problems and tips on planning and overcoming challenges. But in doing so it is apparent that encouragement to meet these challenges is not always forthcoming from clinical teams.

It would appear that a knowing strategy is required to negotiate these conversations, but this requires a higher degree of confidence on the part of the patient.

M: *"I think, when I have my diabetes appointments, I kind of feel so much more confident about things, I almost don't allow people to talk to me in that way. I ask them "well, what can I do? Look, you know, what would you suggest," you know, things like that? Because even now, at Moorefields, they do this like I said, "I've told her, she should be doing this, she should be doing that to manage her condition" letters written to my doctor, and I'll say "give me a copy." You know, "I've told this lady that she needs to be doing this, she needs to be doing that, to keep everything under control," and it all kind of just reminds me of my past? And actually, next time I say to them "No, you didn't actually say that to me in my appointment. You're just telling the doctor that you said I need to do this or that"... you know, it's funny."*

5.1.3 Capacity to Control and curtailing access to Skills, Knowledge and Tools

The National Institute of Health and Care Excellence provides evidence based clinical guidance and criteria for treatments and services. They are clear that guidance should be used to help make sound clinical judgements and that they have calculated cost effectiveness as part of the guidance. However, there are plenty of incidences whereby some treatments are discouraged for people that might benefit from them greatly. Reasons cited are often to do with cost or resource implications. Resource implications are more complicated than outright prescription cost alone. For instance, a diabetes team will need to be trained and familiar with a particular pump in order to support patients using it (although this resource expense is predominantly to do with time for training since the training itself is invariably free, given the manufacturer will invest heavily in making sure their equipment is privileged in the prescription budget). There are also plenty of good clinical reasons for not recommending certain treatments as appropriate that are not about cost, not least that it does not suit this particular patient at this particular time in their own judgement. One frequent example is "I don't want a pump because being attached to it will be a constant reminder of my diabetes." Another is that some patients achieve optimal management without extra technology that would present more complexity unnecessarily.

However, Co-researchers narratives bear out that sometimes curtailment of their access to certain treatments and services are puzzling. The following examples highlight the possibility that some curtailment of access to Skills, Knowledge and Tools is a subtle tautology that inhibits opportunities on the basis of not being a "good" diabetic, in other words a non-explicit assessment of a person's Capacity to Control.

C: *"... obviously when I was a child, I'd only ever been to the one hospital. I mean I still go to the one hospital for my diabetes, and just having now having the experience of the adult side, and actually having more opportunities for things and experiencing different nurses and different doctors, it really opens my eyes to just what they were actually doing... when I was a child, and how much even. I had one nurse who clearly did care a lot about me. Even she wasn't able to get me all this stuff that it's* *essentially... well to me it's almost... This is life saving. This is extended... actually not only just extending my life but actually given me a better quality of life."*

Through the Co-researcher reflection and discussion process, co-existent with many of the changes in care that have occurred for C, she experiences real surprise that these approaches to Skills, Knowledge and Tools were not discussed or offered earlier.

"Yeah, that was the same nurse who told me that I had to be better in order to get the pump… to make me better..._and I can see now... that makes no sense"

"…it was a weird kind of… I don't know whether they were trying to sell it [the pump] as kind of like a reward? Or for doing... Okay? Or better?"

From the perspective of Skills, Knowledge and Tools it is possible to see that engaging with diabetes (for instance doing more testing) can develop into active learning from experience and the acquisition of skills and knowledge that produce a fit with access to tools. What C seems to have experienced however, is a message suggesting that she needed to prove she was capable of becoming a better diabetic before being rewarded with access to the very means of increasing active learning and use of technology - supported patient education, an appropriate pump therapy assessment and treatment trial. Given the evident benefits and improvements this has brought – "…not only just extending my life but actually given me a better quality of life."

"That they can turn around to a child and deny it... It's… astonishing."

Curtailment to accessing Skills, Knowledge and Tools often leaves people with diabetes feeling isolated and embattled.

M: "*I think that's quite difficult… especially when I was struggling to get test strips and things like that. When I was pregnant, I tried to get more test strips, you know. Just to have these doctors saying, "not allowed to get any more, not allowed anymore". It's just, like… a constant battle actually. I'm trying to get extra test strips.*

I managed it eventually. They'd say, "why are you testing so much?" And I just say, "well I'm pregnant. And sometimes I you know, because my blood sugars when I was pregnant were just nuts. They went really low. They're really good, actually. A great HbA1c for the first time ever. 6.3. Um, but yeah, and it was just difficult actually getting test strips. So just being questioned about it all the time."

It is still common practice, despite campaigns to consolidate criteria, that occurs when a PWD is taken to hospital as an inpatient with another illness. Direct access to blood glucose testing, insulin and hypo treatment is often taken away from the patient and controlled by general ward staff.

M: "*I mean, I've had my insulin locked in a cupboard, you know, when I was in hospital once, and that was only a couple of years ago. I went back and spoke to this nurse after I'd just got pregnant, I was in hospital. I went back in she was there, she recognised me when she known that she locked my insulin away. And this nurse had given me 50 units of insulin… she'd dialled up five, zero units of insulin. And said, you need to take this… because I said, five units is what I need. And she went away and drew it up in a syringe… I've never used a syringe before either. And I looked at and said "you've just given me 50 units to dose." And I was just like, Oh, my God, if I hadn't been looking... you know, if I was in my right mind and knew that 50 units is going to go on a long time to inject into myself. If I hadn't been in my right mind because I was ill and she was the one having to inject me, that would have killed me. And I said to the nurse in charge, "one of the nurses on your ward almost killed me". And she was "Oh, I recognise you… because you kicked up a stink then..." and I was like "I'm going to kick up a stink now".*

Inpatient settings produce particular kinds of curtailment.

M: "*They put me in a ward having had a caesarian... where it was quiet time for mother and baby, but I just come out of my operation. And they said, "no family can stay with you". I was sat in this bed not able to move, didn't have a blood glucose meter or my injections. And I was like, "where is it?" I was kicking up a stink in the hospital… sounds like you can't take me anywhere, you know? But it's a lack of education, I think, and communication within the NHS or within hospitals, people* *don't communicate. So the diabetes team should have come to see me at the hospital, after I had a baby, and they didn't come and see me. And then they're supposed to come and see me… a few days later and they didn't come and see me. So no one told me that breastfeeding was going to take all the lactose out my body. I didn't even know this, I never I never knew that. And so I sat there breastfeeding. And I thought "what's wrong with me?" And they're talking to and I said to my partner "can you check my blood sugar?" Weird… it was 1.6. And I was just completely oblivious to the fact that breastfeeding was going to do that. So it was all quite strange."*

C: "*Listen, it's very difficult for GPs. Because I know even with my GP, I have fought hard tooth and nail just to get test strips before. And the only reason why I now get the amount that I need is because of the fact that one of the receptionists that works in my doctors actually used to work in the pharmacy I went to. And that pharmacy, which unfortunately changed hands and became a whole circus... they were very much person centred. They knew you by name, they knew what you had, they were always willing to, if the doctor messed up with your prescription, they were willing to give you a little bit just to tide you over until the next one. And she actually managed to slip under the doctor's nose the fact that to change my prescription so that every time I requested the strips, instead of a box, which is what he used to give me, he gave me five instead. And he signed off on it, because he didn't quite figure it out, he hadn't realised what he was doing. And so now every time I get as many as I want sort of thing, just because I made the person feel bad for me, almost. She knew because she knew the fight I used to have just to get these boxes. Um, but I mean this GP also brought me in to show me the book of prices."*

Me: Right.

M: *"[gasp] No."*

C: *"I was still under the children care. So my mum was in the room with me. And because it was the meter… I can't remember what it's called, glucose metre that has a cassette?"*

Me: You mean… they used to be called a strip drum.

C: "*Yes. So he pulled us in and demanded why I was suddenly on these expensive strips, showed me how much the cassette thing costs, and showed me how much my previous ones cost and asked us who it was said I could have these. It was my nurse at the hospital who had given me this. I've never decided what metre I use, what strips I've used. I've always been just told this is what you're using now. And he demanded us to justify the extra money. And my mom just turned to him and said, "well, how much is my daughter's life worth to you?" At that time, I was having multiple DKA admissions in hospital and some were getting quite bad. I mean, my worst one I've had, I actually had to have an IV in my neck. It happened every time I went to hospital, my veins are quite small, and they disappear very quickly. So it's always been a case of get an IV in don't care if you don't use it, just get it in there because my veins are going to disappear. So that's why she actually had to say, "well, how much is my daughter's life worth to you because if she's not worth the strips, then why are you a GP?" It didn't help the fact he's the head of the budget because he was on the CCG as well."*

M: "*I think I tell quite a lot of... not white lies... well yeah actually... white lies. I think it was to do with Apidra, short acting insulin. And I wanted to change and they told me that it was too expensive. And I think I might have made up a few white lies… because it's necessary, getting what you want. For instance, my humalogue just wasn't as fast as Apidra. And I don't know, you know, I was on something else. But it just seemed to slow down a little bit. I went back to my own doctor, and I said, I was at a type one event with lots of healthcare professionals. And they suggested that I try Apidra. And I told him it's making me really unhappy. I think sometimes if you kind of make it sound a little bit worse than it is they cave in. And I'm actually saying another healthcare professional has suggested it. I think they don't like to be told by the patient."*

Me: Does that mean then that you've had to find a way to create your own sort of diplomacy in making a dialogue with health care professionals?

M: *Yeah, absolutely. Because I think I have to play the victim a bit more. So I have to say, "it's making me depressed" or "I'm having hypos all night, I'm finding* *everything quite hard to manage, and I'm trying to do a job and I'm trying to do life, and I'm trying to do everything. And you just kind of have to be a bit more dramatic.*

Having to knowingly deploy tactics to counter attempts at curtailing access to Skills, Knowledge and Tools reveals the extent of the issue. But care is well known as a postcode lottery.

M: *"So when I moved. I've got the best doctor, ever, the best pharmacy ever. They will prescribe me whatever I need, I get an appointment on the day, I get reminders about certain things I need, or equipment I need, appointments I need. It's just a level of care that I never, ever, ever, ever, ever, ever, ever received before. I've literally given like, so many good reviews because I can't believe my luck. But being in London it was a constant battle to get an appointment or try and get something changed. And then doctors giving me stupid bloody blood glucose machines that didn't even test correctly."*

A particular form of curtailment that has an impact for women with diabetes concerns pregnancy. Blood glucose levels present a number of risks to mother and baby during pregnancy that require extra input to mitigate. Ideally, a woman with diabetes would be advised to plan pregnancy carefully taking extra care pre conception and throughout the pregnancy. This is achievable but a conversation between M (who has had a successful pregnancy) and L reveals other meanings.

L: *"My clinic at the hospital has quite a large pregnancy service. So they deal with a large group of people who fall pregnant. The way it was explained to me was something that I really struggled with. They made it sound as if they have to sign off on becoming pregnant. You have to get their permission. And it's something that I really struggle with, because I understand that if you're looking to become pregnant as a diabetic you would want to… like we said… mitigate the risks. But the way that they made it seem as if they had that level of control. It always just really bothered me. Um, no plans anytime soon by the way [laughs]."*

Me: So L, if we were speculating. What do you think that would be like, if you came to clinic and said "I've just done a pregnancy test looks like I'm pregnant?

L: *"Well with my history, there would be a big part of me that would question whether they would ask me to terminate."*

M: *"No [shocked]"*

L: *"But I really believe that they would put in my head that due to my current control, and my history of control, that they would say it's not in my interest to continue."*

This is probably unlikely unless neonatal tests established definite problems with the foetus. However, that L believes from her experience that an unplanned pregnancy would be met with a negative attitude to pregnancy care is telling.

Often peoples' bafflement at the curtailment of their access to Skills, Knowledge and Tools is accompanied by a sense of being patronized and/or deemed an awkward patient for requesting access.

TCD on DUK Forum: *"Hmmm. I'd say the only threat to my mental health is lack of proper physical support - I would be fine mentally, thank you very much, if the diabetes consultants would only provide me with CGM* [Continuous Glucose Monitoring] *instead of constantly telling me I need to have fewer hypos and offering no clue as to how I'm supposed to achieve this… this is a serious suggestion intended to deal with a very serious problem, not just me being an awkward patient, and patronising responses are not the way for them to go..."*

TCD is also linking that curtailment of Skills, Knowledge and Tools has a direct impact on her mental health.

Sometimes people make a comparison with other medical conditions noticing a difference in the level of care and involvement that is often missing in diabetes.

RB on the DUK Forum puts it this way: *"…my husband had a Retinal Artery Occlusion the other day (aka an eye stroke). Because of the National Stroke Initiative,* *he was referred to the TIA clinic, and spent a whole morning being thoroughly tested for everything, and now there are follow up appointments, further tests, etc. He's very fit, and not overweight, so they are scratching their heads a bit, but if this were diabetes we were talking about, I suspect he'd have been given some pills and a diet sheet and sent on his way."*

Sometimes there seems to have been a judgement made without any explicit clinical reasoning given.

SP on Diabetes UK Forum: *"Had a review at the hospital on Friday. Gained 3lbs and my HB1AC down to 7.8. Doctor was v pleased but I wasn't! I think the drop is due to the number of hypos I'm having. Nearly had 3 in one day but managed to catch 2 before I dropped below 4. So at the moment I'm eating to avoid hypos, which isn't helping my weight gain! After asking for 2 years, the Consultant has finally admitted I won't be doing the DAFNE course because they don't think it's suitable. All they can offer is 1:1 session with a dietician. But this won't help my feelings of isolation because they won't be able to answer from a diabetic's point of view - at least I'd meet other diabetics on the DAFNE course!!"*

SP is unable to be clear whether the Consultant is saying the DAFNE course is unsuitable or SP is unsuitable, or both. There appears to have been no explanation or discussion about what might improve "suitability". SP clearly believes there is suitability in the sense that it would address her feelings of isolation by meeting and learning with other people with diabetes.

Ch on the DUK Forum: *"I saw my GP yesterday as my waking numbers are high & he's now given me long acting basal [insulin] which I hope will help. However when I asked him for a C peptide test to see if I'm type 1.5 LADA as the dietician and nurses suspect he said I'ts expensive and the outcome wont make any difference its all about managing it. I asked him if I can be referred to a specialist who can help me get my insulin right etc but he seemed hesitant. I've agreed to go back & see him in 5 weeks. He indicated that he's under pressure to keep costs down. I am basically now on a basal, bolus regime the same as many type 1's but because I'm T2 on paper I don't* *qualify for the hospital support or carb counting courses. He's advised me to start my basal really low and just build up carefully if necessary."*

Ch is experiencing multiple curtailment of access to Skills, Knowledge and Tools. Her diagnosis is indeterminate but registered as Type 2 diabetes. However, her treatment is basal bolus insulin as with Type 1. The GP states cost implications for not agreeing to a C-peptide test that would establish if her insulin production is compromised (suggesting she has Latent Autoimmune Diabetes in Adulthood). In addition she might also have a GAD antibody test that might confirm she has Type 1 diabetes. It seems unlikely cost is the issue as both tests are readily available from a hospital haematology lab at under £10. Ch is told it won't make any difference and it's all about "managing it" despite the fact she is aware that a diagnosis of Type 2 will curtail her access to a dedicated diabetes clinic, DAFNE, future pump therapy and flash monitoring.

Many diabetes clinics are supportive and encouraging of Skills, Knowledge and Tools for their patients and find that following NICE criteria and the evidence allows them to establish "suitability" for individual patients is best achieved by trial period. The practice includes assessing benefits with the patient 6 months after initiation, discussing quality of life as well as relevant biomarkers.

