

Turning points in self-management of type 2 diabetes

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Background

The illness integration process in type 2 diabetes has previously been described as the 'science of one' where people's lives and diabetes fit together and this is a new way of living. The process of illness integration as well as self-management includes turning points.¹ A turning point refers to a powerful emotional experience or insight that leads to a fundamental change in a person's life and the development of a new approach to management of the illness.^{2,3} In a phase of the illness integration where a turning point is nearing, the disease and its management cannot be ignored or diminished any more, and those with illness become interested in learning more about managing to live with their illness. Passing a turning point brings a sense of confidence and power, where diabetes fits into people's lives and the illness becomes integrated – not only as new routines, but also on an emotional and existential level. However, turning points in self-management are not sufficiently

Summary

A turning point is described in the literature as a powerful emotional experience or insight leading to a fundamental change in a person's life, and requires a new way of managing the illness. However, turning points are not sufficiently described in the literature, particularly not with respect to diabetes.

The aim of this study was to throw light on turning points in self-management as described by people with type 2 diabetes.

Eighteen participants diagnosed with type 2 diabetes within the previous two years, and who received treatment in primary health care, were invited to participate. Semi-structured interviews were analysed using qualitative content analysis.

The findings demonstrated that the turning point in self-management among individuals living with type 2 diabetes included four themes: being in a life and death struggle, being at a crossroads with no return, being the one who decides, and being the one who can change the outcome.

Turning point transitions include existential and emotional aspects that can increase inner motivation and power for changed behaviour. Turning points are possible to identify, and self-management could be facilitated if more attention is paid to the emotional and existential aspects of having an illness.

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Key words

type 2 diabetes; turning point; self-management; illness integration; patient centredness

described in the literature and particularly not in relation to diabetes.

Living with type 2 diabetes often entails lifestyle adjustments. The disease management is frequently demanding, since it implies adherence to treatment recommendations focused on normalising blood glucose levels and decreasing cardiovascular risk.^{4,5} Self-management, though, could be experienced as very simple or very hard. The shifting experiences of wellness or illness in the foreground of daily life mirror the complexity of having a chronic illness. Newly-diagnosed people often adhere to an illness model and create self-management routines, trusting in professional advice.⁶ However, Thoolen *et al.*⁷ argue that, usually, people initially do not experience severe emotional distress about the changes in their lives, since they are far from integration of the disease into their lives. Over time, people come to adhere to a wellness

perspective, where life is seen as more important than disease management; i.e. life over disease.^{6,8} Most people want to live their lives as usual and act as normally as possible in order to minimise the impact of type 2 diabetes on their lives – this has been described as a paradox: to live well, people must take disease management into consideration.⁶ It can be problematic to adapt to a diagnosis such as type 2 diabetes because the disease, initially, is silent, but people must perform self-management activities to deal with the potential future health threat.⁹ Some people downplay the seriousness of diabetes and thereby their self-management needs, because doing so entails lower emotional stress.⁷ People with another understanding of the risks and the benefits of preventive self-management activities experience higher self-efficacy and, for these individuals, self-care entails lower emotional and psychosocial distress.^{10,11} When

people receive their diabetes diagnosis, it is important to observe their emotional reactions and perceptions of the disease, and how they adapt and engage in self-management activities because these emotional responses are crucial for their motivation for change.^{12,13}

The developmental process to succeed in self-management of diabetes is described by several researchers as: 'developing expertise';¹⁴ 'learning to live' with diabetes;¹⁵ 'the staged process' towards a normal way of living;¹⁶ 'illness integration and self-management' as parallel processes;¹² and as 'transitions'.¹⁷ This developmental process concerns the period from feeling symptoms and/or being diagnosed to a state of becoming 'successfully ill' (that is, living well and simultaneously managing the disease). Reaching a balance between a meaningful life and the impact of the disease and its management relates to successful cognitive, emotional and existential processing. Turning points are essential parts of this illness integration leading to a fundamental insight or changes in people's lives.² In our literature review, we did not find any studies that focus on how people with diabetes describe turning points in self-management. To support, and possibly also speed up, this process, it is important to identify when 'it clicks'; i.e. when people are reaching a turning point and could easily be motivated and pushed by health care professionals to develop a new insight, or a changed approach to management of their illness.

