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Understanding the diversity and dynamics of living with diabetes: a feasibility study focusing on the case

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Abstract

Despite growing evidence about treatments, many people living with diabetes have poor diabetes control even when health care is available. One difficult issue is how to apply medical evidence to individuals. This feasibility study explores change over time and the diversity of pathways to similar health outcomes, to understand how evidence can be tailored to the individual. Six people living with diabetes (2 with type 1, 4 with type 2) agreed to a series of interviews and diary keeping. Reading the data set for each individual reveals a person changing over time through interactions with people and their context. Identifying time as a theme is difficult as it is ubiquitous. Outcome means little to those living with diabetes: they are living on through time. We developed attributes for each participant relevant to diabetes outcome, describing how they related to others and their environment, capturing emergent properties rather than detail. A similar health outcome could be achieved very differently. Comparison of patterns of attributes may be useful. However, the dynamic, relational nature of the attributes is easily lost from view. How people function in terms of time, change and interaction, may be most important for tailoring interventions for improved health outcome.

Understanding the diversity and dynamics of living with diabetes: a feasibility study focusing on the case

Introduction

There is a considerable evidence base for the treatment of diabetes, both type 1 and type 2, and much of this evidence has been used in the development of guidance for practitioners both locally and globally. [1][2] Evidence on the most effective treatments for people living with diabetes is continually reviewed.[3] There is guidance for practitioners on how to tailor clinical evidence to individual patients [4] but health professionals remain concerned about applying evidence/guidelines to individual patients. [5] In general practice practitioners may only occasionally read evidence or guidelines, relying on internalized guidelines. These may be based on evidence but are reinforced by their experience and what others say including colleagues and patients.[6] This use of evidence embedded within a practitioners experience has been called evidence informed practice. [7] The importance of involving the patient in deciding on how far they should adhere to guidelines has also been highlighted. [8]

There is a growing literature on the experience of living with diabetes and of diabetes care. (Reviews of this literature include [9] and [10][11]) An interview study from the UK highlighted how different the experience of living with diabetes could be for different people and the frustration of being offered standard responses to their needs rather than a tailored one. [12] Knowing and valuing patients as individuals was identified as a characteristic of helpful healthcare interactions in a review of qualitative studies. [11] In a study of diet-related self care among people living with type 2 diabetes in Canada, interviews revealed influences on diet which could be categorised as individual, diabetes related and contextual. The author highlights that although these themes could be identified across the data, the 'configuration and weighting of the influencing factors was unique to each person'.[13] By virtue of the complexity of individuals, each one living with diabetes will have, at least to some degree, a unique response to the disease and treatment. [14] Besides diversity due to socio-cultural influences (examples include:[15][16]), qualitative studies indicate a number of ways in which individuals' experiences of living with diabetes become diverse. A UK interview study that recruited people within six months of diagnosis of type 2 diabetes and followed them up for a year, revealed the co-evolution of health care and disease experience. Delivery of health care influenced how they experienced their disease and this influenced their expectations and preferences for health care. [17] This process of co-evolution is influenced by the diversity and variation in health care experiences. For example, a focus group study on adherence to therapeutic regimes by people with type 2 diabetes revealed a lack of consistency of advice received from doctors and fluctuating tolerance of the patients during follow up. [18] Individuals learn from others about living with diabetes in various ways. Examples include organizations such as Diabetes UK[19], local health initiatives in the community [20] and websites reporting individual experiences.[21] Individuals also learn about their own bodies responses to diabetes and treatments [11] and experiment with medication to learn more. [18] A meta-ethnography on lay experiences of diabetes and diabetes care recognised the diversity of responses of individuals to diabetes[9] but identified six key factors as important in enabling a person living with diabetes to manage their diabetes effectively:

Basic Knowledge
Acknowledge diabetes is serious
Effective support from providers
Time passing/experience
Trust in self
Less subservient approach to care providers.

The authors suggest that individuals living with diabetes have to pass through certain stages and overcome certain barriers to manage their disease effectively. However, they also suggest that not all stages have to be achieved to the same degree by everyone nor do they need to be achieved in a particular order.

Despite substantial evidence on how health outcome for people living with diabetes can be improved, there remains a shortfall in what is achieved in the real world, even in countries such as the UK where health care is free at the point of access and substantial organisational and policy initiatives have been implemented to improve diabetes care (for example a National Service Framework for diabetes[22] and an expert patient programme [23]). This paper focuses on just one aspect of this concern, the difficulties encountered when applying clinical evidence to individual patients. It examines this in terms of the diversity and yet similarity of individual patients [24] and explores the following research questions:

1. How do individuals develop and change over time and through interaction with their context (which may also be changing), and how does this impacts on health outcome?
2. Is there a diversity of pathways to similar health outcomes (i.e. how people may gain the same health outcome but by different means) and can understanding this diversity help health professionals tailor interventions to improve outcome?