Cost and resources are often cited as primary reasons where this approach to practice doesn't appear. However, these invariably go hand in hand with performance in health being target driven.

R works at DUK as a Helpline advisor and also in the Healthcare Professional Engagement team. Working in both she has insight into the HCP and NHS perspective and the patient perspective.

R: *"… they want to balance the books as well… And the fact that, you know, the targets to meet and stuff like that."*

R is identifying that cost and targets are interwoven. She also points out that this appears to be a current issue.

“And the GPs’ now have to take finance into account in a way that they didn't have to many years ago… they didn't have to think about how much it was going to cost, it was a clinical judgement or adjustment or whatever… but money didn't come into it… they didn’t have to really worry about.”

The loss of retaining a purely clinical role for clinicians is apparent in R’s experience but the tension this creates may not be so clear.

“When I hear about "cost"… it’s another word that triggers me because to be honest I don't actually know what it means. Really. I know vaguely that has to do with having to meet certain targets.”

R is noticing an entanglement between cost, resources and targets evinced by the vague sense of opaque meanings. Our discussion progresses to considering the systems in place: NICE guidance, for which analysis is conducted in terms of cost, clinical efficacy and savings (including reduced hospital admissions and expensive treatments for reducible health complications) and the Quality Outcome Framework that assigns budget for patients diagnosed with different conditions. Care Commissioning Groups (CCGs) are regional NHS institutions responsible for managing health and social care and balancing the books. The most common practice of CCGs is to calculate the gross prescription and health care costs for treatments and services locally rather than the savings to be made as NICE do and regularly review. A problem arises in that CCG budgeting is short term, year on year, so long-term savings cannot be easily considered. NICE is not under the same restriction and has a more global, flexible and updateable calculation primarily driven by clinical benefit. In addition, NICE has a UK wide agenda while CCGs must account (literally) for local budgets. This might suggest that NICE has less local influence on GP and hospital clinics than the demands placed on CCGs and carried over to local NHS services.

The above discussion surrounding health finance and structure is not an arbitrary one. The tensions produced at a local level sometimes appear to be arranged within the same theme as Capacity to Control with patients viewed as a burden on resources when they do not fulfil an expectation of using stretched resources responsibly i.e. being compliant to the treatments offered even if these are not clinically indicated but cost effective in the short term. Clinicians that are not free to make clinical judgements without considering cost restricting may be considered to not have the Capacity to Control their patient population i.e. to persuade their patients to comply with thrifty treatments.

Another resource related to cost is time. Consultations are brief and there may be a tendency with this constraint to curtail the information and deliver basic messages that further imply that diabetes is straightforward and simple.

N on the DUK Helpline: *"I think sometimes what is concerning is doctors, sometimes will give lots of advice... or sometimes it's even just probably what is a few off the cuff remarks. But I think sometimes people, particularly older generations, almost take it as a prescription. And instead of someone kind of providing a bit more information or a bit of a starting off point to look into their diet, they're thinking this is a prescription… so now I don't eat potatoes, I will never eat that and probably a lot of people we never speak to, will continue to do that. Which is a real shame and that's why sometimes I think people think of certain food is bad and good and it starts that again, rather than no food being inherently bad but some food not being highly nutritious."*

Reflective reminiscence. I am reminded of a caller many years ago, when I started at DUK, reflecting on N's words. He had never rung the Helpline before and asked, quite sheepishly as I experienced it… "Would it be ok to mix 5-6 raisins in with my porridge at breakfast?" I explained this would be a normal portion of fruit, about spreading portions out over the day and suggesting other options by exploring what other fruit he liked. Then I asked him "so what sort of things do you have for breakfast on other days?" The line went quiet for a moment and he said… "well I don't have other things. I mean, I was told porridge was a good choice by my GP, but don't have fat or sugar… so for the last seven years I've made porridge soaked in boiling water every day. Is that not right?" I remember feeling something of N's response "what a shame it was" and said spontaneously "I'm sorry that's what you were told… I feel like you've not had breakfast for seven years and instead simply dosed oats like it was medicine.” This is an example of the reward in my work as well. His palpable, emotional sense of relief at discovering all the other healthy options for breakfast he might have led to his explicit gratitude in having been freed from this constriction. I felt as though I had encountered Ben Gunn from Treasure Island and been able to say, “… since you mention it, I have a piece of Wensleydale in my bag if you fancy it.”

N echoes this idea of a restrictive/ascetic approach born from too little Skills, Knowledge and Tools “…or sometimes it's even just probably what is a few off the cuff remarks.”

When a belief that a simple, achievable approach is the solution to a complex condition like diabetes and can be set out straightforwardly in “a few off the cuff remarks” it reinforces the notion that a lack of improvement must be down to the patient’s behaviour rather than endocrinology. The voracity of the patient comes into question also.

N: *“I think in health care... appointments... that can be reinforced by "what things have you really been eating"... sometimes people have actually been trying really hard if their HbA1c hasn't dropped as much and it’s, "you can't really have been doing that can you."*

Another form of curtailment can be discerned in the connection between obesity, Type 2 diabetes and bariatric surgery. A study followed 621 people who underwent a Roux-en-Y gastric bypass with a median follow-up of 4.9 years. 77% achieved T2D remission following surgery. At one year of follow up this had fallen to 74% with rates continuing to fall to 73% at one to three years, 63% at three to 10 years and 47% after 10 years. Remission lasted a median six years, and for up to 22.4 years and the median time to relapse was 5.3 years (Pessoa et al 2019). Type 2 diabetes remission is associated with greatly reduced risks for future complications and this study confirms the high remission rates for bariatric surgery. However, the UK has the lowest rate of conducting bariatric procedures, seven times less than France, and Belgium and Sweden conduct twice as many procedures with a sixth of the population (Bosely 2017).

BF on the DUK Forum: *"I've been trying to loose weight for 25 years and for the last three my BMI fits the NICE criteria for bariatric surgery. I've spoken to my GP and she says I have to lose weight to demonstrate I'm suitable. She has calculated a target amount of weight for me to lose… if I succeed then I won't meet the criteria for bariatric surgery and if I don't meet it she says I won't fit the criteria because I haven't shown that I can lose weight… uh!"*

This seems very similar to C being told she needs to *be* better in order to receive the treatment that will *make* her better.

Comparing the concept of Type 2 remission from bariatric surgery and GP led, very low calorie, weight loss programme (DiRECT, Lean 2018) remission rates were 37% at two year follow up rather than 73% at 1-3 years for bariatric procedure. The DiRECT trial included guided weekly support over 10-16 weeks and gradual reintroduction of normal balanced eating. Despite this Diabetes UK has seen a rise in people at risk of diabetes and with new diagnoses being told by primary care clinicians and prevention educators to cut out all carbohydrate and/or fruit, or follow the DiRECT protocol without the support used within the trial. Clinical advice that is short on detail and support surely can only logically be deemed achievable if there is a belief that people are capable of adherence and compliance to a simplistic regimen despite evidence to the contrary.

R: *"... and there is a perception of right or wrong… there is the "right thing to do". And there's the "wrong thing to do" and generally the right thing to do is to follow the medical advice, and the wrong thing to do is to go against medical advice, and the language is… So, if you're in hospital and you want to leave the hospital "You discharged yourself against medical advice", which makes it very clear... "this is what you want to do it's up to you and it's your right... do it, but very much as this is "wrong" and you know… but there is a clear idea right and wrong. So, patient do this... good outcome. More likely, don't do this then "it's your fault". So, It's very much a right or wrong."*

Bariatric surgery, evidence based supported weight loss, patient education, diabetes technology and appropriate testing to establish accurate diagnosis are all examples of Skills, Knowledge and Tools applied in a contextualised sense for individual patients. The evidence seems strong that access to these is often curtailed by a notion of "it's all about managing it" without evidence based education, support and treatment. In other words, a state achievable by an effort of will to do the right thing that is central to the notion of Capacity to Control.

5.1.4 Capacity to Control and burnout, rebellion and denial

T: *"I was diagnosed in 2014. So not that long ago… so I was pretty much in a stage I wanted deal with it myself... when you first got diagnosed is just so much information that I just had no idea what's going on... Um... to a certain degree. And I kind of just went with it. I wasn't really shocked... well… obviously I was shocked... but wasn't like, denying it or anything. And then. And then a couple years down the line now kind of I think I went through a mild degree of burnout as well."*

An intriguing possibility for understanding burnout may emerge. Distress and emotional strain may be less to do with the burden of managing diabetes than in failing in the attempt to follow recommendations and be a "good diabetic". The "burden" may be the strain of attempting to maintain the Capacity to Control implied rather than working with one's Skills, Knowledge and Tools to the best of ones current ability and context. T is identifying a process of learning and coming to terms with the challenges he faces from diagnosis "just so much information that I just had no idea what's going on" and distinguishing this from following recommendations "I kind of just went with it".

T: *"I was just looking at everyone else and thinking why... can they deal with this... and not have to do the stuff that I do. I'm not everyone else I'm myself ... I just kind of... got fed up."*

T having to do "the stuff that I do", unfavourable comparison with others management, trying to find himself and his way of doing things, leads him to being fed up. Perhaps sometimes Capacity to Control attacks the notion of discovering an identity of being with diabetes and obstructs the notion of an individual and contextualized process of acquiring Skills, Knowledge and Tools for oneself. This might be because Capacity to Control already implies *the* identity required (disciplined, responsible and compliant) which brokers no room for a personalised diabetes identity.

T: *"I'm not letting this, this shit control me any more."*

T seems to be faced with a limit situation that necessitates a "rebellion" against "this shit" and its capacity to control. One form of rebellion against Capacity to Control might be oppositional: denial, accepting defeat or actively choosing the opposite actions to those presented as control i.e. eat what you like, dose what you like, run blood glucose levels higher. However, T's response is a different kind of rebellion.

"I just start exercising... erm... I started... actually like... vigorously, sort of making sure I was counting everything right… making sure my ratios' perfect... well obviously not perfect, but as good as I can physically get them..."

This may at first appear to be conforming to Capacity to Control, by becoming the type of person that controls his diabetes. However, the purpose of this intense engagement in activities for T reveals itself to be closely linked with gaining a personal sense of mastery of Skills, Knowledge and Tools, an identity of "me" with diabetes, leading toward his taking up weightlifting and interest in his sports coaching degree. In order to take ownership T rebels against conforming and this is revealed in his attitude to his health consultations:

"And so my latest HbA1c... which is really funny talking about the nurses always wanting more. I'm currently at 5.6%. But they're telling me that I need to go... I need to go up. So... um... I just kind of laugh… but take what I can from it."

A low HbA1c may signal to HCP's the possibility of frequent or severe hypos. I mention this to T and his response: "I have hypos… not problem ones." This may reveal an unchecked assumption on the part of T's HCPs. T has picked up on the implied notion of "lower is better" and questions why this has changed. His response to running blood glucose levels higher is to “laugh it off” and only take what is useful to him in pursuit of personal goals i.e. maintaining a level of management suitable to his passion for weightlifting as a sport.

C: *“Quite frankly, I hate going to the consultant, because it's just always a constant, “you're doing this wrong you're doing that wrong” completely ignoring any improvement really that I've actually had with the HbA1c. So it's kind of it's for me, it's more a tick box… yes I'm complying I've been doing this, but I'm not paying attention to anything they say, and I'm walking out of there and then probably going to buy myself Lindt chocolate to make up for the experience.”*

C: “*When I was following the instructions of my nurses and everything and testing frequently it would be constantly high, and then go to the appointment, get told off for them being constantly high then be fed up. Then I’d stop doing everything go to the next appointment, and then be told off the same amount for doing that. And so for me it was kind of a case of, well, if I'm just going to be told off either way, I'm going to save myself the stress of having to look at those numbers and not do it, which, quite frankly landed me with DKAs on multiple occasions.”*

C’s experiences of clinic over the years have produced ambivalent relationships with her HCPs that have occasioned many styles of rebellion in conjunction with burnout.

C: *“I saw my nurse this morning, quickly and I've got an appointment with the actual doctor at the hospital next week. And for once I'm not dreading it. Because I'm hoping, after I saw my nurse today, that I can rub it in her [the doctor] face.”*

Me: Okay. So what happened with your blood test today, that gives you a big smile.

C: *“Um, well it wasn't so much the blood test part... because I needed to go see my nurse to arrange everything and so she said "while we're waiting for that to go through lets have a quick catch up and see how you're getting on”. And of course she pulled up all the results and everything. Although it's not going to be 100% accurate, because I haven’t been on the LIBRE for a full 90 days, but at the moment I’m at 7.5%. So if it's anywhere near that I get to rub it in her face next week.”*

Me: Nice. So tell me a bit about rubbing it in her face what prompts you to want to rub it in her face?

C: *"Well... obviously I've had it for years since I was a kid. As we said before my diabetes is rubbish, I have rubbish control over it. These are things which are complete rubbish to say to a child. And then when I went into the adult side of things it almost felt that they were trying to make it worse in the way that I feel as an adult. They have almost higher expectations of you, especially because I've been diagnosed for a number of years. It's not a new thing to me. They've got this ideology that I should know everything about it by now. And I should just be perfect all the time you know, rather than it being more luck sometimes. Maybe a tick box, kind of thing to say yeah we saw her you know, there's nothing wrong, she knows what she's doing. And because I wasn't being that... it was like, "Oh, you're not doing what you should be… still." What doesn't help is, and I don't know whether it's just my doctor, but it very much felt like, not only was she talking down to me, she was insulting me. Which obviously is not something that you want to have an appointment about, something that affects every aspect of your life. So, me being able to go back to her and show that because I was allowed my DAFNE course, because I was put onto a pump, because I've now been put on the LIBRE and given that assistance too. Look at what the change has been. I mean, to be honest, with the HbA1c most the time I don't really care about the numbers, it's the way I feel. So me seeing that, that's my smirk, it's purely just waiting for Tuesday when I have this appointment. [Pause] I've been gloating about it all day."*

C gleefully seizes the opportunity to demonstrate to her doctor that her blood glucose improvements have nothing to do with her being a good, compliant diabetic and everything to do with access to Skills, Knowledge and Tools. This also proves to her that past scolding and insult were unwarranted and irrational. C's rebellion is the chance to right a serious wrong.

BC from the DUK Forum shared something she had written when she was experiencing burnout.

"It's all about numbers. Keeping between two lines. There's a target range for blood glucose test results. It's between 4mmol/l and 7mmol/l. Imagine those numbers as two lines on a graph. Since the age of 11, my all-consuming ambition has been for my test results to be numbers between those two lines. Always. I am told on a regular basis – often, in fact by the very healthcare professionals who gave me the target of those two lines to stay between – that I'm too hard on myself, and that I should ease up. After all, a few numbers here and there that don't fall between two lines are okay, surely? Well, are they?

"If you tell me to keep between two lines, then it is right to keep between two lines; ergo going out of that range is therefore wrong.

"How does that compute, exactly? 'You've got to be right, but actually, being right all of the time is wrong, so it's okay to be wrong even though you need to be right'. Eh?"

