

## **Learning to live with chronic illness in later life: Empowering myself**

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*Type 2 Diabetes is both an incurable illness and a hidden disability that has reached epidemic proportions on a global scale. It has obviously spawned a huge clinical literature, but no scholarly accounts of learning to live with the illness on a daily basis from a feminist perspective. As an older woman, I have made use of a somewhat controversial autoethnographical approach to explore how far I consider myself empowered to live with, and manage this condition for the rest of my life. Self-management is an idea that is central to both the United Kingdom (UK) National Health Service (NHS) philosophy of supporting patient choice and within a feminist perspective on health care. Learning to identify, access and use the necessary resources to manage my condition suggests that there are regional differences within the UK as to how much practical care diabetes patients are offered or can access. The paternalistic nature of the health care team/patient relationship appears to militate against the concept of patient empowerment.*

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## **Introduction**

As awareness of ageing populations grows across the world, enjoying a sense of physical and mental well-being by remaining active in society and retaining independence for as long as possible have come to be seen as desirable aims. Adult educators have been especially persuasive in emphasising the importance of continuing to learn throughout life as an essential ingredient of healthy ageing. Indeed, there is growing international evidence that learning in later life offers a whole range of benefits not only to individual learners as they age but also to their families, their communities and to the societies in which they live. Yet we know that for many people, the later years can bring varying degrees of ill health and the chances of growing older in good health vary greatly between countries. From a European perspective, it is fortunate that most people can generally still expect a good standard of health care in later life. Nevertheless, poor health in later life can be compounded by isolation or increasing poverty as well as by inequalities in accessing good quality health care.

What is surprising is that those involved in researching or facilitating later life learning rarely contemplate their own ageing or consider what it might mean to be forced to live with an illness or disability as they grow older. Yet as people approach their later years, some degree of change in well-being is inevitable. Understanding the nature of such changes is important in helping to cope with the challenges of daily life and with maintaining an acceptable lifestyle with age as well as enabling researchers to gain an insight into the lives of some of the older people with whom they work. As an older woman living in the United Kingdom (UK) who was diagnosed with Type 2 diabetes ten years ago, my aim in this paper is to explore and reflect upon my own experience of learning to live with this incurable illness over a decade using an autoethnographical approach. Have I empowered myself to live with this condition for the rest of my life and could my personal experience be meaningful for others? In this context, I understand empowerment as the ability to identify, access and make use of the resources necessary to take control of my illness, an idea that is central both to the UK's National Health Service (NHS) philosophy of supporting patient choice and within a feminist perspective on health care. My first aim is to offer a new and potentially valuable empirical resource since there are no scholarly accounts of learning to live with Type 2 diabetes from the perspective of

an older woman. A second aim is to question whether the health care that older women with Type 2 diabetes currently receive is appropriate; and thirdly, to consider the possibility of making changes that might make a difference to the lives of older women who are grappling daily with the practicalities of this stressful illness and their families.

### ***What is Type 2 diabetes?***

Type 2 diabetes is both a chronic illness and a hidden disability. It differs from Type 1, an autoimmune disease which is the result of the pancreas being unable to produce sufficient insulin, a hormone that regulates blood sugar (glucose) levels. In Type 2, some insulin is produced but the body is unable to use it effectively. Type 2 accounts for the majority of people with diabetes and usually affects people over the age of 40. Over a long period, since high blood sugar levels can damage tissues and organs of the body it is necessary to keep these levels under very tight control to prevent serious complications. Dealing daily with an incurable condition can also lead to depression and there is emerging evidence that diabetes is a risk factor for dementia (Strachan, Reynolds, Marioni & Price, 2011) as well as increasing the risk of premature death. The World Health Organisation (WHO) points to the economic impact diabetes can have, not only on the individual, but also on families and on health care systems through increased medical costs (World Health Organisation, 2016). It is also thought that one in two adults with Type 2 across the world are undiagnosed (International Diabetes Federation, 2015).