For enabling the best health care and health outcome, qualitative research indicates these to be important issues.

The paper presents a small feasibility study undertaken to test research methodology for exploring these issues. The development of the study formed part of a programme of research on developing research methodology in relation to Complexity and healthcare[i]. It responds to calls for the development person centered methodology for understanding how individuals progress through illness[25] and its development drew on literature on complexity sciences, case based research methods and how we understand time in our research (key texts include:[26-30]). The study focuses on methodological issues rather than looking for new substantive issues.

Methods

To take a fresh look at methodological issues and to ensure our study was grounded in the individual's experience of diabetes, our first step was to ask people living with diabetes

about their experiences, capturing as much data as possible in a relatively unstructured way. We discussed our data collection approach, involving interviews and diaries, with the Warwick Diabetes Care Research User Group [31] to ensure it was minimally intrusive and appeared relevant to people living with diabetes.

Recruitment
Volunteers were recruited at a local Diabetes Awareness Day in 2004 organised by the local branch of Diabetes UK in association with the local Primary Care Trust. The event was open to the public and provided information on various aspects of diabetes. Leaflets about the study were distributed and the names and contact details of 20 volunteers were recorded. The study aimed to recruit six volunteers with diverse experiences so six were contacted, three female and three male with a range of ages of which one was from an ethnic minority. One declined and another could not be contacted so a further two were contacted and participated (see table 1).

Table 1 Summary of participants

Participant	age	gender	Type of diabetes	In paid employment
A	51	F	Type 2	No
B	61	M	Type 1	Yes
C	74	F	Type 2	No
D	44	M	Type 1	Yes
E	62	F	Type 2	No
F	64	M	Type 2	No

Data collection process
In the initial interview the participants were asked to tell us about their life in general before focusing on diabetes. This was to ensure we understood something of their context. The interviewer then asked about living with diabetes, starting wherever the participant thought appropriate. The participants were encouraged to talk about how their diabetes was viewed by others, particularly those close to them, their beliefs about diabetes, factors affecting their diabetes, past and present experiences related to their diabetes including coping strategies and diabetes controllability. They were also asked about the health professionals they consulted about their diabetes and how they related to them. The interviews were audio-recorded and lasted between 90 and 120 minutes and all took place in the participants' homes.

At the end of the interview the researcher negotiated with the participant about keeping a diary for a minimum of two weeks and the method for recording this: on paper, e-mail, audio-recorded or by phone diaries. Participants were asked to record in their diaries what they felt was important in relation to their diabetes. Participants were also asked to nominate a family member to be approached for interview. The family members were interviewed within 2 weeks separately from the participant. The interviewer asked about the same issues as the participant but encouraged to talk about them from their own perspective. No issues discussed with the family member were subsequently raised with the participant living with diabetes.

The initial interviews with the participant and family member, and the diaries were analysed prior to follow up interviews to identify questions for clarification and further discussion. Analysis was done independently by FG and each interviewing researcher, and then discussed.

Follow up interviews were undertaken up to three months after the initial interview. Each participant was asked what had happened since the last interview and was asked questions informed by analysis of data collected earlier, both the participant's own and other data from the study. For example, in her initial interview participant A described considerable confusion about what to eat to help her diabetes control yet claimed to have lots of information. At follow up the interviewer asked participant A to show her the information and discussed it with her in order to clarify how much of her apparent confusion was a difficulty with literacy. An example of a question asked of all participants arose from Participant B. Talking about health professionals he said 'they are only giving me what they think is good for me and I don't know any better'. To explore this further, in the follow up interviews we asked all participant's their views on their own role in informing the doctor about how they were managing their diabetes and in finding out about other treatments.

The initial round of data collection undertaken by NA and EC, commenced November 2004 and finished February 2005. After analysis (mid 2005) FG and UM sought to undertake a further interview with participants to discuss the results of the study generally, ask additional questions particularly about changes over time, timeliness and diabetes time. Only two of these interviews were completed. These included a brief questionnaire completed before starting the interview asking about attributes of study participants that were developed during analysis. A presentation of interview analysis results was made to the Warwick Diabetes Care User Group (10 participants) and the questions about changes over time, timeliness and diabetes time were asked of this group. The discussion was audio-recorded.

All audio-recorded data was transcribed. NVivo software was used to assist data handling in the analysis phase.