BC eloquently expresses the double bind presented by Capacity to Control, supporting the idea that the burden that leads to burnout stems from the struggle to adhere to a strict target range, "between two lines". She experienced the early implications of Capacity to Control and introjecting or falling in with this so that even when her HCPs' suggest she could relax (actually delivered as "being too hard on herself") she is unable to relinquish the notion she needs to be "right". However, the bitter irony of this double bind is evident in the felt sense of her compliance to Capacity to Control being construed as "too hard on herself", perhaps even obsessive, while too little compliance or not in target range is wrong and will lead to complications. BC's bitter irony may also be considered a rebellion against the unfairness of this double bind. In her story, shared retrospectively, one can discern the solution she discovered and eventually gained access to:

"Things are different now - I'm on a pump, I have a Libre, I have discovered exercise and I choose to not base my diet around much carbohydrate. And I'm finally feeling that I am actually living my life."

In other words a better fit for Skills, Knowledge and Tools is associated with improved management of blood glucose and health outcomes, but also an increase in quality of life.

If Capacity to Control is implicated in generating the antecedents of burnout and the negativity associated with it can occasion rebellion, another commonly cited response is denial. Being in denial has entered popular culture and is linked with the notion of putting things out of one's mind, a kind of forgetting as a protection against future consequences. To be in denial is to repress knowledge that generates "threat" and render it unconscious. It appears as an underlying explanation as to why a person with diabetes does not accept Capacity to Control and comply or otherwise engage in healthful behaviours.

C: *"A lot of the time, where I've grown up with it, I've been in quite deep denial. And it was very strange, because for a number of years, even though I would get on with it enough to be able to go about day-to-day sort of thing, I would just completely push the whole idea away. It wasn't until I had got to a point where my nurses said I needed to go talk to someone about my diabetes. Because I was... well, a lot of the time I would say the things in the appointment just to get out of it. "Yes, of course I'm going to go from never testing to doing it four times a day". And then obviously never do it. And having to really sit down and think, having to go through with someone like what it actually means on a day to day basis and how that could potentially be affecting me really kind of showed just how much I kind of... it's a weird thing to say that I was both in denial and fully aware of what I was doing."*

CK on the DUK Forum asks for help in relation to a friend:

"I have a friend who was diagnosed with T2 in March 2019 with a very high Hba1c. She is currently on Metformin. The problem is that she is in 'denial'...thinks the diabetes will go away. The added problem is that she comfort eats, and is continuing to eat sweets etc and drink coke like she did before. She is also very overweight, and does not exercise. So basically has made no changes to her diet etc. Is there any advice, as her friend, that I can give to encourage her to change. What are the consequences if she does not accept her condition."

After some replies to her message (which I shall return to later on another matter) including a suggestion to join the Forum, CK follows up:

"I have already suggested that. Alas, to know avail. Her own admission of being in denial is not helping. I will keep trying encourage my friend to take things more seriously"

DT responds to CK:

"I was diagnosed 2016, but still in denial. I can relate."

Here arises an intriguing possibility. If it is possible, as DT and CK's friend have, to admit to being in denial then it cannot also present itself as an unconscious state. C also gives a flavour of this in her comment "it's a weird thing to say that I was both in denial and fully aware of what I was doing." Is there another possible interpretation for denial? As an adverb of "deny" it is possible that C, DT and CK's friend are all too aware, hyperaware, of serious consequences but deny or "repudiate" the pressure to *be* different and change if this entails compliance and strict adherence to the unrealistic expectations implied in Capacity to Control.

LZ on the DUK Forum seems to spot this in her response to CK query:

"Maybe she doesn't need you to persuade her. Maybe she already knows what she needs to do and how much it will help her. Maybe she has been told that so many times, she isn't interested in hearing another person say it."

LZ follows with a suggestion of her own that acknowledges that CK's friend may respond more positively to accepting there are challenges and negativity in her experience (a "sh*t time"), a commitment to listening, understanding and support that acknowledges readiness, empathy, compassion and encourages reflection on positive aspects of her as a person:

*"Try a nice card and a mug, perhaps with some special tea in or whatever she likes that isn't pure carbs, and a little note that says: I know you're having a sh*t time (reword as appropriate) but i just want you to know I'm here for you. I hear you that you don't want me to talk to you about your diabetes / diet any more, but I'm here and ready to listen and help you to change your future if and when you're ready. Meanwhile I wanted to you to know that you're super, that I've always admired you for X, Y and Z and that life's nicer when you're around. I promise not to mention diabetes again unless you ask me to. Fancy a movie Tuesday night?"*

LZ finishes her response with her own take on the value of friendship that is readily recognisable in place of "encouraging my friend to take things more seriously":

"Cos whatever else your friend needs to do, she needs love most of all."

For LZ it seems "friendship" and being there is least demonstrated by initiating conversations about weight and diet and what someone ought to do however well meaning. It is about creating a relational environment that nurtures responsiveness to the value of love, compassion and understanding. LZ realises that suggestions about how CK's friend should live and take things more seriously, strains the value of love and acceptance in friendship.

Burnout, rebellion and denial (now reformulated as at least sometimes, "repudiation") are close neighbours of responses to Capacity to Control. Although it will occasionally be true for some that burnout is a response to the burden of diabetes per se, that some rebellion is wilful rejection of reflecting on acceptance and a need to respond and make changes, and some denial is an unconscious defence mechanism to the threat of a changed life or future complications, the possibility is strengthened that this pre-reflective neighbourhood of responses succumbs to or repudiates a narrow and restrictive notion of being that flows from the notion of Capacity to Control. In its most extreme formulation, is it possible that Capacity to Control justifies a stance on people with diabetes (or at risk of Type 2) that allows for "tough love", "school of hard knocks" or utilising "shock tactics"? Does this open a door to a tendency to be moralistic or stigmatising? Is this a direct threat to love, acceptance and compassion?

Reflective reminiscence. On the DUK Helpline I often find myself discussing with callers who are loved ones or family of people with diabetes their “conversations” or encounters. Often people are asking about strategies to “make” their loved one change or take on board what they ought to do without necessarily understanding what that might look like. I am likely to explore how these conversations are initiated and commonly it is by the person calling, and a description of the encounter reveals they will engage language along the lines of “you ought to test more”, “you shouldn’t eat that”, “are you testing enough” etc. When appropriate (meaning if the caller is amenable to reflection) I might ask, “Can you describe why it matters to you what they do?” Frequently people are nonplussed by the question and I might refine as such “What makes you ask them in the first place… what does it mean to you?” Commonly, the reply is along the lines of “I love them… I don’t want to see them hurt or die.” Along the lines of LZ’s approach I might ask “How many of these conversations start with “I love you and I don’t want to see you come to harm or die, I want to be there for you”… the response is often surprise, that this ought to be obvious to my partner, lover, sibling, child… that merely exposes how often we might speak from the problem as we see it and not from the significance it has for me. This highlights the difference from “don’t you think you should…” from LZ’s love and compassion, patience and empathy.

5.1.5 Capacity to Control and moralism, stigmatism and the myth of “being cruel to be kind”

The most stark and extreme form of the conversations above seem to generate stigmatising linguistic messages that appear to flow from moralistic beliefs. We have seen the possibilities in the arrangement of thinking in terms of Capacity to Control that who a person is and the link to their behaviour and choices can influence the moral judgements made about their self care (or carelessness, denial or wilful rebellion). Also, that these judgements are barely considered openly and may be accepted without evidence (or actively against the available evidence), can curtail access to, or even negate the relevance of Skills, Knowledge and Tools. Even that this entanglement is characterised by fixed or ossified beliefs as opposed to flexible and contextual thinking. Furthermore, an unsubstantiated claim is made as to the nature of a person that is supposedly revealed by their health monitoring and outcomes.

This section explores how Co-researchers and participants experience this moral dimension and how it leads to stigmatism.

We have met R before who works for Diabetes UK Helpline and the HCP engagement teams.

"Yeah, I mean there's a lot of people who ring up and say, "I know I've been bad" or… they use language that is apologetic at the get go. But there's quite a few uses of… "I've been bad, been naughty, naughty… I know it's naughty." I suppose the source of that is I think it's really like saying "good girl", "good boy". Good. It's that kind of, you know, patronizing… and… you're under the doctor, literally."

R's impression is that conversations with PWD commonly include language like "naughty", "good and bad" and as earlier mentioned "right and wrong". These can be added to "should/shouldn't", "ought/ought not". These phrases have a moral tone regarding behaviour. They are polarising words that imply either/or to situations that actually contain a wide spectrum of choice according to the evidence. Instead R feels that callers to the Helpline often apologise from the outset. This in itself is intriguing being that apologists imply a number of underlying assumptions: starting on the "wrong" side; asking for support or information or encounter that is undeserved; wasting time and possibly self –blame. This may be evidence of introjecting some of the common language used.

When Capacity to Control attributes cause and effect in a simplistic behavioural way, self-blame becomes apparent and appears justified. Prevention in Type 2 (prevention of Type 1 is not currently possible) stops becoming a risk reducing strategy with practical involvement and becomes another entangled tautology that "proves" diabetes is a deserving moral outcome of carelessness or wilful rebellion.

N again, who also works at DUK on the Helpline:
"I guess, in terms of when I started I noticed a lot of, what I found, quite infantilizing language that people would use which I found quite interesting. So, "I've been naughty… I shouldn't have done this", particularly, mostly, around food. I'll be

having quite nice conversation and sometimes I'll hear so much a shift in their voice like it's a slightly… 'I've been really naughty.' Kind of going into that slightly childlike voice."

"And definitely in terms of health care professionals and family as well like someone's "bad". They shouldn't have done that, that was kind of naughty… things like that… immorality, in terms of what people shouldn't do, being a bad diabetic. Yeah. So I found that really fascinating because I haven't really found that with other health conditions."

N chimes with R's experience. The word "naughty" does seem childlike by comparison to "bad" and it is also interesting to note the sense that naughty presents itself more as a minor infraction as opposed to a sin. Could this be an attempt to mitigate an anticipation of admonishment or punishment? Or perhaps the childlike nature and vocal tones that N has experienced in calls (that I have also frequently encountered) are hoped to engender sympathy and forgiveness.

N: *"I think there's a more, particularly with type two, there's a lot of blame in terms of weight and kind of perception that if you're overweight, then you've caused it yourself. And also that, which is laughable, the way that it's so easy to control as well… and there's not complex issues going on behind the scenes there. So yeah, I think there's a sense of when I speak to people they feel that they may have deserved it particularly if they are kind of overweight or very much people wanting to separate themselves from people who are overweight... so I have heard, "I'm really healthy I'm not like those people"... like I was speaking to someone yesterday… who was saying "I don't get it, I'm not like those fat people you see" and "If you saw me now you'd think I'm so slim. It's such a shame these people put so much stress on the NHS"... you know, attacking those people so they could feel completely different. These are adult people going into appointments and again, I keep going back to this, because it does feel like… almost regressing… like you're back to school where it's like... "Well, did you really put effort into your homework because you haven't got a good mark in that". And because it does feel like that in terms of tests and marks and also languages like it being "controlled" rather than, "how do you manage it"... it's... "What's your control like?"*

Blame is also recognised by E on the Helpline: *"Well the first thing I kind of picked up very quickly from answering the phone is that there's a lot of self-blame around for diabetes people, they get a lot of messages they internalise. A lot of this is your fault you know, you've done the wrong things to have this terrible life affecting condition and they give themselves a hard time, at every opportunity, and like it… sometimes it breaks your heart… when you speak to, especially older people who maybe that diabetes is happening because their pancreas isn't working as well as it used to, rather than they're hugely overweight or any lifestyle risks. They feel a sense of blame, self blame, which is making them more anxious and more distressed about what they've done wrong and how they're going to have a worse quality of life or lose limbs or eyesight, how it's going to affect their relationships. Sometimes it breaks your heart. So, I've experienced this people feeling self blame for people with Type one as well which seems really curious to me, type 1 would have this."*

N: *"I spoke to a woman last week she was like, "Well do you think I can have like a quarter of a scone when I go to see my friend"... her husband of 45 years had died recently and she goes to meet her friend... her only social activity doesn't have any children... is going to like a tea shop in a village once a week with a friend and she was like "well maybe I can bring along an oat cake. And that would be better". And I said "well is that the thing you would most like would you prefer that over a scone. She was like "well no of course not at all"... well "no definitely... really have a scone and really enjoy that if that's your part of the weekend…" the rest of the week she was adhering to... so I just thought it was so sad"*

There is an intertwined relationship between moralism, stigma and a belief that harsh or punishing messages are justified to constrain and restrict people to a narrow meaning of Capacity to Control in managing diabetes. Co-researchers and colleagues who work empathically with this often experience emerging emotions like E "it breaks your heart", N "it was so sad" and R who experiences anger.

R: *"Of course prevention is important, of course it is. But the language often used, the message that makes me angry is "I'm gonna die", not an increased risk, possible* *diabetes, and these are the things that could possibly help it's, "I'm gonna die… and it's my fault."*

There is room to compare these phenomena in respect of other conditions. N explored the moral tone in her conversations "I found that really fascinating because I haven't really found that with other health conditions."

Later N is reminded of similarities with the early cases of HIV and AIDS that have since reduced the stigma associated with diagnosis that was apparent in the 1980's.

N: *"In the same way that… obviously is shifting, thank God… but with HIV and AIDS… of it being you're an immoral person you've revealed yourself to be immoral… either being homosexual… like gay, promiscuous… or you do drugs or things like this."*

RoS on DUK Forum: *"Ironically, I was taught about diabetes last year at university and all I took away from it was "type 1 happens in childhood and is auto immune. Type 2 is caused by obesity and laziness nothing else" this stereotype is constantly reinforced in the media."*

In Type 1 diabetes this rationale is sometimes applied to secondary complications like TW's retinopathy:

TW on the DUK Forum: *"Personally I think a massive issue is the media portrayal of diabetes as a 'getting what you deserve' condition - untrue, unfair & unhelpful. I have been through the experience of needing loads of lasering [a treatment for retinopathy] & ultimately a vitrectomy [surgery to replace haemorrhages from retinopathy] for diabetic retinopathy worsened by pregnancies & the side effects from lasering...at one hospital it seemed like every time I was seen I got the judgemental & dismissive comment "Uh. Retinopathy? You MUST be badly controlled then." Actually, my HbA1cs have been rather good for a long time, thank-you very much... My thinking is that the major problems are lack of education for diabetics (ie like DAFNE, showing people the cause & effects of medication, exercise, food etc etc)...and not giving people (whatever 'type' of diabetic) the tools they need to live* *safe, full, well controlled lives, be that an insulin pump, test strips, access to dieticians, etc etc."*

TW tackles this directly and evokes examples of Skills, Knowledge and Tools as a potential remedy. However, it seems extraordinary that any outcome as distressing as vision impairment should be glibly passed over as "their own fault" and this signifies the impact a moralistic position has on empathy and understanding.

I asked E where he thought the idea of blame came from.