The aim of this study was to throw light on turning points in self-management as described by people with type 2 diabetes.

Method

Design

The study used a qualitative, descriptive approach based on initial interviews as a part of a larger study aimed at examining and supporting

illness integration among people with type 2 diabetes (reported elsewhere).

Participants

A convenience sample of 18 participants (eight women and 10 men) diagnosed with type 2 diabetes within two years were invited to participate in the interview study. The participants were aged 40–80 years (median 59 years).

Interviews

The participants were invited by letter and then contacted by telephone to decide where and when the semi-structured individual interviews should take place. The 30- to 90-minute interviews were performed either in the participants' homes (n=13) or at their work places (n=2), or in the university department (n=3). The interviews were audio-recorded and transcribed verbatim. All interviews were performed by the first author and followed an interview guide with the topics: *'The diagnosis experience'*; *'Personal experiences of being ill'*; and *'The development of self-management'*. Examples of questions were: 'Please tell me how you experienced the diagnosis of diabetes'; 'Please tell me about your self-management activities now and in the past and your plans for the future'; and 'Have you experienced periods when self-management has been easier or harder?' The questions were followed by probing such as: 'Could you explain it further?', or 'Please, tell me more about it', and 'How did you feel then?'

Ethical considerations

The regional ethical review board approved the study (Dno. 06-126 § 140/06 061107).

The participants were informed about the study orally and in writing and gave their informed consent to take part. They were also informed about confidentiality and were told that participation was voluntary and

could be terminated without giving a reason. The possible risks of the study, such as transferring feelings of shame and doubt, or offending integrity, were seen as low and were considered to be outweighed by the benefits; for example, the possibility to improve care for this group of ill people.

Analysis

The interviews were analysed with qualitative content analysis, described by Graneheim and Lundman.¹⁸ The interview text was read several times in order to get a basic understanding of the content. Text corresponding to the aim was identified and separated (approximately 40% of the transcribed text), constituting the unit of analysis. Text that did not correspond to the aim was excluded, but will be presented elsewhere. In the next step, this text was divided into meaning units, and condensed (i.e. the text was shortened, but the core message retained), and labelled with codes that described the content. We then continued by comparing and contrasting codes to find similarities or dissimilarities in data defining various aspects of turning points.¹⁹ Codes with similar content were sorted into themes and sub-themes. Themes are threads of meaning that run through the sub-themes on an interpretable level. The analysis was characterised by moving back and forth between the whole text and parts of the text. The codes, sub-themes and themes were discussed among the authors in order to reach consensus, which sometimes led to rearrangements. Sub-themes and themes were then validated in the original text. Finally, four over-arching themes remained.

Results

The themes – 'Being in a life and death struggle'; 'Being at a crossroads with no return'; 'Being the one who decides'; and, lastly, 'Being the one who can change the outcome' – express insights people have had

Themes	Sub-themes
Being in a life and death struggle	<ul style="list-style-type: none"> • It has become more serious and threatening now • It is heavy and frightening • It is too early to die
Being at a crossroads with no return	<ul style="list-style-type: none"> • It is now or never • I cannot turn back • It is time to change to avoid complications
Being the one who decides	<ul style="list-style-type: none"> • I have to decide and do something on my own • I, myself, want to change • I have my own motives for change
Being the one who can change the outcome	<ul style="list-style-type: none"> • I have regained power to change • It is possible for me to manage self-care • I have seen the effect of self-management • I must manage the disease but on my terms

Table 1. Themes and sub-themes

when they reached a turning point in self-management. Emotional as well as existential expressions were common in the interviews, which have influenced the formulation of the themes. Themes and sub-themes are presented in Table 1 and also as running text with exemplifying quotations from the original text.

Being in a life and death struggle

Reaching a turning point was described as being in a life and death struggle. The participants expressed it as an insight into the seriousness of the condition. They described this as heavy and frightening, an existential, emotionally upsetting experience due to, for example, earlier experiences of relatives and friends dying of the disease. *'I thought of a girl in my class who actually died... She had had diabetes since childhood and mismanaged the diabetes a lot, and she died when she was only 39 years old... and got everything you can get from diabetes. She was blind, both her legs were amputated, and she had heart and kidney disease.'*

Some participants expressed that they were too young to die and that too many people were dependent on them. They described no longer being able to ignore the seriousness of the disease. *'Now I understand that I*

can die of... or the consequences of the disease. I am more motivated now – it is about life or death. My children should not grow up and have no mother.'