Table 2 Data collected

Participant	Initial interview	Diary	Family member interview	Follow up interview	Review interview
	(all face to face)		(Face to face unless specified)	(Face to face unless specified)	
A	Yes	3 weeks handwritten	Husband	Yes	No
B	Yes	2 weeks	Mother	Yes	Yes

	(mother present)	typed paper			
C	Yes	2 weeks hand written	Husband	Yes	No
D	Yes	No	Wife (telephone)	No	Yes
E	Yes	No	No (lived alone with no local relative)	No	No
F	Yes	2 weeks e-mail	Wife	Yes by telephone	No
Warwick Diabetes Care Research User Group				Facilitated discussion	

Analysis process and results
There were three main stages in the analysis process planned for this study and a final tentative analysis developed as the study proceeded. The analysis process and results are described together as analysis process and results each informed the other.

Analysis stage 1: Qualitative thematic analysis
This analysis mostly informed research question 1 and used thematic analysis. Two of the research team, FG and UM read and re-read the interviews (both those with individuals living with diabetes and with family members) as the transcripts became available and discussed it with the interviewers (EC and NA). At this stage of analysis two issues became apparent that shaped our coding and subsequent analysis. Although diabetes was the focus of much of the interview and was an ongoing issue for the participants needing their frequent attention, it was striking how small a part of their life was spent considering their diabetes (for both type 1 and type 2 diabetics). The analysis therefore focused on identifying where diabetes interacted with other aspects of life. It was also very striking how similar the participants' experiences were with the system of health care and health interventions although they used a range of different primary and secondary health care providers. Most of the time for most participants, regular health care checks were done in a similar way and most of the time their medication was effective and unproblematic. The analysis therefore focused more on the participants' detailed interactions within the health care system rather than the nature of the health care organisation or their treatments.

The diary data was mostly a record of what was eaten. This may reflect the importance given to diet in managing diabetes, as explained by participants in the interviews. However, the interviewees may have assumed we were asking for a traditional medical model of a diabetes diet diary. The diary data was used to inform subsequent interviews but was not used in the main analysis.

Analysis process

FG developed a thematic coding scheme based on reading the first four initial interviews. She then coded two interviews, defining the codes as she applied them to the data. UM then coded the same two interviews independently, adding new codes and refining the definitions of codes. FG and UM then reviewed the coding, discussing and agreeing any differences in their coding. UM then coded the remaining interviews (interviews with F were available late in the analysis process – see below). The thematic codes were of the following types:

1. characteristics of the individual (index case) e.g. age, type of diabetes, health literacy, attitude to diabetes, management skills, use of routine, sense of control, relationship with household, relationship with health professional, reactivity to change (Example given in definition of the latter: how long feels side effects before taking action)
2. what they did and what happened in relation to diabetes e.g. blood glucose monitoring, diabetes and their work, use of comparison with others, diet restriction, routines, self-observation, social support, acute illness, prolonged physical symptoms,
3. interaction with, including influences from, social context e.g. household, friendship network, health care provision, self help group, medical suppliers, legal frameworks, policy
4. outcome – data that indicated the individuals view of health outcome and any mention of 'medical' outcome such as weight, HbA1c, complications of diabetes.

With such a small data set the research team became very familiar with the data and through this familiarity, comparison between all cases started during the thematic analysis. For example, the strict use of routine by one participant highlighted for the team the lack of strict routine in other accounts.

The concurrent reading of literature on complexity and the dimension of time highlighted for the team how the process of thematic coding tended to loose of the sense of interactions and dynamics in the participant's accounts. One approach used to counter this was a further coding round to identify a fifth category of codes related to time and change. This coding was wide in its scope initially as we were refining our ideas about how to incorporate time and dynamics in the analysis. However, time is a dimension of everything and change was part of many codes so the time codes were reviewed and reduced to avoid duplication with existing codes. The additional codes created and kept included: linking events in the past present and future to a health issue, change over time, timeliness and diabetes time (stage of diabetes).

Searches were undertaken to identify and compare the themes across the six cases, often including several closely related codes to ensure all relevant data was found. The following data extracts are from searches of coded data about diet and diet control and are chosen to illustrate the type of data within one theme and the contrast in the content between participants on the same theme:

Participant A

I've got a freezer full of Mars Bars and everything. I mean… and it is so hard and I keep saying to them (family), 'Eat a Mars Bar, eat a Mars Bar'…

Participant B
(I eat) at exactly the same time every day. It's boring! I keep saying it's boring! Yes, well you get in a routine.

Participant C
I have a breakfast and if I fell like it then a little snack mid morning … cook a main meal … and eat lots of salads and fruit….we used to go on one or two little holidays, only in this country, but we don't bother with those… what's in the food, you know? I would like the right ingredients to be in the food… but you can't guarantee that.

Participant D
If I'm at home I'm drinking low carbohydrate beer ok? ….If I'm out, then I give myself Insulin for each drink that I have, which because I'm on an Insulin Pump I can do because I know the Carbohydrate content of what I'm drinking.

