'With age comes wisdom almost always too late': older adults' experiences of T2DM

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Abstract

Background: This article describes the results of qualitative work aiming to highlight and understand the experiences of older adults who have lived with type 2 diabetes (T2DM) for approximately 20 years.
Methods: Twenty-eight participants (mean age, 70 years) were interviewed using a triangulated research design of in-depth, semistructured interviews, two quantitative questionnaires and the main findings from theoretical frameworks on chronic illness literature. One of the questions that the study sought to address was the advice that participants would give to a person newly diagnosed with T2DM, thereby determining self-reported priorities in the illness trajectory. The research analysis was grounded within an interpretative paradigm with emphasis on a life course approach.
Results: Several themes emerged; denial and acceptance were inherent in these older adults' experiences of being diagnosed with diabetes, as was the need to fight the illness rather than let it take control of their lives. The need to prepare people for the degenerative nature of diabetes and therefore the need to commence insulin was also apparent within the sample.
Conclusion: These findings indicate the diabetes journey that individuals may experience from diagnosis, acceptance and changes to self-identity. Currently, older adults with T2DM and their experiences of the illness trajectory are a little-used resource. Their 'pearls of wisdom' – sometimes recognised too late to assist themselves – may inform others with T2DM and perhaps alleviate the psychological disturbance that many feel at diagnosis and later on at the commencement of insulin.

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Key words
Type 2 diabetes; diabetes biography; older adults; acceptance and denial

Introduction

In most parts of the world, especially Europe, people are living longer[1] thanks to improved living standards and great progress being made in the medical field. Infectious diseases that previously killed many people at a young age (such as cholera and diphtheria) are now treatable and largely preventable. Although longevity is considered a positive development, one of its side-effects is that people who might have otherwise died of infections now live longer but suffer with more chronic degenerative diseases such as diabetes.[2]

Although type 2 diabetes (T2DM) now occurs in children and young people,[3] it remains primarily a disease of ageing.[4] For example, in the UK, 2.1 million people have T2DM with 66% of those affected being over 60 years of age.[5] Similar patterns of incidence are seen throughout Europe.[6] From this viewpoint, T2DM can be regarded as an age-related condition which is set to become one of the most consequential epidemics of the 21st century.[7]

Life expectancy is reduced for people with T2DM,[8,9] but improved treatments have enabled more people with T2DM to live longer, albeit with more diabetes-associated complications.[10] Such people are likely to have witnessed changes in the way that healthcare is provided, in knowledge and received wisdom about what diabetes is and how it should be controlled, and also in the way that patients are expected to manage the condition. Their knowledge about, and attitudes to, the illness are thus likely to have been enriched or hindered by some or all of the above.

Evidence suggests that older people form a significant part of the global T2DM population.[11] However, they tend to be excluded from health research, including diabetes-related studies.[4,12] Methodological reasons, including the presence of comorbidities that might confound findings, may be blamed for causing clinical trial exclusions.

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In general, however, while the ageing paradigm has always been of some interest to social scientists, it has always been more of a sideline than a major focus of research.[13] Biomedical influences that perceive ageing as a period of natural decline may also be partially responsible for older adults being excluded from studies.[14] The net result of this exclusion is that older patients' views and the effects that diabetes has had on their lives are under-researched and under-reported.

We reasoned that older people are a particularly useful group of diabetes patients to study. The reasons for this are multiple: first, they make up the largest population group affected by diabetes and one which is likely to grow even larger;[15] secondly, they hold vital information about how to manage diabetes (successfully or otherwise); thirdly, given their lack of representation in research (noted above), a complete diabetes biography from diagnosis to old age is incomplete. Furthermore, although diabetes research has traditionally adopted a quantitative approach, the role of qualitative methods has increasingly been recognised in understanding the psychosocial aspect of many chronic conditions.[16] Such research has also been found to be instrumental in influencing policy and local guidelines.[17]

Here, we report findings from a qualitative study that aims to understand older adults' experiences of being diagnosed with diabetes over 20 years ago. In particular, we sought to discover the most significant advice participants would give to people newly diagnosed with diabetes, to determine priorities for living with diabetes from the lay perspective.

Methods

Study participants

Participants were recruited from the East End of London, by inspection of electronic medical records, and provided written informed consent. Ethics approval was obtained from the City and East London Ethics Committee and Roehampton University, and full indemnity from the Research and Development office of Barts and the London NHS Trust.

All patients >60 years of age with a registered diabetes diagnosis of >20 years, who could understand written and spoken English, were invited to participate. Invitations were conducted by ethically approved letters and patient information leaflets. The voluntary nature of the study was emphasised both in the letter and at subsequent interviews; other family members and carers were also invited to participate if appropriate.