E: *"From all sorts of sources, unfortunately including healthcare professionals. Also the Daily Mail, Daily Express way in which they exaggerate things and demonise people. Those kinds of media messages are certainly the case. But, health care professionals who have the kind of one size fits all, you know, the kind of idea that everyone who gets diabetes is severely overweight is eating for the wrong reasons is lazy is, you know, not taking care of themselves, and therefore costing the NHS loads of money. Those kinds of attitudes."*

E: *"I mean I have spoken to people who said they've directly had those messages, you know, the doctors have been kind of rude and saying things like, "well, you know, we're not going to help you if you can't lose the weight that kind of very direct message. And, I mean, it makes me wonder what benefit they think is that's going to mean for their treatment of their patient and for the patient's ability to look after themselves, because you know I've not worked on this line for very long but you know my life experience, says that you don't really tell people what to do in that kind of way to get them to engage. You have to be more kind of supportive and encouraging to get people engage. So that's the thing I don't understand why clinicians would take that approach and think it can be helpful, and I just don't understand maybe if that's your project. Now I'd be really interested in knowing that."*

E points out how barely credible it is that clinicians' who use such a negative approach can also consider it as helpful or necessary rather than counterproductive to the point of cruelty. This does seem to support the notion that this phenomenon is out of awareness, pre-reflective or unconscious. A reflective reminiscence for me relates to calls I received on the helpline during the heuristic unfolding of my conversations with Co-researchers. When it felt appropriate I would share with a caller some of these proto-ideas. Two calls particularly stand out. One was from someone that lived and worked abroad for 15 years. As the dialogue unfolded she noticed that since her return to the UK she had observed that attitudes towards lifestyle in general had become rigid, moralising and stigmatising. The other call was someone who had recently been diagnosed. In discussing recent health appointments I mentioned that sometimes PWD experienced a degree of stigma. This prompted a memory that she had a good and supportive relationship with her GP around a number of illnesses over the years. That is until she was diagnosed with diabetes [I paraphrase from memory here] "She had always been quite sympathetic and understanding, a really good bedside manner when it came to the infection last year and my cholesterol. But the appointment about Type 2 diabetes, I hadn't said a thing and she immediately launched into a vitriolic and angry scolding of me. [The next section I remember very distinctly] I was shocked because she kept jabbing a finger at me and she was almost purple in the face and their was a speck of spittle on her lip she was so furious. And I left never having said a word and got in my car and thought, "what the hell just happened there?" That a HCP can behave entirely out of character around the subject of diabetes may be evidence of an unconscious bete noire.

This is not exclusive to HCPs but seems to occur despite HCP training and practice. If conversations about diabetes can be this fraught it is little wonder that some people eschew them altogether resulting in isolation.

E: *"So in a sense although with Type 1. One of the ways in which you could arrange your thinking around it's not my fault because it's my pancreas has failed because something's going on there, but once you're handed the responsibility now it's all your fault if it doesn't come right. And I've just done a search a little bit because there's two things I want to say one is that nudge unit it's called the Behavioural Insights Team that's the thing I wanted to say about how small changes are made by public policy, putting a different message across. But what you've just said my makes me think about the other thing I wanted to mention which is the isolation of people with diabetes feel. Because as well being made responsible for things that people can't be responsible for I also speak to a lot of people who say they can't talk to anyone about* *their condition, whether it's Type 1 or Type 2, you know that they can't talk to family or friends because then the family and friends aren't living with it, or they have their own weird and wacky ideas that kind of get imposed upon them. They don't know other people who live with the condition so they have that internal message, and it just goes round and around for them inside."*

E is postulating with nudge theory that it is possible to impart subtle positive messages to engage people. The definition of a nudge is a change in environment or messaging that is not enforced like "eat more fruit and vegetables" but a subtle shift like placing fruit and vegetables at eye level in supermarkets. But this also suggests an unconscious negative nudge is possible, for instance, accepting responsibility for something you have no influence over that suggests you deserve to be alone with it and not discuss it out of shame.

E: "*And so the only people they can speak to are their professionals who they see for 10 minutes. They've got a lot of questions but then they're seen as demanding sometimes because they got a lot of questions. That's really shocking isn't it that's going on. That's really is setting people up to be sustained in, in feeling rubbish about themselves and feeling self blame… the message is sustained over time."*

Nrthnr on the DUK Forum: *"It's like they are saying 'we told you not to get it, now you have so don't expect much sympathy because it's your own fault and it's up to you to live with it and the consequences'. Often, those consequences are spelled out to put the fear of god into the patient - that it is progressive, they will inevitably get worse, threaten them with insulin and be continually critical and negative without really having any good advice to offer because the GPs and nurses themselves are covering up their lack of current knowledge. People become depressed, fatalistic, control gets worse (as predicted by the HCPs) and they lose their quality of life."*

Nrthnr clearly states the potential for a vicious cycle stemming from Capacity to Control and moralism, that can produce a self-fulfilling prophecy of poor outcomes related to carelessness that is deserved. However, it is unwarranted and not supported by the scientific evidence.

Another feature is that a moralistic position seems to produce an entitlement to pass judgement and comment directly on PWD lives and choices, even to the point of verbal aggression.

KC on DUK Forum: *"A woman in Starbucks treated me to a mini lecture because I was eating a cookie (and had my glucose meter there), apparently I was irresponsible, and costing the NHS far too much money. I was hypo at the time and wasn't sure whether to cry or wipe the floor with her. She got a verbal tongue lashing, the force of which surprised even me."*

Lau on DUK Forum: *"I joined a group on facebook about healthy eating and today I mentioned I was Diabetic and got a tyrade of people telling me it was my own fault, that it was because I am fat (even though I was underweight when I was diagnosed at 6 years old) and that if I eat better I can cure myself. Some of the messages were really unkind (quote: Diabetes is a FAT problem and nothing more)…"*

One might be tempted to attribute these encounters purely to misunderstanding or lack of knowledge if it were not for the apparent absence of a questioning or curious attitude. Moralism appears to produce a position of certitude and a sense that any issue related to diabetes is both simple, obvious and fair game for comment, even to strangers. One might wonder whether this serves a purpose in mitigating anxiety about the uncertain and threatening aspects of life by projecting peril as the moral responsibility of others and their behaviour. Perhaps this is why it can appear within Capacity to Control and moralism as a "justifiable" attack on the "unjust" and sure up a defence against uncertainty that 'all will be well if only we do the right thing,' combined with jettisoning those that do not to their own fate.

In health care settings moralism produces another kind of untenable but common meaning as we have seen from abstraction; the belief that it is possible to accurately predict an individual outcome from the behaviour or biomarkers. This can transmute information from accurate to brutally honest.

C: *"I said before that all my doctors and nurses were getting into trying scare tactics. Things like bluntly saying to me, whilst I was still on to the children's, and that "if you* *continue, you will die. That is what is going to happen, the amount of them, there will be one time in the future, if you continue that you will come into hospital with a DKA, and the treatment will not work. It will be too late. And you will die". And they would say that straight to my face. And I'll be like, OK. And like you said, I was just kind of filtering it and just trying to get on with that day. I just didn't want to think about anything else."*

As we have seen, there is some bafflement expressed as to how the use of fear could be considered a motivator for positive engagement.

C: *"It was very difficult for them. Because obviously, in their heads, it's like, "she needs to do this, she has to do this. Nothing else is working". And let's try absolutely scaring her into doing it. If we give her this outrageous example of what will happen, then she'll be so scared she'll do it every time. And then they didn't understand when that didn't work. That was probably their tipping point for sending me away to go find what else could be wrong with me? And making me go and talk to someone about everything."*

Invoking the threat of complications and death seems common enough in PWD experience and we have seen how access to Skills, Knowledge and Tools can be curtailed on the basis that a patient ought to be compliant in order to become deserving enough to receive them. However, this is not the only kind of threat that can be deployed.

C: *"It was very interesting because I went to see my nurse this morning, and I was imagining that it was going to be a quick look at the charts and everything, see if there's any slight adjustments we need to do, and didn't quite turn out that way."*

Me: So what happened?

C: *"Well, first of all, I ended up waiting an hour for my nurse past the time that we were supposed to meet, which was fine because I'm off work at the moment, I don't really care about that. And then we went in and she got the Libre view and logged in, and everything. And due to the way that life's been over the last few weeks, I haven't* *been able to use the notes part of the Libre. So I've been scanning and scanning a lot but I haven't actually noted down, like how much carbs I've had how much insulin I've had on the Libre notes because that information is on the pump. So, then she had a go at me because I hadn't been using the note section. Even though it's been quite clear that I am using the pump, because my count hasn't just shot up. And if that wasn't bad enough, she reminded me my pump can be taken away from me if I don't play ball... which is really motivating."*

M: *"No. I'd make a formal complaint C. Seriously that is blackmailing people with long-term illnesses. I mean, "hey you've got cancer but you know what if you don't listen to me. I'm not going to give you chemo, I'm not going to give you any treatment I'm just gonna take it away... if you don't listen to me and do as I say"... like that is… horrible [emphasis]."*

C: *"Well if I did that M, I would have a long list of complaints to the NHS because I've had it for years."*

M: *"I don't put in the notes from my Libre. I don't put in how much insulin I've taken and you know what? That takes a lot of energy and time if you're doing it in your pump, and they're asking you to do it in your Libre as well."*

C: *"Work hard for an easy life on their part."*

M: *"And just say "have you ever tried to attach upon yourself and Libre on your arm and then, you know, done your daily tasks, and then have to eat regularly, and go to a Christmas party, like, you know, fit in a bit of exercise, and then eat a bit of cake. And then, you know, just normal life, you ever done normal life, having to input data into everything?" I mean that's so unbelievably unrealistic that literally drives me.... Oh my god... nuts."*

Research data that has supported that relatively stable blood glucose levels, blood pressure and cholesterol mitigate the average risk for onset and severity of complications seems to have been inverted into a narrative that the worst outcomes of diabetes are a just judgement on the unjust. This creates tension and division in which we might find peoples' attempts to extricate themselves perpetuates more stigma.

N: *"I was speaking to someone yesterday… who was saying "I don't get it, I'm not like those fat people you see" and "if you saw me now you'd think I'm so slim. It's such a shame these people put so much stress on the NHS"... you know, attacking those people so they could feel completely different."*

N is identifying that stigmatising others may have its roots in avoiding being "tarred with the same brush" as the saying goes. This can also justify dismissing people's Skills, Knowledge and Tools or their very experience of living with diabetes.

N: *"…in "loves executioner", there's a whole chapter where he's absolutely disgusted by this woman purely for her size. That's quite an accepted thing really, because there is some kind of morality around that. So, people want to almost push that away and view people as a bit less human. I mean in that sense of... it being very much... "Othered"... the person with diabetes, as someone who has kind of "brought it on themselves… a bit lazy... like a bad diabetic for not doing all of these things"... not realising how difficult it was for someone to do it."*

Particularly noticing N's use of the term "Othered" in reaching for further understanding of this entanglement suggests the possibility of coining a new verb "othering" as a process for differentiating for the purpose of psychological distancing, a form of socially or self, -imposed alienation. Once 'othered' an individual would be at a greater enough psychological distance for 'otherers' to have quit the firing zone and feel, at least momentarily, safe. This connects with broader forms of theory concerning stigmatism too great to explore in depth here, however the possibility for a process that distances and simplifies diabetes into the blameless type and the blaming type must in some way reveal the degree to which blame and shame are attached. R echoes this also:

R: *Well, somebody said to me I haven't got "full blown" diabetes. So, "I've got type 2 it's not, it's not like... it's not "full blown." They wanted to say, "I'm ok I haven't got full-blown diabetes".*

This seems reminiscent of M’s manager asking if she had the “good” or “bad” type of diabetes.

Earlier we heard CK on the DUK Forum asking for advice in encouraging a friend with Type 2 to deal with her denial and take diabetes more seriously. Though most responses were supportive and positive, others demonstrated a propensity for suggesting an approach of being “cruel to be kind” as a kind of shock tactic or aversion/flooding approach for dealing with the defence of denial.

DRM on the DUK Forum: “*I lived with my grandmother who had uncontrolled type two - diabetes mellitus as it was called back then. The process of deterioration is not something I can write about, except to say it was dreadful.”*

DRM is attributing her Grandmother’s deterioration to her “control”. It is not uncommon that Capacity to Control is used to account for poor health in past generations of people with diabetes. However, most likely these negative outcomes are attributable to poorer Skills, Knowledge and Tools as medications and equipment for treating and testing were not available and the significance of HbA1c, blood pressure and cholesterol was not established within the research. Add to this the UKPDS finding that a third of all Type 2 patients on the day of diagnosis had already had diabetes for more than fifteen years without knowing. Despite this, Capacity to Control is more readily evoked and DRM seems to imply that perhaps CK should highlight how dreadful her friend’s deterioration will be if she doesn’t take things more seriously.

IF0 on the DUK Forum: “*Unfortunately if a person is really in denial then all you can do is try to be there for them when/if they decide to take back control of their life.”*

For IF0 “being there” for someone with diabetes that is struggling seems to be contingent on Capacity to Control. Does this mean for IF0 that perhaps it is not worth being there for them if they do not “take back control”?

IF0: *“I have heard about Type 2 diabetics who have left it very late, even to the point* *of having the first amputation (big toe in his case), yet have managed to get off all medication and down onto the normal range for HbA1C. Personally I would hate to be blind and unable to walk, but some people prefer their favourite foods to avoiding that, just as a hard drug addict will sacrifice everything for the next fix."*

Again, Capacity to Control is evoked as an explanation for secondary complications and the sense that not complying with restrictive eating is a simple choice between "favourite foods" and being "blind and unable to walk". IF0 likens this to drug addiction although it is unclear whether this signifies sympathy, immorality and further stigma or even criminality. It is also accompanied by a belief that it is possible to "get off all medication and down onto the normal range for HbA1C" and implying this is a simple matter of doing the right thing. The use of the word sacrifice is also intriguing in respect of the moral tone – some people sacrifice their health for the sake of favourite foods, yet if they sacrificed their favourite foods they would spare their health? Is health in diabetes equated with a state of virtue achieved by sacrifice to compliance and rigid adherence? It certainly seems to echo the sins and virtues of antiquity and early Christianity (Bejczy 2011). However, the seven sins and virtues were explored as a way to engage in one's own moral behaviour and spiritual hygiene but have been used as ways of assessing other people's choices moralistically. This might also reveal the propensity to view food as "good" and "bad" rather than considering food in terms of nutritional properties. The British dairy industry 30 year ago advertised cream cakes as "naughty but nice", Magnum ice-cream lollies issued a special edition set of flavours under the heading "the seven deadly sins" and Ferrero Rocher's famous advert in the 1980's declared how the "Ambassador was really spoiling us". Sin, extravagance and indulgence have been advertising high calorie and luxury foods for years, establishing a social language connecting these products with our carnal pleasures. To overindulge realistically increases the risk of weight gain but cannot be said to be a single factor given the known complexities of obesity. However, the moralism associated with Capacity to Control in diabetes may have it's roots in a much older dilemma and the propensity to counter the obesogenic environment with simple notions of nutritional austerity, restriction or asceticism is not warranted by the evidence.

Again this entanglement of language can push beliefs in the direction of a justification for chastising people with diabetes as the lady in KC's coffee shop did and Lau's Facebook group.