Participant E
In the evenings I like to (eat) early enough so that it doesn't increase your sugar … I noticed if I eat late by blood sugar is high in the morning

Analysis was undertaken iteratively with reference to appropriate literature. Although the project aimed to explore methodology, reference to the literature ensured the substantive content was externally valid. For example, an understanding of the use of routine or habit in diabetes care has been described. [32]

The data was also re-read as a set of data (all interviews and diary) for each participant.

Understanding how individuals develop and change over time and through interaction with their context (which may also be changing)
When reading the data for each participant as a set, development and change and interaction with the context could be identified. There was a sense of constant activity and change with time. We illustrate this with examples from Participant D by summarising much longer accounts in the interview.

This is an example of short term interactions exacerbating an illness. Although short term, the episode was vivid in the participants memory.

Participant D had appendicitis which led to difficulty controlling his diabetes. The effect of the illness was on his physiology, his decision making ability and his behaviour including his self-monitoring blood glucose. His health professionals focused on the appendicitis and gave little advice about his diabetes. He felt depressed as he was ill and not getting better, exacerbated by his difficulty controlling his diabetes. As someone who normally manages well with an

emphasis on good control his depressed mood was exacerbated by his sense of failure at controlling his diabetes.

A very different example of interactions from the same participant lead to improved control.

> Participant D plays a lot of sport so is knowledgeable about carbohydrates and metabolism and the exercise helps diabetes control. He drinks alcohol as part of the social life of the sport so needed more understanding of the carbohydrate content of beer. Through seeking information about this from professionals and literature he developed his skills in managing health professionals and health information. His ability to manage alcohol in relation to his diabetes enables him to include in his social life a regular meeting with peers with diabetes in a context acceptable to them (a pub). He was also able to manage the working lunches required in his job. His job involves management and relationship skills and these skills enabled him to negotiate for and use an insulin pump to improve his diabetes control.

The ease with which participant D talked about his experiences made it easy for the research team to identify interaction from his data. His ability to 'tell the story' was a skill he used in his work and social life. However accounts from other participants reveal similar interaction, for example between their social roles and diet.

> Participant A was a mother and shopped for her family, including in this shopping sweet foods such as Mars bars and biscuits. She perceived her family as refusing to give up sweet foods which she herself had difficulty resisting. Interestingly a very different account was given by the family member who was interviewed who did not eat sweet things and was concerned about participant A's continued consumption of these.

> Participant C gave a very different account of the interaction between her social role and diet. She usually avoided sweet things without much difficulty. However she found herself under pressure to eat cake at social functions to avoid being considered rude. As illustrated in the following extract, the social pressure included the trivialising of diabetes by others which itself may have been enhanced by seeing what other people with diabetes do.

> R.. you go to things and people say to you, 'Oh go on, you've only got Diabetes, you can eat that.' And they produce slabs of cake and chocolate biscuits and all this sort of thing you see and they say, 'Well it won't hurt you just for once.' But that's the sort of thing where you think to yourself, 'Oh if only!' you know?

> I: Yes, so how do you deal with that?

R: Well I just sort of refuse, I say 'Well I won't if you don't mind thank you' you know. I just leave it like that. I don't argue the toss because these people haven't got it, these people don't know what they're talking about really. It's just… my friend's got Diabetes and she indulges you see? So…

I: Right. Is that just within that circle you've had to put up with…?

R: Oh no, no it's wherever you go. If you mention… if you refuse things and they… people look at you as if to say 'You're being a bit rude', so you ultimately have to explain, 'I'm awfully sorry but I have Diabetes and I really shouldn't partake in that.' You know, but their attitude is 'Oh it's only Diabetes, you'll be all right.'
(I=interviewer R=respondent)

Food habits prior to a diagnosis of diabetes has been reported as a particular challenge for people attempting to change their eating patterns. [33] Issues related to food and its social function has been identified in other studies[34] as has a lack of understanding of diabetes in people's social networks. [35]

Through reading the set of data for each participant, we built up an understanding of each participant as someone developing within themselves, interacting with their context and influencing or at least attempting to influence their context. Each participant was unique. As other qualitative studies have found, participants talked about similar themes in relation to living with diabetes, although what they said about that theme varied (e.g. [13]. There were also similarities between participants in terms of the types of dynamic interaction within themselves and with their context but diversity as to how this was lived out. These dynamics were mostly incorporated within the thematic codes such as use of routine, reactivity to change and the participant's relationships with family, friends and health care professionals. An example is the way in which participant B and F were both conscientious about maintaining a healthy lifestyle, however participant B demonstrated this by sticking to a strict routine of carbohydrate counting and a rigid eating routine, whereas participant F took a more varied approach including trialing different recipes and incorporating regular exercise into his life. Later stages of analysis aimed to identify common patterns among the many influences and interactions and how they link to health outcome.