In the UK, there are an estimated 4.5 million people living with diabetes (around 25 per cent of these are probably undiagnosed) and 90 per cent of these have Type 2. Audits suggest that around 56 per cent of all adults with diabetes in the UK are men and 44 per cent are women. In England and Wales, the highest prevalence is seen in the 70-79-year age group (Diabetes UK, 2016). In Australia, diabetes is the greatest challenge facing the health system with around 1.7 million people affected overall; Type 2 is estimated to affect 85 per cent of these and numbers are growing (Diabetes Australia, 2015).

Increasing age, being overweight with an enlarged waist circumference, lack of exercise, having high blood pressure and a family history of diabetes are well-known risk factors and diabetes is more prevalent in people in certain ethnic groups. Although fewer women than men are affected by Type 2 diabetes, they are subject to some additional

risk factors and there are some differences in the way they experience the illness. There is also some evidence that complications are worse for women than for men due to a combination of factors but with differences in physiology likely to be involved (Gebel, 2011). I have therefore chosen here to focus particularly on women coping with Type 2 diabetes although I acknowledge that some of the issues I raise may be also applicable to men.

### **Methodology**

Although still subject to some criticism, the use of autoethnography as a legitimate and useful form of qualitative inquiry has grown considerably in recent years spawning a considerable literature. It is an approach to research that systematically describes and analyses personal experience in order to connect that experience to the broader social, cultural and perhaps political context (Ettorre, 2016). There are diverse forms of autoethnography, one of which is writing a personal narrative (Ellis, Adams & Bouchner, 2011). In the context of illness, this can offer a therapeutic experience for the author even if it sometimes requires uncomfortable personal disclosure. It can also be a tacit invitation to the reader to enter the writer's world, to try to connect with his/her experiences and feelings (Méndez, 2013) and to reflect on the wider significance for their own lives. However, Chang (2016) is especially critical of descriptive illness self-narratives unless they also critically address wider issues as I will do here.

Another point that arises in writing an autoethnography is what Ellis (2007) calls relational ethics whereby researchers should critically reflect on their ethical responsibilities towards those who are involved in, or implicated in their research. In reflecting on my learning journey, I have not directly involved anyone who could be identified although I mention others with whom I have been in contact at some point or whose roles impinged upon and influenced my experiences in some way. Because it has not been possible to obtain informed consent or to check out my perceptions, I have ensured that no-one would have cause to be upset or angered by my interpretation of events even where I have been critical of some episodes in my journey.

Shortly after diagnosis, I kept a diary for a short time, recording symptoms, my reactions to treatment and my feelings as I adjusted to

a new identity as a diabetic. I have also re-examined my various test results over a ten-year period. I have participated in three very different but relevant educational courses concerned with chronic illness as well as two more informal local day events and recorded my observations and reactions to these learning experiences at the time. In addition, I have tried to keep myself informed through a considerable amount of reading around the subject, partly on-line but also through membership of the leading diabetes charity, Diabetes UK. Recently, I joined a local support group, which consists of people of all ages with both types of diabetes. Finally, I reflect critically on my experiences in relation to the care that older women with diabetes can expect in the UK.

## **A learning journey**

### ***Reactions to diagnosis***

My story begins from the point when I received the diagnosis of Type 2 diabetes following an oral glucose tolerance test carried out by a doctor. My immediate reaction was a mixture of shock and a degree of relief that there was a genuine explanation for why I had been feeling vaguely unwell for several months. Yet inwardly, I was not altogether surprised since both my parents had been diabetic in later life. I therefore assumed there must be a strong genetic factor in my diagnosis but there was also a lingering sense of guilt that perhaps I had brought this on myself through an unsuitable diet and lack of exercise.