CK receives another response in the same vein:

ZMB on the DUK Forum: *"Take her to visit a hospital diabetic ward when they're busy with more extreme cases. That might shock her into taking it seriously. Not a fun experience at all (I got taken in with keto-acidosis and ended up a few days on a ward and I never EVER want to be going back there). Seeing people with more extreme symptoms is both eye opening and sobering. I felt terribly sorry for a young kid who had T1 and was obviously in a sorry state, but there were a few people on the ward that clearly hadn't heeded the warning signs, it was shocking to see what a sorry state they were in, even if they didn't want anyone to notice. Stuff like people hobbling around with hardly any feet left, or with legs that caused them so much pain they couldn't lie down in a bed. If she doesn't wake up after seeing that, well I can't imagine anything you do would help. Seeing it in person has much more of an impact. Maybe see if you can get an appointment at a hospital on a diabetic ward with a diabetic nurse?"*

This is in stark contrast to LZ responding with love, compassion and understanding. ZBM is advocating that CK arrange for her friend to encounter the most frightening and devastating consequences of diabetes. ZBM has clearly experienced a shocking encounter of this sort but distinguishes between the "young kid who had T1 and was obviously in a sorry state" that engenders in him sympathy and those "that clearly hadn't heeded the warning signs". Significantly if we compare LZ and ZBM's positions something emerges in the two strategies: as ZBM puts it "*If she doesn't wake up after seeing that, well I can't imagine anything you do would help."* This means this strategy is a onetime solution that if it fails relegates CK's friend to the position of a lost cause (unless of course CK can find even greater horrors to "wake up" her friend with). This might also justify CK giving up on her friend or even their very friendship and seems to imply that whatever inevitable unfortunate outcome befalls her is down to her. Therefore, in this moralistic arrangement of Capacity to Control, CK, IF0 and ZBM are all absolved of any responsibility for CK's friend and her future and they are “cleansed” in some way, justified in setting her adrift to her own fate. LZ advocates her understanding approach on the basis that the very horrors and restrictions being proposed are the problem and her solution requires CK’s abstinence (from forcing her friend or being pushy or nagging), persistence (in sticking with being there for her even without a satisfactory resolution, for CK at least) and positive regard (despite CK believing her friend is “wrong”). In these discussions filled with tensions, whose tensions are being eased in the two approaches? It would appear that it is much easier to banish one’s own frustrations or tensions if the responsibility for a change is deemed to belong elsewhere. This is the release that comes from cutting loose but being in a position to say, “well, I did my best.” But LZ is telling us “your best” is to stay with the tensions and the struggle, despite knowing there may be no clear resolution.

In the following conversation R explains overhearing a strategy that seems to rely heavily on playing a blame game.

R: *“I overheard a conversation in another team about patient groups. Oh yes, about the new thing that might be coming is having group appointments with a GP rather than one to one. So the idea is to have diabetes health care checks in a group. And somebody said, "actually that works quite well because patients themselves will be able to be more critical of each other" you know "why did you eat that or why did you do that?” That will matter to doctors that find it difficult to do. So it's something about, "it's a good thing really because basically doctors or nurses can cop out of actually using that language. But when they're in a room together the patients don't have any qualms about that so they will criticize each other. This is a positive outcome because they will say, “well you know you need to lose weight.” They're going to pussyfoot around it less.”*

Me: The way you heard it was one of the benefits of having patients in a group setting is that you can marshal them to compare each other into "better", "best", "worse" or "worst".

R: *“Yeah, that actually that's quite good because that's a resource, because the patient's themselves will call each other “out”. And basically it's kind of like the* *doctors wont have to, it's like "where angels fear to tread" so the doctors won't have to have use negative words to do it. So I think the thinking is that healthcare professionals find it difficult or don't know how to say these things."*

Me: In your experience, talking to people who have come to us. Having spoken to their GP or nurse. Would you say generally that they've experienced their nurses and GP's being reluctant to say such things?

R: *"Absolutely not."*

Reflective reminiscence: This reminds me of working with an NHS patient with Type 1 that also had a sibling with Type 1. The paediatric diabetes consultant decided to give them joint consultations with the explicit strategy that she would pit the siblings against one another in a competition around their control of diabetes. In this way she could shame one of the siblings using the results of the other. My patient felt that this situation formed the antecedents of the diabulimia she was referred to me for.

5.1.6 Capacity to Control and the involvement of psychology, counselling and psychotherapy

When HbA1c results are "read" as an indicator of Capacity to Control it attributes attitude and behaviour as primary factors. A problematic HbA1c becomes equivalent to a problematic patient. This feeds back into an interpretation of the person with diabetes being "uncontrolled" or "non-compliant"/"non-adherent". This produces tensions for a HCP in terms of clinical responsibility – to take responsibility for improving matters the solution would need to be getting the patient to be more compliant and change their attitude or behaviour. However, a person's behaviour or personality is not a matter for physical medicine and so it is outside a HCP's remit. It is not unreasonable then for a HCP to question whether they can be responsible for addressing this at all. This tension can generate an HCP approach that justifies making the patient more aware of the consequences of their behaviour (risk expressed as "threat" of complications as we have seen) whilst handing back the responsibility to the patient (it's down to you). Where the facility is available, a psychologist may be called in to assess and "fix" the behavioural problem. In my own NHS practice it is very common that a PWD is referred to me with a reason along the lines of "patient has uncontrolled diabetes, becoming frustrated and needs to be motivated to take on health behaviours". It is possible to discern a prevailing belief amongst HCP that a counsellor or psychologist's input is in applying skills that "motivate" or "convince" a patient to become more "adherent" or "break down" the patients "resistance" to compliance, or perhaps even to force people out of denial.

You may remember that when C's diabetes team became frustrated that scolding and shock tactics had not proven effective in increasing her compliance they sent her to see someone about it.

C: *"I had to go to CAMHS. [Child and Adolescent Mental Health Services] so when I turned 16, "Okay, bye now. We know we're not done with you. But bye get out... we'll send you a letter it's fine" sort of thing?"*

Me: Did they actually offer you a service at that time? Or did they just assess you?

C: *"I was receiving weekly or monthly appointments. And then when I left, they told me that they were going to refer me to something like "time to talk", like the adult version. Then the issue with that was, I said to them, "look, I'm 16 I'm in school. I'm in school between these hours. So I can't talk during these hours. And they'd call me during those hours. So obviously, that was set up to crash and burn. And it was never really looked into again."*

Me: So what was CAMHS support like? What do you feel you gained from it? How did you know, they work with you?

C: *"Um, so I went, so they gave me a mix of talking therapy and antidepressants. I should say, before I went to CAMHS, um, I'd mentioned to my GP that I was experiencing what turned out to be mild panic attacks. And it was just when I was laying flat down, I would struggle to breathe properly. And they said, "oh, that's mild panic attacks and take this medication that will that will help you. And that was about it. There wasn't any real explanations or other strategies or anything like that. And then once I went on to CAMHS, it was upping my dose, then changing the medication* *and changing it back then upping it again and all these different things. But it was a lot of trying to talk it through. And what it was like day to day. And it was a case of where I would I had this almost front up, you say? I would shut down all my emotions about everything. And they were trying to break that. So the one thing, apart from my DKAs, that terrified my mum was, I grew up with my grandma living next door and because my mom would be out at work she practically raised me during most of my life. She passed away. And the thing that that terrified my mom was at her funeral I didn't cry. I just had a straight face during that entire thing and carried on. So obviously, my mom told them about that. And they wanted to dig into it, because they were sure that I needed to have this broken out of me. They said I had a need for me to be to show every emotion."*

Me: Can I check C, was that the sort of a message you got? Or is that the explanation you remember being given.

C: "*What they said that I needed to kind of work my way through things and be able to show emotion instead of locking away my emotions, actually experience them when they occur. So they weren't exactly saying like "Oh you've got this, this wall, and you are refusing completely to show any sort of emotions" or anything like that. In that direct way saying that we need to break that, we need to stop that. They were really pushing like this whole idea of mindfulness and things like that. I mean, it didn't help that personally, whilst I do understand that things like mindfulness do work for some people but, I don't know how to say this. So my first experience with this mindfulness idea was that my kind of mentor at school, just one of the teachers that was there essentially to almost be like a therapist to the to the kids. She sat me down in a room and said that my unconscious was like a pot. And it's currently overflowing. And I need to learn how to tip it to empty it out. And I generally just sat there like... what are you on? I guess, in a way I've never been able to take it seriously, if that makes sense? So actually in the end whilst I was sent there to actually talk about my diabetes, and explore that, it ended up being just a whole thing about all the other aspects of my life. So it was a major thing about my family. My parents are split and I've had some issues in the past with my dad. And so there was sessions of bringing him in, and almost like mediation and different things. And I was "this isn't why I'm here". And like you said, I've got an extra diagnosis that I've had for a number of* *years, even though I'm in the same situation. And now that's been labelled on me. And I mean I'm still sitting there with the label today.”*

Me: And what is that label?

C: *“So I was already diagnosed with anxiety by my GP, but now I've got depression to add on to that. So my biggest gripe that I've had with the whole experience of CAMHS and everything, is that this so called wall we're talking about? I was left feeling that they did break it down, but there was no "what to do after". So I find myself ever since that's happened. I'm a lot more emotional, in every situation. And that then leads to me getting more upset and more anxious, because I don't understand why this is happening. And what I'm supposed to do with this, and I basically left there feeling that I'm a broken woman.”*

Me: If you had to guess how much of that experience is related to other clues, or triggers, that feed directly back into, “I have this bloody condition that I need to deal with all the time and have often been scolded and told off or punished?

C: *“Quite majorly, I mean, I've now got this thing where before, it was more of a case of my diabetes was an add on to my life, it was an extra thing that I had to deal with a couple things each day. And now it's this enormous shadow that I constantly am aware of, and feels a lot heavier weight than it did before everything got dragged out.”*

Me: Actually leaves you feeling more vulnerable to those vagaries, the ups and downs around diabetes.

C: *“And I'd also tell you that following this, I did have some DKAs before hand, but I would say they became a lot more frequent afterwards. Because I got into this kind of "there ain't nothing I can do about it"... I just gave up.”*

Reflective reminiscence: I have spoken to many PWD on the phone, at events and in my NHS work. Several people have referred to receiving therapy support where these services have been available and specialised around diabetes, often after long waiting times. One takeaway that came up on more than one occasion was around sessions focused on ways for patients' in their consultations to focus on the content of what they heard from their HCP in their consultations, rather than the way it is said.

In our conversation, R focused on particular phrases and language use she found problematic. I present them here because to me they represent language in common between medicine and psychology but perhaps with meanings that are at odds in relation to Capacity to Control and Skills, Knowledge and Tools.

R: *"And there's another thing wrong with that... ah, I can't bare it... it comes up on the screen in "Marjorie" [a meeting room at DUK] on my lunch break... "behaviour change." I can't bare it. I cannot stand that... I actually... I don't like the word "behaviour" either... it's very difficult to work with sometimes."*

Me: And what is "behaviour?

R: *That's a good question "what is behaviour?" It's like "behaviour change" and you know we go on courses that you can do here to teach you behaviour change.*

Me: It sounds like there's a question mark, as to the underlying assumptions.

R: *"There is good and bad behaviour. So there are things like facilitating a behaviour change. That means "doing as you're told"... basically I think... by healthcare professionals. I think it's a euphemism for that. It's increasing the uptake of medication that's being prescribed. So the idea is behaviour change is linked to increased medication compliance [laughs ironically] and better HbA1c control."*

Me: Is there a notional connection, because, I'm kind of aware of it... that actually if you don't behave appropriately you're likely to need more medication?

R: *"You're going to be more expensive. You're not only "mad" because you haven't made the decisions to follow doctors' recommendations. But you're "bad".... because actually you're a waste on our resources. And that's why I'm in conflict... that this is a conflict I have being on the other teams and hearing, seeing it from that point of view.*

I do understand that you cannot run a clinic if you might have 200 people with diabetes that you can't spend an hour with each person, I get that. It's never going to be perfect, but I also feel quite uncomfortable about how data driven healthcare has become that you write a programme you go into practice. And you run a tool about diabetes population."

Me: And people's behaviour become's like a population programme? Behavioural targets?

R: *"If you begin with the implication of behaviour first, "you must be doing the right thing"... or what I've heard a lot of patients saying is my nurse said to me, my GP said to me, "Well, whatever you're doing is working so you must be doing the right thing."*

Me: So the diagnosis is no longer about dys-regulated blood glucose... it's about whether you're behaving properly or not?

R: *"Yeah, that will be the thing that will help your diabetes, to conform and to follow instructions and to be good. But how to mitigate that, to give kind of, realistically give people useful information... and respect people's autonomy?"*

Reflecting on this conversation with R I am struck that there is a plausible strategy in language use for dialogues with PWD. If language shapes meaning as well as conveys meaning then the content of what is said is less valuable than the meaning one holds in speaking. If one can be clear in a conviction of reflected values concerning the ethics of the use of language that integrates genuine compassion and understanding, then perhaps acknowledgement and willingness to struggle with the entanglement can bring forth more meanings that are respectful and mindful of the meaning I wish to convey.

R: "*And actually "normal" is one as well. Compared to what? That's probably why it's got such power with things that we interpret as normal, "your blood pressure is normal... blood glucose level is normal... you're back to normal..." It seems to be like the Holy Grail, being normal. But "normal" doesn't really… it's a word… but doesn't* *really completely exist as a thing. People want to have normal blood pressure is normal blood glucose... they want everything to be normal, and for healthcare professionals, normal is good... so "normal" equals "good" in healthcare. I mean... a case in point… I spoke to somebody this morning. Did the "know your risk" and got to the question about ethnicity, and they answered with "normal". And then they started backtracking from that, you know, that they didn't mean "White English" was normal, "when I said "normal" I didn't mean "normal". And, you know, obviously we didn't really go into it because I thought let's move on to the next question because it was getting, you know... awkward. But, but that's the power of words that that one word, and they were so, you know… not upset but they were back-peddling."*

I have also experienced in calls the opposite effect of the use of normal that informs a clinician that no pathologies for the tests conducted are indicated and therefore everything is normal despite the patient having physical symptoms of something. In one sense the concept of remission in Type 2 is often considered a return to normal and this is perhaps why there is a desire for some PWD and clinicians to classify remission as "reversal" or "cure".

R: *"Actually that's funny. I've just realised that I don't really like the word lifestyle either... lifestyle factors... I find myself stumbling over that and I say, "so called lifestyle factors". It sounds a bit "Sunday Supplement".*

Me: If we said things like your style of living, that it might sort of imply that your style of living is wrong.

R: *"Yes. Because lifestyle it's quite a big word isn't it? To say to somebody "right you may be at risk of diabetes or have diabetes. So lets look at your lifestyle" it's like saying, "get a grip man, you know that you need to change your life."*

Me: If we briefly subscribe to the word lifestyle that actually their lifestyle is fairly consistent with not presenting any additional risk?

R: *"Often, yeah, very often. But even saying that you haven't got any lifestyle risks, again, sounds. Good boy, pat on head.... good moral life. And if not, like you're* *difficult... you're being difficult. There's always one. And it sounds like that kind of message in terms of branding is geared towards something quite punishing."*

Me: Branding and punishing.

R: *"I had a call this morning and I really like this, what this guy said it was talking about meal plans diets. And he said to me, have I got a meal plan for chocolate chips. The Chocolate Chip Meal Plan. But it was kind of refreshing that he wasn't saying, "I know I shouldn't". He wasn't kind of apologising for it or anything about it. It's just, you know, and that was quite refreshing because often the calls are kind of tortured… "I know I shouldn't have this" or "Can I have a biscuit?" or "it's my own fault."*

5.1.7 Capacity to Control and addressing the issue

E: *"GPs obviously they've got a tremendous level of responsibility. So there it is you can see why they would struggle being that real or genuine, authentic. You can see why they would miss that, because they're, you know, looking at just medical results and their responsibility for a wider medical, clinical context. But there's a much wider context on that as well so we're going to general medicine, and we look at the attitude towards how we've measured outcomes and success in medicine. Much like other areas of society over the last 15 to 20 years, it's become target driven."*

We have seen how targets are often received by PWD as abstract and unrealistic and can hamper handling diabetes with exploration, learning and acquiring Skills, Knowledge and Tools. Abstraction also has a tendency to privilege targets over life goals.

T: *"Accept things, this is something that I'm going to live with for the rest of my life. So, I'm gonna live a life. First and foremost."*

T has re-evaluated his priorities to place living a life before meeting the targets and this leads to acceptance of things, including how to handle diabetes towards living. He also explores how HCPs might enlighten themselves by considering living with diabetes as a person rather than in the abstract.