Understanding Outcome
For the next stage of our planned analysis, we needed to define health outcome and have some assessment of its quality. Reviewing the data relating to outcome, we realised that people living with diabetes do not think in terms of outcome because they continue to live through time. An outcome for a clinical trial, for example, is part of ongoing life for a person living with diabetes. In order to proceed with our planned analysis the experienced clinician on the team (FG) assigned categories of poor, moderate and good control of diabetes to each participant based on her reading of the data.

The two participants who agreed to review interviews (both with type 1 diabetes) were asked about 'outcome': the question was phrased 'how you would describe how you are

in relation to your diabetes'. Participant B talked about keeping his blood sugar steady and steadiness in his social life - not putting himself in social situations where he may be a burden to others (if something went wrong with his diabetes). Participant D talked in terms of being aware of signs that his blood glucose may be too high or low (dry mouth, smell of ketones, signs of hypo and his blood sugar measures), that is noticing warning signs of an impending crisis, but otherwise doing everything he wanted to do. These participants seem to have a different approach to outcome with B seeming to avoid testing the boundaries of blood glucose variation and D seeming to test the boundaries. However, both saw outcome as something ongoing, part of the here and now of living with diabetes. Both also valued HbA1c as a measure of how well they were coping with their diabetes.

Understanding the dimension of time
The data clearly had 'time' and 'change over time' woven throughout. We looked closely at the data considering how to explore this dimension more fully, developing further questions for review interviews and the User group (see above). These respondents found it difficult to say much about time in response to direct questions, perhaps because it is ubiquitous. They recognised stages of diabetes, with diabetes time not necessary related to chronological time. For example, the User group talked about some people moving through the stages of 'deterioration', that is needing more medication/different delivery of insulin to control diabetes, quicker than others. Respondents acknowledged change with time and the importance of timely advice, support and interventions but found it difficult to give examples when asked directly. Timely advice has been identified as desirable in other studies.[36] These responses clarified for us the importance of maintaining an awareness of time throughout our research as it can easily be missed and is not easily conceptualised. It highlighted and the various natures of time including body time, in addition to our socially constructed chronological time. [37] Attempting to analyse the time dimension also highlighted for us the dynamic aspects of many of our thematic codes for example, use of routine, work, general health, blood glucose monitoring, use of health service, diet, medication.

Summary of thematic analysis
The interview data read as a set for each individual reveals a person developing and changing over time through many interactions. These dynamic aspects of living with diabetes could be identified through focusing on each participant in turn. Cross participant analysis identified themes already well explored in the literature. This thematic analysis identified time and change but it was difficult to explore these as themes because time and change are ubiquitous: they were relevant to most other themes. Outcome means little to those living with diabetes as they are living on through time.

Analysis stage 2: Development of participants' attributes
This stage of analysis contributed to research question 2 by developing categorical data for use in analysis stage 3. As this feasibility study included only a small number of participants the research team could compare and contrast the participants' accounts without difficulty. The participants clearly had very different ways of managing their diabetes and led very different lives. This analysis developed categories from the

interview data of attributes of the participants so they could be compared in a more standardised way. The attributes can be likened to scales used in survey research, and like many of these scales, the attributes were developed from the qualitative data. We used a constant comparative method [38] as it ensures inclusion of the whole range of diversity found in the sample within the attribute categories.

Analysis process
Researcher FG developed the attributes by reviewing the coded data theme by theme, extracting what the data seemed to say about the participants in relation to living with diabetes. She compared cases to assist in the development of the attributes and to simultaneously develop categories for each attribute. Some of the categories were hierachical such as good/poor but most were categories, indicating a difference between cases but without a 'value'. At the time of developing the attributes, complete data on participants A-E was available. Attributes were later assigned to Participant F by researcher UM.

To illustrate the process we describe the development of attributes related to control of diet. Diet was talked about a great deal in the interviews and from reading the data participants A-E were characterised as follows:

> A: does not have a sense of control over her diet, admits to confusion and giving in to sweet tooth, however does vary diet including eating out.

> B: has sense of control over diet through eating the same week to week; when he is eating out he appears confident about estimating what to eat for that time, but has stopped going on holiday where food is strange

> C: seems able to control her diet including where others suggest eating sweet foods but has restricted how often she eats where she is unsure of the food such as in a hotel.

> D: expresses confidence about his control of food although seems to have chosen to reduce the control now on an insulin pump; he aims to be able to do anything and go any where and eat anything.

> E expresses control of diet. It is not clear if she has curtailed her activities because of diet restriction but it is implied as she talks about eating punctually.