Study design

The study used a mainly qualitative triangulated design involving in-depth, semistructured interviews, two quantitative questionnaires and theoretical frameworks of chronic illness (predominantly, chronic illness as a biographical disruption).[18]

Data collection

Participants were interviewed on two separate occasions by a female researcher with many years experience of diabetes nursing (GH). The purpose of the dual interview method was to provide an environment conducive to rapport and achieve private rather than public accounts.[19]

Using a life-course approach to the interviews meant that participants were often asked to reminisce about their lives with diabetes. The question which is the subject of this paper allowed participants to articulate their own priorities on living with this disease.

Interviews took place in participants' homes over an eight-month period between December 2005 and July 2006. All interviews were digitally recorded, transcribed and coded using NVivo 7®.

Data analysis

Data were then thematically analysed by repeatedly reading the transcripts for current themes (which were then divided into sub-themes), and by using past-appropriate theoretical frameworks on chronic illness.[18]

Results

Of the 121 people who were sent letters of invitation, 31 expressed an interest in participation. One participant died before being interviewed and two others were found to have dementia and were later excluded, giving a total of 28 participants. The low response rate (26%) is found to be common with other studies in health research which cite barriers of age and social deprivation.

The majority (n=19, 68%) of the sample were male with a mean age of 70 years. All participants were of white British working class background, residing primarily in council housing, and were registered with a local hospital-based diabetes centre, although some were being managed by their general practitioners. With regard to diabetes treatment, five participants were tablet-controlled (although the commencement of insulin for one man was imminent and two of the five patients had used insulin but had reverted back to tablets after considerable weight loss). The remaining 23 respondents were on insulin.

Nearly everyone in the sample reported complications allied to having diabetes, with impaired eyesight being the most common cited (n=21, 75%). At least 11 subjects reported having had major heart surgery or attacks and were constrained in their mobility to some degree. Three subjects were severely disabled and virtually housebound.

Several themes were identified in response to the questions, including *denial, acceptance* of the condition, *shock* of insulin initiation*, moderation* and *fight.* These themes emerged through repeated reading of the transcripts for actual responses to the question, which were then categorised through similar use of phrasing and by narrative interpretation. The themes are illustrated using direct quotes from the transcripts. For the purpose of presentation and confidentiality, patients are identified in terms of gender, age and subject number.

Nearly all of those who responded to the question 'What advice would you give to a newly diagnosed person?' needed to convey largely psychological advice and some practical information:

'If only I had the depth of thought now to think, to plan. With age comes wisdom, almost always too late it comes along doesn't it?' (Mr 15, aged 65 years)

When reminiscing, many could understand that in the early days after diagnosis they had been in *denial*, either through lack of knowledge or *acceptance* of the diagnosis:

'And I think you are in a kind of sense of denial but yes you are told to alter your diet, change your lifestyle, most of which you don't do and then a few years down the line, something generally happens like you know, you notice some physical symptom, the feet, pins and needles and then someone says, carry on the way you are and you will lose a limb or your circulation will cause this, that or the other and so eventually something happens that you actually do start taking it much more seriously.' (Mr 11, aged 60 years)

Some participants could describe denial as being related to the lack of symptoms at diagnosis or the personal perception of diabetes as not being as serious as other conditions:

'It [the diagnosis] was a relief to me actually because my sister had just died very young and I thought you know she had cancer.' (Mr 08, aged 63 years)

Others equated the lack of symptoms and the fact that the condition was treated by tablets as a sign that diabetes was only a mild disorder:

'At that time I think I saw a dietitian and went home with tablets. I wasn't very impressed by it all; they didn't seem to do anything to me. More or less, do your blood sugar, just get on with it. Nothing was happening really, you're not really a diabetic. Just a couple of pills, what's the good of that? Real diabetics have more than that. You can't be a real diabetic.' (Mrs 07, aged 71 years)

One respondent also recalled that this attitude of denial towards diabetes may have been due to the fact that the disease was largely 'invisible' and people did not respond to what they could not see:

'Not like, you take a part of your body out that's sick, you know, on an operation and after the operation OK. You can't take diabetes out. You can only see diabetes in your blood. You cannot see it visually inside the human body. You can't see it visually, it's invisible, you can't see it. Unfortunately, for everyone, what we can't see…we ignore. It's not ignorance, we just ignore it, because we can't see it.' (Mr 07, aged 67 years)

Some respondents looking back to the time of their diagnosis could see clearly how they had not accepted the severity of the condition, sometimes at a cost to their own health. The message to others was not to be in denial, not to ignore diabetes, but to take the condition seriously, usually because they had not done so themselves. Respondents seemed to have realised over time that diabetes was a degenerative condition that caused complications, and they may have managed the condition differently if they had been armed with this information earlier:

'If I'd have known, I would probably have looked after myself.' (Mr 06, aged 71 years)

The degenerative nature of the condition also meant that insulin initiation was therefore inevitable. The second aspect of advice for the newly diagnosed was to begin to accept not only the diagnosis of diabetes, with all that it might entail, but to also accept the need later for insulin therapy, because this had come as a *shock* to most people in the sample. Participants were sometimes angry that such inevitability was not fully explained to them much earlier in the illness trajectory, and they wished newly diagnosed people to know the degenerative nature of the condition:

'I was under the impression that once you take the tablets, like everybody else, it's a thing that's never explained to people, diabetes. You think, right you take the tablets, basically you can eat what you want but it's not so and they should tell you. I think they should make more of it and tell people the more you eat, the more you do wrong, the more treatment you are going to need….Everybody I speak to, like friends of mine, it's never been explained to them.' (Mr 08, aged 63 years)

Commencement of insulin was related as a major shock to most in the sample. Many had very vivid memories of being put on insulin:

'Taking tablets, there's nothing memorable in that but the next thing after that was '88 when I stood on this very spot here and the practice nurse tried to get me to stick this needle into me leg. I resisted, standing there, trousers round me ankles…She's kneeling there with a syringe, it was a syringe then...and I'm

holding the syringe and she's pushing my hand to try and get me to stick it in. I'm resisting her; I stuck it out for 20 minutes before it did go in.' (Mr 01, aged 65 years)

For many, the shock of insulin initiation also aroused feelings that others with diabetes would judge them as being a 'bad diabetic', almost as if there was a competitive component to managing the condition:

'Oh yes. Some people feel very proud of themselves that not having gone on the insulin because they were clever and took their tablets.' (Mrs 07, aged 71 years)

For most, insulin commencement was seen as a personal failure and major disruption in their lives:

'I thought, "Oh God what have I done wrong?"' (Mrs 09, aged 64 years)

In looking back, this disruption was due to the more outward display of the condition with a much more public focus on the physical body. People had to think about injections, plan visits and mealtimes, and test their blood glucose, all of which led to a change in self-identity or even a 'spoilt' identity[20] where more questions were asked:

'They think that you may be over-complicating it, you know they poo poo the idea sort of thing…because if you are going for a meal or something like that I say hang on a minute I'll have my jab and come along with you and they are all itching to go and saying "what you hanging back for?" So I think that they need teaching in so much as you just can't do things at the drop of a hat and I think because of the way, the lifestyle that we live in everyone wants to do things then but you need to sort of have 5 mins to prepare yourself.' (Mr 18, aged 61 years)

Therefore, advice to the newly diagnosed was to know that, usually, insulin was inevitable and that preparing oneself psychologically and practically for the time when insulin would be needed was something most people would need to do.

The advice given by the sample did not only discuss the negative aspects of living with diabetes but also demonstrated a great deal of confidence. When this confidence is achieved, usually over time, people become experts of their own condition and can decide for themselves what advice they will accept from healthcare professionals, family and others in society.

In particular, participants suggested that people newly diagnosed with diabetes should ignore the mainly negative advice that healthcare professionals give their patients and instead should live life in *moderation*:

'I think that's what makes a person uptight when they've got to keep on reading this and reading that and you can't have this and you can't have that. It's best to push that to one side and have a little of this and a little [sic], don't go mad, like you used to, because you liked a lot of fatty stuff. Just forget about that. You are still going to live; you are not going to die.' (Mr 12, aged 70 years)

Implicit in the advice was the understanding that people have to have confidence in the choices they make:

'I'm trying to pass on my experiences. A little bit of what you fancy. Don't stop ice cream, don't stop biscuits, don't stop eating.' (Mr 06, aged 71 years)

People were also able to look back over time and realise that they know their own body and their diabetes better than anybody else:

'And I think to myself now, even now from this, like when I was diagnosed, there's a lot of things you can do and I feel, my opinion is, I feel, that you know what your body can take.' (Mrs 02, aged 80 years)

This confidence also derived from a positive attitude towards diabetes:

'I try to look in a very positive way and I look upon this as possibly a life saver because if I hadn't contracted diabetes, I would probably now weigh 15 stones and I would have probably have had a heart attack, I've never had a heart attack. So you have to be positive and you say this is a tap on the shoulder and because of it I look after myself far more carefully than I used to.' (Mr 03, aged 76 years)

In most cases people also conveyed the need to continually *fight* the disease as a coping mechanism – and not to give up this fight:

'I think also, what doesn't help a person with diabetes is they give up. They let the diabetes rule them.' (Mr 07, aged 67 years)

Advice to the newly diagnosed was to carry on fighting the disease and to maintain control, rather than diabetes controlling the person:

'You become a slave to it. I know I still am a slave to it but not to that extent and if I can get off it altogether again I will. I will go down fighting – I will!' (Mr 15, aged 65 years)

Discussion

The intention of this study was to explore a sequence of events from diagnosis to 20 years on, so that important aspects of the diabetes biography for older adults could be articulated. To present as unbiased an account as possible, we invited everyone on the register who matched the criteria to participate. The low response rate of 26% was disappointing but consistent with other postal invitations to at-risk groups in areas of social deprivation,[21] and within the constraints of observing local research governance and data protection.[22] Consistent findings from the sample about their advice for newly diagnosed others has indicated many similar facets and realities, although any firm assertions or cause-and-effect relationship from such a small sample cannot be claimed.[23]

Acceptance and denial of diabetes from the point of diagnosis and beyond was found to be a poignant emotion for many in this sample. Attitudes towards diagnosis of a chronic condition have been previously found to be a significant event that governs attitudes towards the illness trajectory.[24,25] Of the numerous studies on chronic illness diagnosis[18,26,27] and diabetes,[28,29] most report the shock and upset that people feel when first told of their condition.

However, in our study the majority reported little reaction or shock to the diagnosis. This may be directly related to why acceptance was viewed as important by this sample. The significance attached to acceptance of the condition may reflect the attitude that most people had towards diabetes at the time, nearly 20 years ago, when public and scientific knowledge concerning diabetes complications was much more limited compared with knowledge today. Therefore, a T2DM diagnosis was not considered to be very serious. Many participants talked of other stressful life events which may have taken precedence, and some appear to have attributed diabetes symptoms (such as lethargy and frequent urination) to normal ageing. Lack of symptoms and general invisibility of the condition[30] may have meant that some of the study participants never really accepted their diabetes.

Certainly, participants voiced the importance of accepting the seriousness of diabetes. In this context, insulin therapy is a likely future consequence and the shock and psychological suffering for people when this happens could be largely avoided with better understanding. For the sample, the commencement of insulin was seen to be a critical situation[31] for several reasons that have been well researched; namely, a dislike of needles and the physical act of injecting,[32] a curtailment of social interactions[33] and the stigma surrounding hypodermics and drug users.[20] However, this sample indicated different emotions as a result of commencing insulin therapy, such as the feeling of being a failure or a 'bad diabetic' and the thought that their condition had entered a more serious phase.

Oral treatment for diabetes may have implied that the diabetic body had been somewhat repaired and restored to former health.[34] Such health restoration would confirm that people were not victims of diabetes because they were actively living and controlling the condition by tablets, and therefore the situation was not serious. Insulin therapy may change this because it reinforces the notion of a body which is out of control and alien to self-identity.[35] This body then became a threat to former concepts of self and ways of living.[36] Employment, social and family situations were threatened and there were feelings of failure, guilt and disappointment in not being able to control diabetes or the physical body.

Most people with chronic ill health may have disruptive events in the illness trajectory that threaten self-identity.[37] It is proposed that insulin initiation in most of our participants posed a threat to a former self-identity, which may be why so many talk of the fight to gain control. The fight is not only to control the diseased body but also to control the changing identity; consequently, greater importance may be attached to the need for acceptance.

Despite this, most adults in the sample – even those with comorbidities – had a positive outlook for the future and were confident to continue their lives with this chronic condition. Many participants articulated their attitude towards the future in terms of a quest narrative.[35] Rather than striving towards a return to former health, these narratives articulated the experience of living with diabetes, the acceptance of illness and ways of living successfully with it.

It was this message of achievement that many in the sample wished to pass on to newly diagnosed others. However, those who were less positive about their diabetes were more likely to look towards the future as unknown and describe their lives as being in a perpetual moral dilemma.[38]

These findings have important implications for healthcare professionals who manage newly diagnosed patients and those further into the illness trajectory. Healthcare professionals, especially diabetes nurses, need to be aware that patients may vary in accepting the diagnosis. Although a diabetes diagnosis was not shocking for most people in the present sample, commencing insulin therapy appeared to be a traumatic time in their diabetes biography. We speculate that the reason for this shock is that most people with T2DM are still totally unprepared for this inevitability.

Currently, older adults with T2DM are a little-used resource. It is possible that self-help groups mentored by experienced diabetes patients may assist in what appears to be a struggle of acceptance and denial of diabetes: the changes of self-identity which people experience on commencement of insulin and beyond to a period of confidence in themselves and their bodies. People unable to go through this transition may suffer further in terms of psychological problems and distress. Perhaps, rather than reinventing the wheel in terms of designing new educational programmes for the newly diagnosed, we need to look back at those older people and unlock this potential wisdom.

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Conflict of interest statement:

None

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