Being at a crossroads with no return

Another turning point was described as being at a crossroads with no return. This was expressed as: there was no possibility of postponing the disease management any longer. The participants revealed that they had to make a hasty change in their behaviour to avoid the complications and threat of the disease. Essential and immediate change was emphasised – they had reached a point of 'now or never'. *'I went from a grey tone to either a black or white, and I chose the white because the black one was completely wrong. It is time to change if I want to have some good years before I become old and decrepit.'*

The participants also revealed that they had reached a point of no return, when they realised that this would cause major consequences for them and their life, with complications such as changes in vision and amputations of extremities. *'The values [HbA_{1c} and blood pressure] increased even when I took my medicines and exercised... then I realised that this didn't work if I didn't change and try to do something about it... and I must do it now. Now it's acute... I'm*

only 44 and I know that diabetes is serious and I do not want to have complications.'

Being the one who decides

The participants said that one turning point was when they realised that they were the ones who had to take a decision to make a lifestyle change. Being the one who decides was expressed as finding their own motives and willpower to change. *'If you don't wish to change lifestyle, there is no-one in the whole world who can convince you. It is only up to me, who can ensure that this will turn out well. I realised that when you get diabetes you must do your best to manage it, and you have to take these walks even if you don't like it.'*

The diabetes nurse could seldom give them impetus for changes; the motivation had to come from within themselves. This was described as a decision that they themselves had to make; no-one could affect or influence them, it had to come from them. They also emphasised that it was their own responsibility to decide upon change, and then carry out the behaviour change themselves. *'My wife used to nag me about eating too few vegetables and not exercising enough, but her concern did not help me... When I decided to modify my lifestyle, I changed my eating habits – meals with lots of vegetables with regularity. I also started to exercise regularly. These habits are no problem; I consider that I can manage the illness by myself.'*

Being the one who can change the outcome

The last turning point was when the participants realised that they had a possibility to change the outcome. They felt that they had the power to do so. Having a possibility to change the outcome was expressed as an insight about diet and physical activity as a kind of treatment that one can control by oneself. However, such a change demanded power for planning and performance. Participants said that they had found a way to improve their self-management.

Seeing the effects of improved self-management – that is, lower blood glucose levels and increased weight – gave them a boost to continue. Getting pep talks and support from others (e.g. families and health care professionals) were experienced as prolonging the behaviour changing initiatives.

'I cannot get rid of the disease but I can keep it under control for a long time. When activity results in improvement, it feels better and I get the power to continue.'

Participants also said that they had to arrive at an insight that they had the disease, but now the disease management fits into their lives. Things that previously had felt awkward and difficult had now become a new way in which to live. The possibility of finding such a balance between life and disease management was expressed as important in reaching a turning point in illness integration. However, the changes had to suit and be adapted into everyday life, and sometimes also the identity, of the person with illness. The disease had to be managed, but on their own terms. *'To self-manage the illness goes smoothly... it rolls on without thinking about it... To reach wellbeing, the disease must be managed, but on my terms.'*

Discussion

The results demonstrated that the turning point in self-management has important elements. These elements concern: the existential part of being ill; the personal decision-making aspect; proceeding self-management; the power and self-efficacy important for performance; and, lastly, the integration of disease management into daily life, which is highly related to the personal and social dimensions of life.

Illness integration and its relation to self-management are described by Hörnsten *et al.*¹² and are seen as a developmental process with three phases that precede the turning point transition.