From the above summaries, an attribute was created: 'Participants sense of control over diet' with the categories 0=absent 1=present. The categories were assigned as follows: A=0, B-F=1. (The use of numbers to label the categories is for convenience of reading tables of comparison and does not indicate a numerical value)

This attribute is not very discriminatory for this sample, which includes mostly people confident about their diabetes. This may be due to the method of recruitment and intensity of the data collection. The attribute also does not capture all aspects of how

participants approached diet. A further attribute was developed to try and capture the use of routine by some and not others including the loss of activities that required flexibility such as holidays. The attribute was called: 'use of routine to control diet with the loss of other things requiring flexibility' with the categories 0=little, 1=moderate, 2=high. The categories were assigned as follows: A=1, B=2, C=1, D=0, E=1.

These two attributes seemed to capture the key aspects about diet that impacted on their diabetes as described by the participants and the categories captured the diversity of what the participants said in relation to diet. The validity of these attributes is ensured by the detailed and open approach to data collection from the participants, it was their story that was important.

The attributes developed and used in the next stage of analysis were those that seemed to impact on living with diabetes and diabetes control, based on the data. They were also found to be important in their own right rather than a surrogate marker for other attributes. Other attributes were developed then abandoned. For example, gender, age, numbers in household and marital status did not seem to be important in themselves although are likely to have influenced other attributes. Diabetes type was initially thought to be important because it implies time of life/length of time of having diabetes and type of treatment. Years of living with diabetes, was another possible attribute, important as people develop their coping strategies over time. However, reading the data led us to abandon these attributes. An elderly person with diabetes for 20 years may be very different from a 40 year old with diabetes for 20 years. Different people took different amounts of time to develop their ways of living with diabetes which seemed more influenced by other factors captured in attributes such as health literacy and family support than by length of time.

Number of people in household and marital status, although relevant, did not capture the diversity of experience relevant to diabetes for the participants. More important was whether there was significant engagement with family and what this was. We considered a number of aspects of family and support. There was variation in whether and how the participant acknowledged the support of their family. A didn't seem to acknowledge it and saw them as part of problem; B and D acknowledged it but very much as part of just getting on with life; C directly acknowledged it and felt positive about it. E didn't comment. When we compared accounts of diabetes from each participant with the account from their family member, we found some were very different. We considered categorising this as whether the family seemed more or less concerned about the participants' diabetes than the participant. We also looked at participants use of support groups and whether they talked to other people about their diabetes or learn about their diabetes through comparison with others. Having looked at these different aspects of family and social support we brought the focus back to the individual participant and considered what it was that they perceived that was particularly important in relation to their diabetes. From this we developed the attribute called 'sense of support' with the categories 0=sense of being alone, 1=some support but not enough, 2=sense of being supported.

Employment and educational status were considered as attributes but reading the data the influence of these was through other attributes. A major influence of employment on living with diabetes was the structure it placed on the day. The attribute 'use of routine to control diet with the loss of other things requiring flexibility' captured aspects of this. Participants doing voluntary work or in employment where there was routine, worked with the routine in managing their diabetes. Those in work requiring flexibility found ways of managing their diabetes within this framework, often requiring more management skill on their part.

Participants gained and used information about diabetes in many ways. Their ability to use information and the skills they employed to manage their diabetes did not directly relate to their educational status, defined as highest formal qualification achieved. However, from reading the data we developed related attributes that seemed to influence their diabetes. There was data about the participants approach to managing their own diabetes. Participant A seemed to have no system for managing or did not make it apparent. B used routine but noted and dealt with out of routine issues such as unexpected blood glucose results, in a way that got him back into routine. C slowly accumulated and processed information and experience that she used to manage her diabetes. She was also relatively slow in taking actions such as reporting side effects of treatment to her doctor. D used a flexible approach rapidly responding to signs (such as bodily symptoms or blood glucose measurements) and to information (such as about new devices). For E, it wasn't clear from the data. Both B and D needed to respond quickly to bodily symptoms/blood glucose data as they were on insulin. However, they approached new information very differently. We re-examined the attribute and the data and developed a different attribute that captured aspects of management skills (and did not overlap with 'use of routine to control diet with the loss of other things requiring flexibility'and related to the use of information. A seemed to use information erratically; B used it very selectively, using that which fitted with his approach, so tended to be conservative; C and E used information consistently, taking time to consider it and were slow to change in response to information; D used information, trying things out, experimenting. The attribute was called 'style of use of information (about diabetes in general and about themselves such as test results) with the categories: 0=erratic; 1=conservative; 2=consistent; 3=experimental.

All except A expressed a great deal of knowledge of diabetes and an ability to use it, as would be expected from this sample. This was important for them in living with diabetes. The attribute 'knowledge of diabetes' was given the values 0=poor 1=good for this sample.