T: *"I'd find it really interesting to talk to a either a nurse or doctor who themselves are diabetic. I'd find that really interesting, to see what they preach, versus practice, maybe because there's this element that becomes very highlighted. I find when I speak to any person about my diabetes in the medical field that even though they have all the knowledge of what my body's doing as a diabetic. They've not lived one second, of what it actually truly means to be a diabetic."*

M echoes this in exploring how HCPs can move away from abstract knowledge by encountering PWD in real world settings.

M: *"Some of the HCP would go away on these events to live with people with Type 1. I always wished that these people like the diabetes nurses, you know, a lot of them throughout my life I've seen, they haven't been and lived alongside someone with Type 1… and actually the ones that have lived alongside someone with Type 1... even if it's just for two, three days, there is a dramatic difference in the way in which they approach diabetes. And you know, the way they speak to people when they have a better understanding of daily life really."*

M: *"The best diabetes nurses that I've had in my lifetime are the ones that have actually gone out and spent time with someone with Type 1 diabetes and actually if you don't have that as a healthcare professional, especially a diabetes nurse then I'm sorry but not many type ones are actually going to ever listen or take what you've said completely seriously. Like I honestly feel that most of the DSNs that I've spoken to have actually done some volunteering or spent time with people rather than sitting in their little white walled rooms. And, you know, spouting out what you shouldn't be doing. I think the language is different when it comes to someone who has actually spent time with people with type 1. You don't get it so much."*

She also tracks changes in her own way of being with diabetes and how these have come about.

M: *"I don't feel like I'm being told, so much anymore. And I think I have so much more knowledge. Especially since Diabetes UK because the way in which I can talk to* *health care professionals has perhaps changed and when I go into appointments I can tell them what's been going on with my Libre and I kind of say I know about my HbA1c, you know, good at the moment. I don't feel like I'm being told. Now."*

Me: So now is opposed to some other time?

M: *"I would say, 2016, I think."*

Me: Not so far back.

M: *"No. And I think it was down to confidence, actually. My health care professionals would tell me what they thought I should do. I don't know whether I didn't listen to them… to be honest. I think maybe after the whole diabulimia thing and not getting any support and actually to be honest probably the best advice that came either from you about increasing background insulin, and then do a bit of fasting and seeing what happens that day, and doing it so very almost... delicately and monitoring myself so delicately then I started realising how my body responded to different things. Then also talking to other type ones at events. I didn't really receive much useful information on how to manage it, or explain. Explain [emphasis]. You know, whereas when ever you talked to me you'd always go into detail and use analogies and I'd think, "God it's fascinating and I understand, you know?"*

Me: Talking about diabetes in a way that allowed you to be interested in understanding better?

M: *"Exactly. And I think the moment they started thinking that I had a bit more knowledge and actually I was an ok diabetic because I worked at the time for Diabetes UK. I think the view of me having type one changed. So them finding out that I worked for Diabetes UK worked in my favour. I've definitely felt like it's worked in my favour them taking me a bit more seriously and I think they think that because I do know what I'm talking about, they listen a little bit more, and it reflects badly on them if they don't listen to me. And that's given me confidence, I think, to be able to get what I want, not what they want from me."*

M found that working for Diabetes UK in the past and having conversations with HCPs and PWD that attended events increased her curiosity about acquiring new Skills, Knowledge and Tools. Demonstrating these in consultations and dropping in that she worked for DUK she feels changed the attitude of her team who had to take her more seriously, raising her confidence. This also included acquiring a fresh understanding of language.

M: *"I changed my own language by calling it a condition rather than a disease, you know?"*

C also experienced a change in confidence during Co-researcher action research as she acquired access to Skills, Knowledge and Tools.

C: *"Well I've had both meetings with doctors and nurses this week. And for once, I actually preferred my doctor's appointment, than my nurses because usually I end up going in there and it's head down, "yes I know I've done bad. I'll do everything you say. Can we finish now?" Whereas, this time I was actually, I felt a lot more confident to just actually sit with the doctor and talk through things, and actually discuss some of the changes that she wanted me to potentially make as well."*

In conversation with R potential challenges in handling or changing language emerged.

R: *"It does deserve thought, you know, but we can't all think in advance about every word that's going to come out of our mouths because apart from anything else the Helpline would grind to a complete halt."*

A potential pitfall in becoming more mindful is over thinking the problem and becoming too sensitive about how our language is received.

R: *"That's another tension is trying to find a language that doesn't overly present things more seriously than is warranted. That can cause the kind of fear in terms of not being able to do anything, because I can't do the kinds of things, I've been told to do. But on the other hand, finding language that doesn't minimise."*

R is identifying that the fear of complications can hamper a thoughtful discussion about diabetes and attempting to strike a reasonable balance.

R: *"I think that takes time more than words. There is, there won't be the ideal that works for everyone. It might work for one and not the other and some people might actually quite like robust language some, some people really value it, they don't like any kind of dancing around them, you know? It's partly dancing around audiences because we have a culture that's also got this "political correctness?" And actually are we trying to find a politically correct way of talking? Which some people will find really awful."*

Also that attempting to find language that is more neutral might be construed as political correctness that has a poor reputation. But R is involved in this process of struggling with language in order to avoid conveying certain meanings.

R: *"When someone's lost a lot of weight. And I don't really know what to say because I would say, "well, in terms of health, diabetes that's a positive step. But I feel uncomfortable saying, "well done," because it feels… it sounds patronising."*

R: *"And "managing" is another one, it's suggested instead of "well controlled... well controlled blood sugar" but "managing my diabetes" or "not been managing my diabetes" implies that there's a… a consistent way of doing it, where the outcome will be "correct" or "ideal". It doesn't really take into account that it's not an exact science. But "management" sounds really organised."*

An approach to language in Language Matters (NHS England 2018) has included tackling the issue by suggesting alternative words and phrases of which the above is one example. However, this presumes that meaning will follow the content of new language rather than the conveyance of meaning will flow from the beliefs and values of the interlocutor into whatever language content is used. R sees this in using the phrase "managing diabetes" and that using this does not guarantee that meanings like "correct", "ideal" and "organised" are not conveyed if the underlying belief is in Capacity to Control.

In summary the findings reveal a consistent underpinning value system concerning the meaning of diabetes for PWD and HCP. The entangled discourse of Capacity to Control is shown to be largely unconscious, is capable of causing deep unnecessary suffering, erodes the availability of compassion and empathy in care, is entirely unsubstantiated in the evidence base and can render the notion of ones Skills, Knowledge and Tools as irrelevant.

From my experience at Diabetes UK and from the literature review I had anticipated that language and vocabulary in diabetes might be implicated in obstructing PWD handling diabetes in a fruitful way and have emotional and psychological impact. However, what is clear from the LIDAS study that I hadn't anticipated is that conveying the meaning of Capacity to Control happens despite the language and vocabulary used if it is introjected as a regime of truth. This means addressing vocabulary or the restrictive code/dialect may not be sufficient unless the belief system behind it is exposed.

It was also expected that where certain language and vocabulary was adopted that this may be connected to difficulties in managing, suboptimal outcomes and emotional and psychological strain. I hadn't foreseen the depth of suffering and harm caused, particularly the degree of shame and burnout engendered when Capacity to Control was introjected or that repudiation of the felt sense of Capacity to Control would include dropping out of clinic, refusing consultations, and the generation of serious tensions among family and friends. Equally, I was surprised to find how quickly explicating these phenomena and exploring Skills, Knowledge and Tools as a contextual alternative to give meaningfulness to engaging with diabetes would be quite so quickly and thoroughly transformative for Co-researchers.

This is broadly consistent with the findings in the literature review particularly in comparing consultation styles in other long-term conditions (Bourdieu 1989, Fix et al 2018 and Franklin et al 2018).

6. Synthesis of Findings

The findings of the LIDAS group present a consistent and understandable underpinning philosophical spectrum of belief related to PWD that is conveyed through the use of the language and vocabulary of diabetes. This is similar to other researches into diabetes and language that confirm a restricted code or dialect or offer alternatives to pejorative use of language (Dunning et al 2017; Lloyd et al 2018). Literature into language use in other long-term conditions that have high levels of self-management also support the idea that suboptimal medical outcomes are often seen as a moral failings (Franklin et al 2018). The current findings further this understanding by focusing on and explicating the tensions between Capacity to Control and Skills, Knowledge and Tools and the underlying mechanisms that these beliefs produce in obstructing or enhancing PWD way of being with diabetes.

I propose then, that Capacity to Control is a restrictive oversimplification of what it means to live with diabetes fruitfully and is in alignment with Foucault's ideas concerning regimes of truth and biopower (1961, 1963 and 1976-84). Foucault's concept of the gaze and the Panopticon transfers the power of modern discourse to the three forces that predominate in modern discourse: hierarchical observation, normalizing judgement, and the examination (1975). The epitome of the modern episteme is to hand these forces or functions back to individuals who monitor themselves (examination) critically (judgement) from outside of themselves, or another way, to see themselves as objects to be controlled (hierarchical observation). In relation to Capacity to Control the findings clearly present examples of these functions and how they produce the forces that maintain Capacity to Control, as with T's comment about becoming "… blood sugar robots." PWD *monitor* their blood glucose (examination) to see if the result conforms to the recommended *target,* literally putting themselves to the *test* (judgement). Just as Foucault also pointed out the genealogy of how acts of crime gradually became an internalised notion of criminality, these discrete numbers on balance are viewed as a measure of a PWD Capacity to Control as either controlled or uncontrolled. This is how the mire deepens for a PWD through another notion Foucault (1976-1984) presented: that of confession. It is beholden upon PWD to go to clinical consultations with blood glucose readings and, even with some modern technology, to upload their readings directly to the HCP team. PWD are appraised according to their measurements. Appraisal itself is not a problem as it is the reasonable basis from which clinical challenges can lead to collaboration over possible solutions. However, if implied messages have consolidated an internalizing of Capacity to Control this can lead to feelings of pride if all is well, or more commonly, shame and guilt if one is judged uncontrolled. This is because for Foucault the instruments of power in this discourse are the sequelae of medieval religious practices marshalled under modern forces that inscribe themselves onto bodies and people. This may be the route by which moralism enters the frame of Capacity to Control that begets the apparent justifications of stigma and punishment (with threats of future horrific complications presented as a living hell) if they don't adhere or comply. This was redolent in the LIDAS group's findings: "you will die", "rubbish at diabetes", "if you don't we wont give you this", "we can take that away", "the pictures I was shown", "shock tactics", "hobbling around with no toes", "take them to a ward with the worst cases" etc. It occurs to me that it would be entirely possible to assemble an honest photographic collage of diabetes outcomes to rival the most lurid of Hieronymus Bosch paintings. Bosch was either cataloguing religious beliefs of the day or reinforcing stories about the wages of sin in the afterlife and equally, a modern pictorial would either clinically catalogue *possible* outcomes of diabetes to broaden knowledge, study or awareness (e.g. the clinical surgical features of lower limb amputation for HCP teaching purposes, or symptoms to be aware of for PWD requiring urgent care and not prevaricating in seeking this) or act as cautionary tales designed to constrain morally unacceptable behaviour of PWD like the horrific morality tales for children of Hoffman's Struwwelpeter (1845)

Here it is significant to point out that although the primary focus of the LIDAS group's findings was to explicate the use of language for PWD it is possible to extrapolate that a similar discourse dynamic is occurring on the other side for HCP. This is consistent with Foucault (*ibid*) and Friere's (2004) notion that both the oppressor and oppressed are in the same influence of forces in the discourse. The tendency towards Foucault's arrangement of biopower and regimes of truth are out of awareness and affect all participants within the discourse. HCP cannot be viewed as willing agents in a knowing conspiracy of oppression against PWD however this may be felt by PWD. This would make no sense, as it would be too obvious for both parties and would be resisted by HCP simply because it does not conform to medical notions of *care* or ethics. Therefore, the phenomena must occur reciprocally between both parties and mostly out of awareness in a way that is resonant with regimes of truth. My contention is that a parallel arrangement of a pre-reflective version of Capacity to Control is tacitly held by some HCP and avails itself within the same tensions we have seen up to now. The clue may be in Dahlberg's et al (2009) work that exposed a belief in the UK care model via the NHS. Patients that seek treatment are predominantly perceived as both consumers of healthcare or citizens accessing rights to healthcare. Successive Governments and policy makers over at least 20-30 years have produced public policy regarding health on these lines. According to tensions related to responsibility and accountability, receivers of medical care are either consumers of health or health conscious citizens. HCP therefore are viewed in the light of improved healthcare outcomes for consumers and citizens driven by targets that are also tested and appraised. In long term health conditions where the majority of health management tasks are conducted by the patient (estimated at 95-97%, Anderson 1995) it is clear to see the relatively small HCP input reflects these targets having been passed to the patient. The arrangement of forces in the discourse means the patient becomes responsible for fulfilling HCP targets cost effectively, for which the HCP is examined, audited and scrutinised. This places a burden on a HCP felt sense of patient *care* unless target outcomes are reasonably met, and a battle begins in which HCP unwittingly accept that a primary task of their job is to get the patient to maximise their own patient compliance at the least possible cost to resources. The HCP comes under tremendous internal pressure to use their 3-5% input with a patient to determine and control how the patient behaves the other 95-97% of the time. This burden placed on the HCP is as abstract, simplistic and unrealistic as it is for PWD. HCP can no more control their patients' bodies than PWD can control their blood glucose. The notion has no medical research evidence to support it and a great deal of evidence to refute it. However, it is a mythological template for many other diseases in which the gold standard is diagnosis, treatment and cure, restoring the body to full health and therefore these are areas of medicine in which the physician does have control of their patients' bodies and can experience a felt sense of the use of their clinical skill in controlling disease. In such diseases the treatment may fail and the patient dies but it is still possible for the physician to feel they have given of their best with respect and dignity and physician empowerment remains intact. From the patient perspective this also has rewards that strengthen the possibility to accept compliance as fulfilling the treatment plan, which is time limited and results in cure and returning to a state prior to illness. Compare this to a condition in which the HCP delivers a diagnosis with a complex and demanding treatment plan that has a high daily burden and they must hand the responsibility for this state of affairs to the patient with a set of targets to be met that is lifelong with no prospect of a cure. If this also comes with the felt sense of clinical skill and judgement derived from convincing a person that this is doable 24/7 and they must accept this from day one it becomes possible to suggest that for many clinicians this is the least rewarding and most frustrating aspect of their work. If their patient struggles to fulfil the “regimen” they have been given the HCP may equally experience disempowerment and it is under these circumstances that the forces in the discourse are given their power and the temptation to point the finger at the patients’ Capacity to Control creeps in. If the HCP and PWD fall in with this, even to a small degree, the meanings conveyed regardless of the vocabulary used are likely to be experienced by the PWD as a scolding, patronizing moralistic lecture that implies their behaviour is wasting HCP time and NHS resources. PWD responses in such a situation may be denial (actively ignoring what is said), denial (repudiating what is said) or rebellion (actively choosing to be oppositional). All these responses are likely to achieve is confirmation bias for the HCP that they are faced with a difficult, neglectful patient that lacks understanding or is wilfully rebellious, and any sense of alliance and trust from either party is sorely compromised.