In the UK, all health care is free at the point of delivery in accordance with the principles of the NHS and people over 60 years of age are entitled to free prescriptions and medication. I was immediately prescribed an oral diabetes medicine that is used to help control blood sugar levels and additional medication to lower cholesterol and to treat high blood pressure. The only advice I was given at that point was to eat a balanced diet, to see an optician and to return in three months for a blood test. Later conversations with other women with diabetes confirmed that information at the point of diagnosis is often sparse, there is little opportunity to ask questions and the chances of referral to a dietician vary considerably according to location. At the time, I worked in a Medical School where some clinical colleagues had long-standing research interests in aspects of diabetes so I was fortunate in being able to ask informally for advice and to receive comforting reassurance.

Despite this support, the early months were a period of very difficult adjustment to my new identity as a diabetic. Apart from the need to remember to take medication several times a day, the emotions I experienced were akin to the stages of bereavement identified by Kübler-Ross (1970) as I came to terms with the loss of a previously healthy body. Shock gave way to denial. It surely must have been a misdiagnosis and I would shortly be told that it was all a mistake, apparently a very common reaction (Becker, 2015). Inwardly though, I knew it to be true and I found myself almost paralysed with fear as I read more about the dire consequences of failing to eat a healthy diet, exercising regularly and adhering to prescribed medicine as well as the possibility of premature death. This fear rapidly morphed into anger that this affliction had been visited on me. I felt resentful and cheated, a reaction I have since learnt is also quite normal both following a bereavement and on receiving a diagnosis of a serious illness. This was nevertheless a difficult and confusing period not helped by additional stresses at work combined with increasing family responsibilities.

### ***Making changes***

As identified in the 'stages' of bereavement, I eventually reached a point of calmer acceptance that life had changed for good and this was the beginning of being able to establish a degree of control. I recognised that I was at the start of a lifelong journey which would involve a degree of active planning and self-directed learning (Tough, 1971) although this is a multi-faceted notion. Through information leaflets produced by Diabetes UK, I learnt that, although the key to my care was self-management, I could expect support from a multi-disciplinary care team with me as the 'expert' patient. However, this is not a team 'sitting around a table discussing your case' (Becker, 2015:2759). These professionals rarely communicate directly with each other and it is the patient's task to contact them individually to undergo the recommended health checks at regular intervals. Although I always requested copies of my test results, some aspects of these were not always comprehensible to the lay person and health professionals rarely have time to explain them, a fact which militates against effective self-care.

All diabetics, whether Type 1 or 2, must make considerable lifestyle changes. For me, this was the most difficult aspect of control and involved some challenging experimentation over a long period.

Initially, since almost every type of food affects blood glucose in some way with carbohydrates the main culprit, an initial task was to learn more about the content of foodstuffs. For some time, I was almost afraid to eat anything but eventually, I settled on a diet based around an eating plan that involved only modest quantities of fat and cereal foods. Nevertheless, it was sometimes difficult to maintain such a diet especially when visiting friends for a meal; some of the optimum foods also tended to be expensive. At this point, I found the dietary advice provided on-line by Diabetes UK to be helpful.

The other key to self-management is to increase exercise levels although, like many older women, I had very little time and no idea what kind of exercise would be most beneficial. After I retired from full-time work, I discovered the GP (General Practitioner) Referral Programme which enables people with chronic illnesses in some areas of the UK to join a local gym and to be offered a 12-week course of exercise suitable for their individual level of fitness devised and monitored by a trained professional. Although this was not free, it was good for motivation and it encouraged me to join the gym after the programme was over. I also began to participate in an NHS-funded weekly health walk with a trained leader in charge. Such walks have been shown to be beneficial to participants in terms not just of maintenance of physical activity but also with respect to increased opportunity for regular social contact (Dawson, Boller, Foster & Hillsdon, 2006).

### ***Non-formal educational programmes***

Diabetes UK recommends that everyone newly diagnosed with diabetes should be offered the opportunity to attend an appropriate group diabetes education course but this was unavailable locally. However, I took part in a local Expert Patients course which is aimed at anyone who is learning to cope with a chronic illness. Again, the basic premise is that the patient is an expert on their condition and they can be trained to take the lead on managing this, thereby improving their health and quality of life. At the time, the programme was a central element of chronic disease management policy in the UK, enthusiastically promoted by the Department of Health as a new and cost-effective approach (Department of Health, 2001).