In relation to medication there was a difference in the participants' confidence and contentment with their medication and they linked this with the health professional who advised them. The attribute reflecting this was called 'confidence and contentment in their medication and in how they and their doctor deals with the medication' with the categories 0=uneasy; 1=moderately confident and content;

2=confident and content. This attribute exemplifies how the attribute is an emergent property of the relationship, not reflecting details about the components of the relationship i.e. the medication, the health professional and the participant

For all the participants, health professionals played some role in relation to their diabetes. 'Relationship with health professional' was categorised as: 0= unengaged; 1=faith with doubt; 2=partnership. Again these were emergent properties. The attribute was not dependent on the role of the health professional(s), for example the key health professional for participants was often their GP but could be a nurse or a combination of GP/nurse. The interviews did not indicate that these different ways of relating were valued differently by the participants. The attribute is a description of how things were from their perspective. The attributes used in stage 3 of analysis are summarised in table 3 (below).

Asking participants about their own attributes
For the review interviews, a brief questionnaire was developed based on the attributes. The questions explained the attribute in terms of our analysis of the study data and then asked the participants to identify which category of each attribute they considered applied to themselves. Only two participants filled in this questionnaire. Each agreed with our assessment of their attribute categories in all but one attribute, 'style of use of information'. This feedback is very limited.

Summary of development of participants' attributes
Through constant comparison of the qualitative data it was possible to develop attributes that, from the data, seemed important for diabetes outcome. Attributes commonly used in research such as 'age', 'gender' 'educational attainment' were not in themselves directly important for diabetes but had their influence through other attributes. The attributes developed in this study were based on what the participants told us and were inclusive of their diversity. The attributes were about how participants related to other people or their environment and captured emergent properties rather than the detail.

Analysis stage 3: Comparing participants in terms of their attributes and outcome
This stage of analysis contributes to research question 2, by examining the attributes of participants and their outcomes to identify the diversity of pathways to similar health outcomes. It begins to indicate the type of tailoring of interventions that may be relevant for participants. Tables 3 and 4 below summarises the participants' attributes and health outcome.

Table 3 Attribute categories

	Attribute categories (as used in table 4)			
Attributes (all are in relation to diabetes)	0	1	2	3
1: sense of control over diet	Absent	Present		
2: knowledge of diabetes	Poor	Good		
3: type of relationship with	Unengaged	Faith with	Partnership	

health professional		doubt		
4: confidence and contentment medication/health professional/individual	Uneasy	Moderately confident and content	Confident and content	
5: use of routine to control diet with loss other things requiring flexibility	Little	Moderate	High	
6: sense of support	Sense of being alone	Some support but not enough	Sense of being supported	
7: style of use of information	Erratic	Conservative	Consistent	Experimental

Table 4 Summary of participants' attributes

id	1	2	3	4	5	6	7	O
A	0	0	0	0	1	0	0	P
B	1	1	1	1	2	0	1	G
C	1	1	1	1	1	1	2	G
D	1	1	2	2	0	2	3	M
E	1	1	2	2	1	2	2	M
F	1	1	2	2	2	2	0	G

id: participant A-F
O: outcome Poor; Moderate; Good

All the participants have a different combination of attribute categories. Given the small numbers of participants this is not surprising. Although the number of potential combinations of attributes is very large, the attributes do not seen, from the qualitative data, to be independent of each other so it may not need a very much larger sample to start finding people with the same pattern of attributes.

With only our six participants there are some interesting commonalities and contrasts. The contrasts may indicate where intervention might improve outcome. For example, participants D and E both have moderate outcome but for attributes 1,2,3,4 and 6 they have the same attribute categories as F (good outcome). If D and E were to increase their use of routine with loss of flexibility and were to become more conservative in the way they use information they may be able to improve their outcome. B and C also have good outcome but D and E are not very much like B and C so it would seem trying to change their attributes towards those of B and C is less likely to work. B and C have found a very different way of achieving a good outcome to F. The attributes represent the dynamic and relational nature of living with diabetes so changing one attribute may have an effect on other attributes and on other areas of life.

Table 4 (above) gives some indication that individuals may gain the same health outcome but by different means. With enough data from enough individuals we may find a number

of different patterns of attribute characteristics for the same outcome. This could inform clinical practice through providing typologies of clinical cases. A similar approach has been explored in a number of health related research areas. For example, various classification methods have been used for non-specific low back pain in an attempt to define classes of low back pain sufferers [39] for use in the evaluation of interventions. In the field of psychotherapy, a data base of 'pragmatic case studies' was proposed, which once large enough, could allow comparison of cases and so a development of typologies of patient characteristics in relation to outcome. [40] A major issue for such studies is deciding what data should be recorded. There is no doubt that if we were to include enough attributes about individuals, then we would find that all individuals were different from all other individuals. In this study we aimed to be open to what the individual participants living with diabetes said was important. During our analysis we found that some attributes commonly used in research, such as demographic data, may have little direct relevance to how an individual manages their diabetes. This study has examined the participants' attributes in a person centred way [25] with comparison made between individuals as a whole rather than comparison of variables. With the use of carefully developed survey tools relevant to the health condition (for example [41-43]), data could be collected from large numbers of people for person centred analysis methods such as cluster analysis and this could be related to outcome. Further research would be needed to demonstrate any benefit of this person centred approach to multivariate statistical analysis over the more commonly used variable directed methods.