So far the discussion has centred on the dynamics between PWD and HCP in consultation. However, the forces of the discourse of Capacity to Control also influence notions of what lifestyles for PWD ought to look like. If Capacity to Control privileges a notion of an ideal person with diabetes as self-disciplined and adherent to a regimen, then the degree to which they are self-restrictive becomes a measure of their success regardless of whether it actually generates greater healthfulness. A door opens to the possibility of misconstruing asceticism with health, which is a category error stemming from Foucault’s genealogy of modern discourse being the sequelae of pre-enlightenment religious practices. So “I’ve cut out all sweets, cakes and biscuits”, “I only eat steamed vegetables”, “I’ve switched to a plain diet” and “I’ve cut out carbohydrate” can all be seen as attempts at an ascetic solution to a physiological problem where they were originally placed to affect spiritual purity. The idea that “natural” remedies and supplements are purer than “poisonous” pharmaceuticals seems to fall in with this. I contend that there may be a connection in this aspect of the discourse that is actually attempting to wrestle with modern culture’s ambivalent fascination with rampant hedonism. Consumerism relies upon encouraging good citizens to consume more but consumers of healthcare are made responsible for consuming less. Is it in this way that diabetes and complications are set up as a consequence of irresponsible indulgence, and expensive treatments and technology can be considered unnecessary and frivolous demands for the latest, rather than valuable, tools? This might also be a useful way of understanding other long term health conditions in which HCP default to an authoritarian medical expert approach when professing to being collaborative and person-centred (Bourdieu 1989, Fix et al 2018 and Franklin et al 2018). It may be that conditions and diseases that can be treated and cured seen as finite in budgetary terms and long-terms conditions costing more. This is a narrow focus at primary care level because “cost” is only visible in the prescribing of tools, treatments and consultation hours and does not factor the savings in terms of reduced hospital admissions and expensive treatments for secondary complications, let alone the amelioration of patient suffering and the promotion of health and vitality.

Foucault (*ibid*) and Friere (2004) also point out that it is fruitless to simply launch a straightforward rebellion against an oppressive discourse. Even if successful in turning the table, the forces and tension simply become rearranged. This would be to accept that PWD ought to be allowed to do whatever they want without considering lifestyle and treatments because they are inherently oppressive. An attempt to assert “I can be as uncontrolled as I like without consequences” would clearly be disastrous, but having problematized the arrangement of forces in Capacity to Control, Foucault and Friere suggest exposing discourse in order to navigate new learning from life (Friere) or fictitioning alternative plausible narratives (Foucault) that disentangle the concealment of the problem that gives it force in being accepted as truth. The LIDAS group Co-researchers identified this by highlighting two points of narrative that were meaningful: 1) that information, explanation and access to tools (that has become Skills, Knowledge and Tools in our discussion) facilitated a more fruitful way to be with diabetes and 2) that HCP knowledge alone tended to abstract them from what life with diabetes is really like and some degree of experiencing their patients as people increases HCP compassion and empathy and erodes abstraction. The LIDAS group primarily discussed HCP brief immersion in normal life activities with PWD to place human encounter and Lifeworld goals at the forefront of their encounter with diabetes.

Heidegger (1977) is capable of helping us here. Firstly in the problem of technology Heidegger helps us grasp the nature of an entanglement in what modern technology may represent in contrast to the etymology of its roots in the Greek *techne*. This was firmly in my mind as my dialogues with other Co-researchers unfolded, and the way in which they experienced technology reminded me there are two ways of perceiving technology. This was also confirmed/revealed in conversations on DUK Helpline. PWD would often ask about technology in a way that revealed a sense of Tools as a calculative apparatus that would absolve them of having to think about diabetes and engage in management for them. In the two decades of my involvement in diabetes the magical Tool in question for Type 1 has been an artificial pancreas that replaces the invisible function in endocrine control and blood glucose regulation and renders it once more invisible and out of awareness. Another is the Type 1 cure that finds a viable treatment that restores beta cell function. Many people I have spoken to are baffled that a modern world that can eradicate syphilis, smallpox and typhoid, put a man on the moon and produce technology capable of destroying the entire planet have not managed to build an artificial pancreas. Heidegger tells us this is a concealed aspect of the calculative function and standing reserve that is capable of reducing problems to a finite restriction of the perfect solution, that for most of life and being this has never been achieved. This hope is born from a misunderstanding of the purposes of thinking that are too narrow, or narrowed purposely to maintain this notion. That all life's issues are reducible to an optimum equation is part of his understanding of the ontotheology of the age that claims to answer these questions. However, Heidegger reminds us that the Greek meaning was likely closer to crafting and skilling and is more open to being. This is what appeared to be the sense in Co-researchers' dialogues concerning the meaning of technology for them and this is intended in the notion of Skills, Knowledge and Tools. When Co-researchers spoke of "My Libre" or "My pump", or indeed "My bag" containing kit and hypo treatments, these were imbued with a significance far beyond their mere function. Phenomenologically this was most apparent when problems occurred in attempts to curtail access to technology like restricting strips for monitoring, claiming control over receiving the Freestyle Libre or taking away insulin from an inpatient at hospital. These were felt as direct attacks on being that evince that tools become part of one's identity with diabetes. When this significance is narrowed, restricted or given a different value like cost, PWD can experience a sense of embattlement that is exhausting and traumatic. This other value for Heidegger is the enframing of PWD tools into the ordering of standing reserve, restricting the view of tools to mere commodity. Care Commissioning Groups costing prescribing for localities, GP surgeries trying to save money and be more cost effective by quantifying consultations into HCP time resource and NHS Trusts setting targets for number of patients seen, all conform to enframing that conceals the true significance for PWD about tools and equipment.

Another aspect concerning tools is the way in which they can open onto understanding and reveal access to Skills and Knowledge. A particular exemplar of this in the LIDAS group findings was Flash Monitoring. Traditional finger prick testing produces snapshot evidence for blood glucose that has a tendency to suggest blood glucose levels move in a smooth way. This form of testing usually comes with a recommendation of doing 4-6 tests a day (6-8 if carbohydrate counting). I first discovered this smoothness was not the case while researching Continuous Blood Glucose (CGM) devices. I had frequently seen graphs of blood glucose fluctuations in other research papers but some of the CGM graphics revealed from scatter plot diagrams demonstrated that blood glucose is continuously moving up and down and other graphics had used the convention of smoothing off the curves. However, CGM devices are cost prohibitive and so their use was not widespread and neither was the knowledge of blood glucose fluctuations. The arrival of the Freestyle Libre and a DUK campaign to consolidate criteria for prescription made it widely available from April 2019. The facility for seeing not only the bigger picture about blood glucose fluctuations but also seeing the trends in movements, has had a profound effect on PWD perception of management and dosing, predominantly the tendency to over control and overcompensate with insulin has reduced for many people because the narrow meaning and enframing of blood glucose as smooth and slow moving has opened understanding to the unpredictable nature of glucose fluctuations. Here a new key skill has emerged which is that of waiting and gathering more data before making decisions about dosing and correcting as it is now possible to do several checks an hour and because stored readings reflect trends in blood glucose levels rather than discrete snapshots. It also serves to prove that the still common notion of controlling blood glucose is a falsehood. With the best of the current Skills, Knowledge and Tools, PWD are not metaphorically driving a high performance car with assisted steering and excellent conditions but sailing a small boat on waters that may be choppy and unpredictable with numerous variables of weather and tides to contend with. It is not, and never has been, possible to test, dose insulin and eat and then predict a blood glucose figure in say, three hours time with anything like precision. One might also say that this notion in connection with Capacity to Control may have come about because Heidegger correctly predicts a propensity in the modern ontotheology of enframing that it "ought" to be so despite evidence to the contrary precisely because all aspects of being and nature should be explicated through the calculative function.

The Co-researchers' second theme relates to bringing HCP closer to the lifeworld of PWD and to empower PWD and this is also assisted by an understanding of Heidegger. Heidegger spoke of a being's concern or solicitude for itself but also for other beings. We could also consider concern or solicitude using the word *care* in order to align it with meanings for healthcare. He proposed there were two dimensions for being's concern for other beings: to *leap in* or to *leap ahead* (Heidegger 1962). Heidegger discusses the possibility for a person on hearing an expression of a concern or problem from the other as the temptation to leap in, taking care of the issue on behalf of the other. However, in this the care is taken from the other, with all its possible complexities and meanings and they become careless, or without care, as the matter is done with, or finished, and therefore should no longer matter when handed back. It also means that the other has no further opening to the other concerns or things that matter that might unfold or evolve in the issue. This is redolent with the arrangement of forces in HCP relations with patients. If the idealistic template of successful medicine is to diagnose, treat and cure leaping in becomes the epitome of rewarding medicine for the HCP: your problem is this, I do that, the problem is taken care of, you can stop worrying. I must point out here that if my problem were cardiac arrest this is a perfectly acceptable arrangement as three minutes of CPR until the defibrillator arrives and fast transport to a specialist cardiac unit is also the epitome of leaping in, albeit as a super analogy of diagnose, treat and cure that saves lives. (It is also noteworthy that in most of our communities a single automated defibrillator will be available in supermarkets, department stores, libraries, civil buildings and hospitals. The least likely place to find one is at home and in GP surgeries).

Heidegger's other response to concern for another being is leaping ahead. This is the sense of being standing before another being and their concern. In this sense a person does not take care away from the other but moves forward to dwell with the other's concern, to foresee, think with and understand the other's problems. This means the other retains their ownership of care and is supported to become free for it. The LIDAS group dialogues produced suggestions that seem to confirm that HCP tendency to leap in could be mitigated by having a better sense of PWD actual lives. Like T who would've liked to speak to a HCP that had diabetes to see how different this is, and M that had met HCPs that had attended events and spent time with PWD's outside clinical settings. Furthermore, leaping ahead gives some sense of the stance HCP might take in introducing Skills, Knowledge and Tools as possibilities to be explored with PWD that are in process of acquiring these at their own individual pace with readiness. Being able to follow a process of Skills, Knowledge and Tools acquisition brings its own confidence that can never be achieved with Capacity to Control. Leaping ahead also mitigates the possibility of seeing PWD as "diabetics," as it encounters the PWD in their whole being and opens onto the purpose of engaging with diabetes not for its own sake, but for having a life. This places a PWD's handling of diabetes in line with contextual lifeworld-led goals and opens to the possibility of lifeworld led care. However, it must be recognised that HCPs will at times be under pressure from PWD when the burden feels too great and they feel a desire for their HCP to leap in and take it away. This in turn tells us something of what must become available to HCP's own acquisition of Skills, Knowledge and Tools in training and reflective practice.

At such times as PWD experience burnout, other psychological difficulties or simply the vexations in life we may all encounter, some HCP (where they can) may turn to psychology, counselling and psychotherapy. This may be done in the sense of leaping in that may place the psychotherapist in a position of feeling similar tensions. The discovery of insulin was in 1922. At that time the two most prevalent psychological theories were behaviourism and psychoanalysis. Interesting to note that one entails the concept of operant conditioning (learned behaviour) and the other that of the unconscious defence mechanism of denial. The LIDAS group have given examples in their findings of both tendencies in Capacity to Control concerning a belief in psychological involvement in clinical care that requires focus on behavioural change and/or the dismantling of defences to accepting the seriousness of complications in order to adhere and to maintain behaviour changes. These two concepts have come into common currency but in oversimplified ways as “being trained to behave differently” (learning theory) and “not facing up” (denial). Psychologists and psychotherapists in their training have access to many more psychological concepts that will doubtless be protective to some degree of accepting simplistic psychological notions in favour of more context rich conceptualisations. However, HCP and PWD may be susceptible in the same manner as other parts of culture and society leading them to imagine these are central to the work a therapist will do with a PWD when they are referred. There are some pitfalls here for HCP, PWD and therapists. One is that if a HCP refers a PWD to a therapist in the belief that they will utilise techniques to install new positive behaviour in PWD or dismantle defences in accepting Capacity to Control, and the patient improves in their engagement with diabetes tasks, it is likely the HCP will experience confirmation bias and account for these improvements as proof that therapy techniques have been marshalled for these purposes. This is exacerbated if the HCP and therapy service are at a remove from one another because there is no platform for or professional relationship to produce honest and critical dialogue. Silo service provision maintains this fiction that patients, PWD, are referred, do therapy work and return to the HCP transformed (assuming intervention works). Multi disciplinary team (MDT) work has long been an ideal of health provision in accomplishing holistic care but the ideal would need to be provisioned so that the disciplines “rub shoulders” in order to dialogue and absorb knowledge from each group. A problem for PWD referred to therapy is an implied message that the PWD has an additional issue to do with mental coping *as well as* diabetes, and if this comes from Capacity to Control it further implies that the problem is being “a bit mad or a bit bad” in which corrective behavioural techniques or removal of defences are required. The patient then attends therapy or psychology that they may have asked for in good faith, but with an unintended and unwanted label. Furthermore, the arrangements of access to therapy may require that the PWD accept a diagnosis of anxiety or depression (GAD 7, PHQ9 or HADS) to meet criteria for inclusion. We have seen in the literature this may be inappropriate if the issue is predominantly one of diabetes distress (DD), as there may be sufficient DD to appear on the DD scale but sub-threshold for GAD7 or PHQ9 and because any anxiety or depression showing may mask that this is predominantly DD. It cannot be assumed that appropriate therapy that has evidence base and focuses on anxiety and/or depression is suitably placed to address DD. However, a therapist may have to capitulate to a diagnosis of mental health co-morbidity to accept PWD because of the criteria for inclusion (despite understanding this is DD) and potentially offer therapy most suited to one, but not the other. If not, the therapist may be under further pressure to muster their notes to comply with this narrative whilst actually providing different approaches with DD in mind so what happens in the therapy is one way and what is catalogued in notes another (M and her eye hospital letters “I have told this Lady…” when no such dialogue took place is likely an example of how notes and correspondence that can be read by other professionals may be written to conform to targeted professional practice rather than authentic to the encounter). To tell accurately how the therapy unfolds may include how it addressed problems in HCP/PWD relations i.e. “let’s teach you to hear the content in consultations but not react to the way it is said.” So notes and discharge summaries may also want to avoid noting the relational difficulties because it involves another HCP’s practice that will have access to these. This maintains a fiction in which the expectations of the HCP in regard to psychosocial intervention are confirmed erroneously. In a service delivery in which future HCP referrals for therapy may be born out of frustrations with some patients’ inability to take on Capacity to Control, any success produces confirmation bias. This is particularly slippery as the LIDAS group confirmed, because HCP referral to therapy may then be prefaced with the PWD explicitly i.e. “I am referring you to our psychology service because you are not coping with your diabetes and they can help you get back on track”, particularly if this follows a typical Capacity to Control conversation experienced by the PWD as scolding or a lecture. An important point in the discussion is to reiterate that I am not stating that there are good and bad HCP that knowingly scold their patients, but that there are pre-reflective moments in which the tensions redolent of the moralism in our whole society coalesce and push people into default mannerisms, that confirm and strengthen the discourse (Foucault) identified in the entanglement of enframing (Heidegger) of the modern arrangements of thinking.

Of course some therapists may also be in the thrall of Capacity to Control as some orientations and theories focus on behaviour change. This may particularly be the case if the therapist in a dedicated service has picked up notions of Capacity to Control in their additional learning about diabetes. It is possible to conceive of a therapist adopting the role of motivator, seeking to use their skills to encourage the patient to adopt a healthier lifestyle or follow the regimen of more testing and dosing by addressing barriers to this. This would simply be a more sophisticated and persuasive method of inveigling the patient into better adherence but may only have short-term benefits if it does not attend to the underlying beliefs because changes would lack a sense of ownership on the part of the patient.