A free course, it was based on a programme pioneered in the USA with reference to work on social learning theory and was originally devised

for people living with arthritis (Expert Patients Programme Community Interest Company, 2007). It consisted of a weekly small group meeting over six consecutive weeks facilitated by two specially trained peer tutors. The course dealt with various aspects of daily living but there was also considerable emphasis on learning to set personal goals and developing problem-solving skills. There were equal numbers of men and women students, all retired, and it was clarified at the outset that the format would be small group discussion and group exercises. This did not sit well with some of the participants and a few did not return after the first week suggesting what Crowther (2000), writing from a critical theory perspective, terms an act of resistance to educational participation. Of those who did return, it was apparent that many of the women particularly struggled with the format, lacked confidence in speaking in public and were reluctant to discuss personal issues with strangers despite encouragement from the facilitators. Personally, although I initially found the course quite helpful as a tool for self-management, I did not retain what I had learnt for very long and, lacking further support, largely failed to put the ideas into practice in the long term.

What seemed to work better were two separate Saturday day courses specifically focusing on diabetes organised by the (former) local Primary Health Care Trust in conjunction with Diabetes UK. Free to attend, these courses were very informally run and consisted of short talks by health and exercise professionals on often neglected aspects of diabetes care such as choosing appropriate footwear. On both days, there was plenty of time for questions and some practical small group activities plus a helpful selection of written resources to take away as well as a healthy lunch. Most of the participants were older women and conversation about personal experiences of living with diabetes flowed much more freely than in the more formally structured course previously described. Sadly, such events are, in 2017, held less frequently, if at all, presumably due to severe cuts to NHS budgets. This is unfortunate since there is evidence from a Scandinavian study that diabetic patients who are encouraged to share their knowledge and experiences with facilitators in an atmosphere characterised by trust and good communication are more likely to understand that they can exercise a degree of control over their illness (Adolfsson, Starrin, Smide & Wikblad, 2008).

Later, I undertook a two-week MOOC (massive open on-line course) concerned with developing a patient-centred approach to diabetes



and attracting what appeared to be a huge range of participants from all over the world. There is now an emerging body of research on MOOCs generally and it is thought that across the globe, many thousands of older people take part in a range of courses on a variety of different platforms and in different languages. However, there is still a comparatively low level of research into understanding how older learners fare with such courses (Liyanagunawardena & Williams, 2016). Accordingly, although there was a very high level of reaction to the course material on-line it was not always clear how old participants were unless they chose to disclose this. Whilst women did seem much more comfortable with expressing their views here, MOOCs students need to be already competent and confident computer users and possess a good degree of literacy as well as a willingness to debate with strangers on-line. Some of the women participants stressed that they were undertaking the course on behalf of a spouse or male partner who had recently been diagnosed as diabetic. These women were keen to learn how to keep their partners in good health by overseeing their diets and accompanying them to check-ups. In this way, they may have become an important resource for their partner's own learning journey; or was there an underlying assumption that men are incapable of taking responsibility for their own health?

The study materials and the readings incorporated into the course seemed popular with participants but there were some areas of disagreement that led to considerable on-line debate. The first of these related to whether Type 2 diabetics should regularly test their glucose levels to establish which kinds of foods were affecting them. On-line debate about this issue was intense and combative in tone. The second area of controversy emerged in very heated discussion of recent research which suggested that Type 2 diabetes can be reversed (but not cured) through the adoption of a very restricted low carbohydrate high fat (LCHF) diet (Taylor, 2013). Many of the on-line participants testified to the efficacy of the diet but others questioned its validity since it contradicted much of the traditional dietary advice that has been dispensed by clinicians in recent years.