Each of the attributes described above includes interaction or relationship that is not static but ongoing. Outcome is also an ongoing concept for individuals living with diabetes. In comparing the attributes of participants in the above table this dynamic becomes lost from view yet was very clearly present during the qualitative analysis.

Summary of Comparing participants in terms of their attributes and outcome
Through the comparison of participants it was possible to demonstrate, within the limitations of the data available, that different people can attain a similar health outcome in very different ways. There are hints that comparison of participants could be useful in indicating the type of tailoring of interventions needed to improve health outcome. However, in undertaking the comparison the dynamic, relational nature of the attributes is lost from view. Although person centred analysis may be useful in characterising individuals for tailoring health interventions, the loss of inclusion of the dynamics in this approach is a concern.

Analysis stage 4: The dynamics of living with diabetes
Our realisation that the analysis above lost sight of the dynamic, relational nature of the attributes, led us to re-examine the participants and their attributes for their dynamics. Time, change, interaction and relationships had all been important issues considered throughout the earlier stages of analysis and the team had formed impressions of how the individual participants functioned. Other qualitative research has explored themes including the passing of time, monitoring and observing their own bodies and interaction with others, as important aspects of learning to live with diabetes. [9] This formed the background for this final and tentative analysis.

FG re-examined the results table above specifically looking for differences in how the participants seemed to function in terms of time, change and interaction, what we have termed, their dynamic. This was then reviewed by the research team and adjusted. One concept that emerged as relevant to most of the particpants was 'testing of possibilities'. This can include behaviour such as strategic non-compliance with medication and observing the effects on themselves and questioning the recommendations of health care professionals. [9] [18]

In summary terms the participants were described as follows in terms of their dynamics of living with diabetes:

A: chaotic - almost no steadying effects except some use of routine
B: entirely stable with almost no testing of possibilities that could potentially reduce stability
C: stability with some uncertainty that may be interpreted as a critical testing of possibilities and so some potential for instability
D: mostly stable but with ongoing testing of possibilities occasionally leading to temporary instability
E: stability with little testing of possibilities
F: stability except for erratic use of information sometimes leading to instability

These summaries took account of our reading of the qualitative data as well as the attributes. As a feasibility study the intention is to explore approaches to analysis and suggest future directions. We are not claiming a substantive result. However, the study does hint at differences in individual's dynamics and that the dynamics may be characterised as a property of the individual. The assessment of each participant in terms of dynamics may not be improved by adding other details about them including the type of diabetes. Neither is it clear that the dynamic is a response to the type of diabetes by the participant. Individuals may interact and change differently at different stages of having diabetes, as hinted by Campbell et al (2003). The understanding of interaction of the biological, behavioural and social aspects of complex living organisms arising from complexity sciences (e.g. [44] [45]) would suggest avoiding any assumption about what is prior, that is assuming there is a determinant of the dynamic. There may be no 'prior' but constant interaction and co-evolution between the biological mechanisms, behaviours and relationships and the wider social context including health care organisations.

Conclusion
This study set out to explore research methodology because of a concern that despite the growing body of evidence about how to improve health outcome for those living with diabetes, this was proving difficult to achieve. The study took a person-centred approach in contrast to the variable led approach of much clinical evidence, and started with individual people living with diabetes ascertaining what they thought was important through qualitative data collection. This paper has charted much of the research journey, although some of the unproductive avenues explored have not been included due to lack of space. The paper includes reference to key literature on related issues but cannot

include all the literature and discussions influencing the thinking of the research team during the project and its write up. We set out with the idea that current approaches to research were missing something and this may be detrimental to the health care effort to improve patient outcome for people living with diabetes. Our exploration hints at the importance of understanding how individuals are functioning in terms of their dynamics, that is how people interact with their context, their social networks and their own bodies, and how this changes over time. People change at different rates, perhaps at different stages of having diabetes. They may be more or less stable or in control, avoid or seek experiences at the boundaries of safety or good control of their diabetes, and cope differently with uncertainty. More research is needed to demonstrate whether dynamics is an emergent character of individuals that can be usefully identified to inform clinical management decisions.

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[i] The lead author holds a UK Department of Health Career Scientist Award on Complexity and Healthcare