A therapy approach that is grounded in the value of a PWD lifeworld and leaps ahead instead of leaping in, is more likely to produce an environment of collaboration in facing the challenges of handling diabetes that open onto an exploration of the Skills, Knowledge and Tools that present the best current fit for the PWD context. This would also acknowledge the flaw in Capacity to Control that supposes blood glucose fluctuations can be controlled, relocates blood glucose targets as unrealistic at least some of the time and shows that the data is clear that any improvement is associated with lower risk and greater future safety. This would explicitly identify the mechanisms of Capacity to Control so that a PWD can begin to add the skill of spotting conversations where this occurs and can choose whether to avoid these or gently but openly challenge them.

Chapter Seven: Concluding Remarks

The criteria by which PAR and the LIDAS group findings can be evaluated are quite different from many other quantitative and qualitative studies. This is partly due to the fact that the process does not conform to the common research practice of clearly stating aims at the outset of research. These can only be "intended", as freedom and responsibility for direction are democratised to Co-researchers. The frequently asked question form readers, peer reviewers and examiners of "did the study realise its initial study aims?" is less relevant than "to what degree did Co-researchers experiential explorations, learning and narratives chime with one another?" This partly anticipates the idea that the real judgement of significance will come from readers in similar contexts, that they might experience the shock of recognition. However, other qualitative approaches may rely on data from participants that haven't met as the researcher reveals consistency from independently corroborated data, whereas PAR Co-researchers corroborate their narratives through recognition of each other's experience throughout the process and analysis. In other words, the parity in their stories speaks for itself and anticipate speaking to others in familiar circumstances.

This shifts the judgement of PAR evaluation from "were the aims to generate a certain kind of knowledge met", to three broad questions we can ask of readers: 1) Does it appear that this endeavour was truly participatory? 2) Is democratic equitability apparent? 3) Does it contribute theoretically to social science but also to the potential for social change?

The limitation in the LIDAS group study was that there were relatively few voices in comparison to other approaches but this is because greater corroboration is incomplete until the findings are disseminated and either fit broadly with PWD and HCP experience or they chime as truthful. This means that where other approaches like IPA or structured survey questions produce a sense of completeness and can be assessed against the original aims, PAR produces a result that is more like an open letter to stakeholder readers.

A similar limitation is that although the gender mix was fairly even among the group participants, female Co-researchers engaged for longer and more deeply producing more of the thinking, dialogue and reflection. This might indicate that female Co-researchers were more readily familiar with exploring their feelings and experiences through social dialogue with others. It was certainly a feature of female Co-researchers that they reported appreciating the benefit of extended cycles of learning through dialogue.

This gender skew may effect the significance or degree of some of the themes i.e. do women more readily introject notions of Capacity to Control for socially gendered reasons? It certainly seems likely that there will be gender specific dynamics involved in female PWD consultations with male and female HCP. Furthermore, the experiences of women from a feminist perspective will likely couch greater familiarity with going unheard or marginalised and this may be echoed in a health care setting when Capacity to Control produces an overt or covert scolding. Indeed, Bernstein and Kane (1981) described the possibility that a gender skew for physicians was to attribute symptoms in male patients more readily as organic in origin but in female patients' symptoms were more readily viewed as psychosocial. Women may also be more familiar with healthcare consultations and have differing expectations from men. Wang et al (2013) found that women consulted HCP on average 37% more than men between the ages of 16 and 60 even after factoring for maternity and gynaecology visits. Of course, after a diagnosis of diabetes the routine care plan of check-ups will even out across the sexes for diabetes, but this will still imply that women will be more familiar with the consulting room. However, male Co-researchers and participants did report and recognise the emerging themes in the LIDAS group and there was little indication that their responses to these experiences differed particularly from female participants. A future possibility for confirming this might be to produce survey questions of LIDAS themes that may provide more parity in numbers of male and female respondents for comparison.

PAR also differs in data analysis. It has been noted (Fals Borda 2006) that PAR does not generally use a clearly defined method of analysis. This is because Co-researchers are not trained in qualitative methodology but develop and adopt practices for reviewing and reflecting on the emerging understanding of shared experience. In truth, my own background and training in qualitative analysis that the transcribing and analysis took a more traditional thematic approach. In considering Heidegger's concept of poesis, I would often conduct a mindfulness exercise and begin by reading poetry in an attempt to loosen calculative thinking in close reading of transcripts. The themes generated from a particular dialogue were then reflected on and read again to refine the emerging findings. However, a major difference to traditional method was that this process was not conducted at the end of a complete data set but throughout. Each pass through a transcribed dialogue and themes were then shared directly with Co-researchers to reflect on, critique, adjust and move dialogue on. Periodically, if a theme returned in a later dialogue Co-researchers would reflect back and refine the theme or generate additional examples in presenting findings. The limitation of this is the potential for latter dialogue and reflection to be shaped by early revealing of themes. This is why critical readership requires considering whether the central theme and examples feel stretched or squeezed into place and whether a suspension of disbelief is required for the findings to chime as truthful.

Some of the LIDAS group Co-researchers continue to meet with the notion of considering methods and purposes of disseminating our findings to the best effect. The narrative phenomena and mechanisms of discourse and entanglements explicated in this study lend themselves for consideration within the continuing wider debate from Mind Your Language, Language Matters, the restrictive code/dialect and DD and burnout and offer a plausible fourth voice to these understandings. However, a dissemination strategy should account for whose hands (our audiences) are best placed to use this effectively.

At the shorter end of this spectrum, for structured patient educators, advocates of technology and HCP specialised in secondary diabetes care services (usually interfacing with Type1 and complex Type 2 cases), the LIDAS findings may simply strengthen their positions in avoiding Capacity to Control and centre on Skills, Knowledge and Tools contributing new vocabulary to enhance the understanding of how these features work and building confidence in efficacy. I anticipate that for HCP exposed to the real lifeworld experiences of PWD this will be a fresh look at an old problem in terms of best practice and practice based evidence. This is equally so for psychologists and therapist working in designated services for PWD including regionally where Improving Access to Psychology Therapy services are commissioned to provide this.

For HCP given responsibility for diabetes in primary care (GP surgery settings) the findings may be more enhancing in terms of awareness as it offers possibilities to extricate themselves from the pitfalls and traps of Capacity to Control and opens onto the possibilities for understanding their patients' access to Skills, Knowledge and Tools. This may help to reduce disparity between the clinical judgements in Type 1 and complex Type 2 between secondary care specialist clinicians and the control and tensions in CCG and primary care prescribing. Potentially this could also enhance an understanding for more straightforward Type 2 positions in which the contextualised individual is in receipt of a better understanding of their individual position. Future HCP training in this predominant area of diabetes might include an explication of the entanglements of encounter with patients generated by the notion of Capacity to Control and enhance the possibilities for perceiving that a contextualised process of acquiring Skills, Knowledge and Tools is the route that PWD embark upon.

Another possibility for HCP in diabetes to increase MDT expertise between medicine and psychology/psychotherapy is the model already used in cancer care. It is mandatory for oncology nurses to receive Level 2 training and attend monthly supervision. Level 2 is part of the mental health stepped care model that identifies four tiers of mental wellbeing (Level 1), mild depression and anxiety or psychological distress (Level 2), moderate depression and anxiety (Level 3) and serious mental health problems (Level 4) (Stonebank 2017). Level 2 training comprises a one-day workshop with oncology nurses that covers Level 1 and 2 of the stepped programme in identifying mental wellbeing and mild depression and anxiety or psychological distress in their patients, but also helps identify HCP stress in managing these patient relationships. This helps with skilling HCP in making referrals, offering skills and approaches that allow the to address low-level concerns themselves. Continuing supervision or reflective practice with a psychology or therapy professionals helps to consider individual patients but also HCP wellbeing, confidence and practice-based learning. This was made mandatory on the basis that HCP found it difficult to justify spending valuable resources on anything other than direct patient care (Laffan 2015). This approach applied to diabetes nurses could well offer opportunities for LIDAS findings to be explored with the HCP/PWD relationship to improve understanding.

However, one of the central contentions of the LIDAS group relates to the experience of PWD either in thrall of the entanglement of Capacity to Control or in midstream of repudiating or rebelling against its effects. This would mean providing PWD the Skills, Knowledge and Tools to challenge Capacity to Control directly/indirectly where they find it and enhancing the notion that empowerment for all PWD will come from considering their current needs for Skills, Knowledge and Tools that will unfold at their own preferred pace. This would suggest that LIDAS needs to consider how its' findings mobilise the largest audience (PWD) to feel more empowered to have reasonable access to Skills, Knowledge and Tools that are contextually appropriate for their situated being with diabetes. It would seem then that challenging or dismantling the means by which PWD are regularly disempowered is the greatest asset in them discovering their own empowerment which flows from loosening the grip of Capacity to Control.

Therefore LIDAS must consider the best ways to disseminate its findings to HCP across the spectrum but predominantly PWD, so they can examine and grow in confidence alongside their acquisition of Skills, Knowledge and Tools.
We will then consider a report for Diabetes UK with the key findings to see how they might use this information on the website and Balance members magazine. In addition we will explore writing articles for publication in both scholarly journals and popular magazines like Nursing Times and Therapy Today. We will also look into presenting findings at the Diabetes UK Professional Conference.

Another point for dissemination is the use of PAR as a valuable means of research. LIDAS has demonstrated it has potential in the medical field in exploring the patient dimension that is sorely needed to extend the fields of bioethics and patient centredness. It's equitability and inclusiveness places patients and the core of their lifeworld experience centrally. However, I would recommend similar approaches in the field of existential phenomenology and counselling and psychotherapy because it offers an alternative to "snapshot" lifeworld hermeneutics and can deliver a "slice through" of lived together lifeworld for Co-researchers that few participants in other qualitative methodologies experience.

The LIDAS group will consider future directions and how to take the research forward. A clear possibility is to use the findings to construct graded survey questions for wider use with PWD and HCP to establish the degree and extent of the phenomena of Capacity to Control. This would provide an answer to a limitation of the LIDAS study: how general are the current findings given the comparatively small number of participants?

Another potential avenue of research is in the field of structured patient education (SPE). It ought to be possible to adapt current structured patient education to include more explicitly the phenomena of Capacity to Control versus Skills, Knowledge and Tools. The curriculum may assist in raising PWD awareness of the pitfalls of Capacity to Control and enhance the understanding of the place of contextual based learning in Skills, Knowledge and Tools. It would then be possible to conduct a traditional double blind clinical trial. We would propose three groups of randomised participants: no SPE; current SPE and LIDAS adapted SPE. Each group would be evaluated for outcomes in pre and post HbA1c, BP and cholesterol, Quality of Life, DD and patient confidence with six month follow up.

Similarly, increasing conscious awareness of the pitfalls of Capacity to Control and the empowering benefits of exploring Skills, Knowledge and Tools can inform psychologists and psychotherapists in ways of supporting PWD that are referred for therapy. Listening for possibilities of Capacity to Control emerging in PWD narratives will help to explicate and expose it, reducing the means of disempowerment. Discussing realistically approaches to developing contextual Skills, Knowledge and Tools will help PWD that they can fruitfully fashion and own their ways of engaging with diabetes.

These findings may also shed light on other long-term health conditions particularly in using PAR to openly lend power and force to the unheard experiences of people that live with them.

The conclusion finds there are some significant possible future dissemination and research developments for the findings of the LIDAS study.

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Appendix 1

Glossary

Adherence – a medical term used to denote how closely a patient follows a treatment plan. Adherence, compliance and concordance have all been used interchangeable according to attempts at mitigating patient disempowerment.

Annual review – yearly medical tests that monitor and track blood glucose, blood pressure and cholesterol and test for detectable signs of complications.

Basal – long acting background insulin.

Blood glucose – saturation of glucose in the blood.

Bloods – shorthand vernacular for blood glucose levels or annual review blood testing.

Bolas – short acting mealtime insulin.

Carb counting – action of calculating the quantity of carbohydrate in food in order to calculate a quantity of short acting insulin for a meal. Usually learnt through Structured Patient Education.

Carbs - shorthand vernacular for carbohydrate.

CCG – Care Commissioning Group. A regional public organisations responsible for the budget and delivery of health a social care.

CGM – Continuous Blood Glucose, a device that measures ambulatory fluctuations in blood glucose.

Compliance - a medical term used to denote how closely a patient follows a treatment plan. Adherence, compliance and concordance have all been used interchangeable according to attempts at mitigating patient disempowerment.

Complications – secondary medical conditions caused by having diabetes.

Concordance - a medical term used to denote how closely a patient follows a treatment plan. Adherence, compliance and concordance have all been used interchangeable according to attempts at mitigating patient disempowerment.

Correction – a quantity of short acting insulin used to deal with high blood glucose levels outside of the carbohydrate in meals.

CSII – a continuous subcutaneous insulin infusion or insulin pump.

DAFNE – a structured patient education programme for people with Type 1 that teaches carbohydrate counting and insulin dosing. The acronym stands for Dose Adjustment for Normal Eating.

DKA – diabetic ketoacidosis. A state of hyperglycaemia and increased ketones that usually requires a hospital admission and carries a serious risk of coma and death.

Flash – flash blood glucose monitoring using interstitial fluid in the skin.

Freestyle Libre – a flash monitoring device manufactured by Abbott Diabetes Care.

HbA1c – a blood glucose test using a venous sample to measure glycosylation of haemaglobin in red blood cells. Measured in either %mg/L or modern standard mmol/mol.

HBG – home blood glucose testing.

HCP – Health Care Professional.

Highs and lows - vernacular referring to blood glucose levels, highs being hyperglycaemia and lows being hypolglycaemia.

Hyperglycaemia – a state of high blood glucose often considered >11mmol/l.

Hypolglycaemia - blood glucose levels <4mmol/l, causing symptoms of shakiness, hot sweats of cold feelings, confusion and eventually feinting or seizures.

Hypos - shorthand vernacular for hypolglycaemia.

Hypers – shorthand vernacular for hyperglycaemia.

Infusion set – a canula

Libre – short for the Freestyle Libre.

Long acting – basal insulin.

mmol/l – unit reading in the UK for home blood glucose testing device.

Monitoring – refers to testing blood glucose levels

NICE – National Institute for Health and Care Excellence. An independent medical organisation that reviews evidence and produces up to date guidance on clinical treatments and protocols for the NHS across all disease and health conditions. These include rationales for costs and savings.

Pump - continuous subcutaneous insulin infusion.

PWD – people with diabetes, person with diabetes

Nephropathy – a secondary complication of diabetes causing chronic kidney disease.

Neuropathy – a secondary complication of diabetes causing damage to nerves.

Regime – usually refers to the tasks of monitoring blood glucose levels and taking insulin.

Regimen - usually refers to the tasks of monitoring blood glucose levels and taking insulin.

Retinopathy – a secondary complication of diabetes damaging the capillaries in the retina of the eye, detectable by digital eye screening pre-symptomatically. Can cause serious vision impairment.

Risk – refers to the probability of future secondary medical complications of diabetes. Is also used to refer to risk factors for developing Type 2 diabetes.

Sensors – used with flash blood glucose monitoring.

Short acting – bolus insulin.

Strips – small, single use items used with home blood glucose monitoring devices.

Structured Patient Education – training courses for PWD in aspects of managing healthy eating, activity and treatment.

Sugars – vernacular for blood glucose level.

Targets – recommendations for blood glucose levels both daily and long term.

Tests - shorthand vernacular for blood glucose levels or annual review testing.

Ups and downs – vernacular referring to blood glucose levels.