I recently undertook a second short MOOC concerned with living well with diabetes with the emphasis being on maintaining health and wellness from a holistic perspective. As before, participants came from all over the world and the sharing of stories about the challenges faced

and differing cultural expectations was a major feature and provided a key learning resource. Discussion here contrasted sharply with the forceful nature of debate experienced in the previous MOOC which I had found somewhat intimidating.

### **Reflective analysis**

After ten years then, I have learnt that acceptance is an important part of empowerment in this context followed by an understanding that it is my responsibility to increase my knowledge of the effect of diabetes and to keep abreast of new developments through the identification of trustworthy sources of information. Having also benefited from discussions with a variety of other people with diabetes from all over the world and with health professionals both face-to-face and on-line, I have improved my ability to more confidently self-manage and to interact with, and sometimes challenge members of my care team. I will continue to update my knowledge and to learn from others' experiences as well as seeking to evaluate new advice. This is particularly important since my condition is likely to worsen with age.

In reflecting critically on my overall experience, it is worth noting that Greenhalgh (2009) in a critique of the ways in which the whole notion of illness self-management and the 'expert patient' has evolved, argues strongly that the evidence base for these models is weak. She advocates a more holistic or social ecology approach in which chronic illness is seen 'as arising from the interplay of influences within a complex system ... acting dynamically through time' (Greenhalgh, 2009:630). Accordingly, she believes that there must be diversity of support provision and that local programmes should be organised more imaginatively to meet the very varied needs of different patients. However, the patient must remain an important member of the health care team since the process of agreeing on and implementing an appropriate care plan should be based on the negotiation of personal goals within the family, social, cultural and sometimes wider political context.

Greenhalgh (2009) makes an important and powerful case. But what can I extrapolate from my own story that will have relevance to the ways in which other older women can be helped to understand and to manage their illness? In the present UK climate where the NHS is subject to severe budgetary constraints it is an increasingly difficult task.

However, a feminist approach to health care emphasises the importance of education for women in relation to a chronic condition however this is provided. To receive a personal diagnosis is a shock and learning to self-manage an incurable illness can be a lengthy, bewildering and exhausting process. Female spouses/partners of male diabetic patients could also be better helped to understand the ways in which they could best provide support. However, it appears that there are some differences within the UK as to how much information, practical help and care newly diagnosed diabetics or their relatives are offered or can access and, because of increased demands on the NHS, on-going personal support is often minimal. The charity Diabetes UK is a useful point of departure, especially through its website, telephone helpline and local support groups, but not everyone is aware of its existence. It would be helpful if health care professionals both in the UK and elsewhere recommended it as a major resource for the newly diagnosed.

Another problem is the sometimes paternalistic nature of the health care team even when many team members are themselves female. Although the idea of a care team with the patient as the most important member with equal status is widely promoted, it appeared that the health professional-patient relationship still tends to be unbalanced. In informal discussions, several male patients also mentioned this. However, it was specifically some of the older women I encountered in the courses in which I participated who reported being reprimanded for failing to adhere to targets or having their concerns about possible side effects from their medication summarily dismissed rather than discussing and agreeing care plans as equals. In the UK, the NHS promotes various toolkits to enable health care professionals to enhance and develop skills and competences for diabetes care but it is important that these professionals understand that their attitudes can affect the quality of care they provide (Liu, Norman & While, 2012). Equally, older women need to learn that active involvement in their care and willingness to ask questions or to challenge decisions is similarly important. Since passivity and deference can lead to poor health outcomes, developing communication skills should be an educational priority for older women dealing with chronic illness. Briefly discussed in the Expert Patients course I attended, it might cover topics such as talking with health professionals, active listening, gaining the confidence to ask questions and clarifying answers (Expert Patients Programme Community Interest Company, 2007).

Following Greenhalgh's (2009) thinking, a further issue is the need for health professionals to acknowledge and understand the sheer diversity of older women's lifestyles. This is especially pertinent with respect to nutrition since making dietary changes is a major aspect of diabetes self-management. However, difficulties in learning what constitutes a suitable diet is often compounded by confusing dietary advice. Many older women live alone which can make menu planning, shopping and cooking a problem especially if they are infirm or living on a very restricted income. In addition, the food practices of minority ethnic populations may vary greatly by age, geographic origin and religion (Chowbey & Harrop, 2016). They may have certain distinct beliefs about food, ways of cooking and eating preferences that current advice about diet in diabetes fails to address. Carr (2012) advocates a series of study days to help health care professionals to understand what kinds of foods their diabetic patients eat and why. In this way, they would be better equipped to help older women learn more about how their condition is likely to be affected by the foods they eat. However, any such interventions would obviously need to be culturally sensitive and to take any language and communication problems into account. A Canadian study provided preliminary evidence that individual diabetes education counselling in conjunction with group education on nutrition adherence was effective in helping a group of Portuguese Canadians shape their eating behaviour (Gucciardi, DeMelo, Lee & Grace, 2007). In a similar way, it would be helpful if health professionals were trained to help older women choose and access appropriate exercise programmes since exercise plays such a crucial role in the control of Type 2 diabetes and related health complications. There is some clinical evidence that women may need different types of exercise regimes from men (American Heart Association, 2015).

In respect of the availability of specific educational programmes, it is probably unrealistic to expect older women to participate enthusiastically in a formally structured course if the format is likely to be unfamiliar or even threatening to them. More informal events with practical small group exercises and the availability of professional advice on coping on a day-to-day basis appeared to offer a more acceptable way of engaging older women and encouraging their participation. Additionally, the potential of MOOCs to offer short, focused courses that engage learners from all over the world who want to learn more

about diabetes and exchange experiences seems promising. However, emerging research has already established that such courses tend to have low completion rates and that the format may prove challenging (Department for Business, Innovation & Skills, 2013). If ways could be developed in which to clarify learner expectations and support on-line discussion more effectively (Ferguson, Coughlan, Herodotou & Scanlan, 2017), short, learner friendly MOOCs could be a useful form of engagement for those seeking support. As more women move into later life with well-developed computer skills, fears about on-line learning should slowly be overcome and it could provide a useful way forward in helping women (and men) to understand and cope with their condition.

Overall, the original work of Lave and Wenger (1991) and the ideas subsequently developed by Wenger (1998) suggest that female diabetics, however they are learning to manage their condition, can form a community of practice where they continually create and re-create their shared identity through becoming active in, and contributing to the practices of that community. This might be at a local level following a short educational course, through membership of a support group or on a global scale through participation in an appropriate MOOC. Since every woman dealing with Type 2 diabetes has an individual history, their shared expertise might offer a valuable networked resource for those newly diagnosed or struggling with self-management – a form of social capital.

### **Concluding remarks: The value of an autoethnographical approach**

Presenting a personal narrative concerning my experience of learning how to manage a diagnosis of Type 2 diabetes has been beneficial to me in that I have been able to publicly and critically reflect on an aspect of my life that impinges on my identity as an older woman but which, like many other people, I have hitherto kept within the private sphere. Richards (2009) discusses the rendering of people living with illness as outside the norm and comments that often, they tend to write in a manner that simplifies and objectifies their experiences. As both the researcher and the focus of my own research, I have tried to avoid this trap by exploring some of the wider issues that my personal learning journey has revealed. However, constructing my story has raised further questions for me such as how I have chosen to present myself to the reader, what I may have unconsciously omitted from my account and the nature of memory (Muncey, 2010) that I will continue to explore.

An unexpected outcome of constructing my story has been that I have also begun to question how older women in some of the Asian and Western Pacific countries where diabetes has reached epidemic proportions cope with a diagnosis. For the many older women where poverty, lack of education and other social, cultural and economic barriers may prevent access to good quality health care, how might they also be empowered to take control of their illness? If we are to make progress in controlling this life threatening disease their stories also need to be heard.

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