- The first phase is to be diagnosed as having diabetes which is not always a linear process – something other researchers have also pointed out.^{6,17} An individual may receive a diagnosis but not experience him/herself as someone with diabetes. A person may also experience or suspect diabetes years before the diagnosis.²⁰
- The second phase concerns the explanation of the illness. Such explanations are, for example, personal models of illness which often differ from professional views of the disease.^{21,22}
- The third phase concerns the time-consuming negotiation about illness and self-management in the social and personal domain. This negotiation has been described in diabetes and other areas of chronic illness.^{12,23,24}

The turning point, as previously described, has been defined as a powerful emotional experience or insight. This insight leads to a sudden or gradual fundamental change in the individual's life or the moment when they find out a new way in which to manage the illness.^{1–3} Our findings describe the insights that are needed for an individual to step forward to and pass this critical turning point and come to a more balanced steady state of disease management. It concerns the moment from no longer being a healthy individual to the moment where that person is becoming successfully ill. It includes not only insights about threats and personal responsibilities, but also options and hope for a future where illness and its management are only one aspect of life.

Self-efficacy is the belief in one's capacity to acquire cognitive resources, motivation and required actions to meet given situational demands.²⁵ It seems important to strengthen self-efficacy among people with diabetes, if we want to facilitate turning point transitions.

Empowerment approaches in diabetes care could support self-efficacy. Empowerment is a patient-centred collaborative approach where the patients are seen as the experts in living with diabetes, and the health care providers are the facilitators.²⁶ Empowerment and patient-centredness enable patients to express feelings, explore problems, and develop solutions to their problems. This approach can also help patients to identify their problems and their needs for more knowledge, and to discuss their opportunities or barriers to changing behaviour and setting goals.^{27,28} However, an empowerment approach is reported to be hard to adapt to among health care professionals, since they must grow into it and find new roles as facilitators.²⁹

Empowerment is not about convincing people of the way to solve their problems.³⁰ Recent studies have stated that there is a lack of clarity about what empowerment actually is, because there is no one definition that is agreed upon and it is unclear how health care professionals use empowerment in practice.^{30–32} Asimakopoulo³³ advocated patient centredness instead of empowerment and stated that patient centredness is the foundation on which patient empowerment can be built. Patient centredness is based on an equal partnership between the patient and health care professionals, where the patient is in the centre of the consultation and the care is planned according to the patient's needs and wants. Patient centredness in diabetes care could facilitate turning points and thereby improve self-management.³⁴

Beside pharmacological treatment, the focus for health care should lie in supporting people in their struggle to manage diabetes in daily life. Self-management support is necessary but problematic, since it is the person living with the illness who manages the disease every day. Patients' goals, priorities, health issues and family

demands, therefore, are also of great concern for nurses and physicians in their support of people's self-management capacities.^{21,35} Diabetes-related self-management might be perceived as burdensome.^{36–38} However, people with type 2 diabetes who frequently follow, for example, dietary guidelines have demonstrated more positive health outcomes, indicating that self-management support regarding dietary change is important,³⁶ but may need attention concerning the approach to patient education or support. Health professionals often tend to focus on metabolic control and long-term treatment goals, while patients focus on day-to-day issues, such as how they feel, and their ability to fit treatment into daily routines and to control their daily lives.^{8,39} Health care professionals usually diagnose, prescribe and adjust medications, and evaluate biomedical laboratory measurements in order to identify the process of diabetes-related complications in meetings with patients. The complexity is that most of the daily self-management decisions are made by the patients themselves, something professionals cannot control.^{28,35}

Methodological discussion

This study is based on the first baseline interviews in a prospective study. All interviews were performed by the first author and an interview guide was used. Furthermore, the research team's diverse experiences of diabetes care have been seen as a benefit and have led to fruitful discussions about the interpretation of data. According to Krippendorff,¹⁹ there is never one single meaning of a text. To achieve trustworthiness of our interpretation, assigning of the analysis codes, sub-themes and themes was discussed and reflected upon among the authors and in seminars with other researchers to validate the findings. A distinct method description and use of quotations from the interviews are included to help the reader

to make their own judgements of the study's trustworthiness.

Conclusion

Turning points in type 2 diabetes are insights leading to lifestyle changes. The results indicate that, when a turning point occurs, diabetes is seen as a serious and life-threatening disease but that there are hope and options to do something by oneself to alleviate the consequences; however, personal responsibility is needed. The turning point transition includes emotional and existential aspects leading to an inner motivation for change. If more attention in patient interactions is paid to the emotional and existential aspects of having an illness, self-management could be facilitated. Diabetes specialist nurses are ideally placed to identify turning points in the process of illness integration and thereby have the possibility to push people, in that important phase, over the threshold to improve self-management.

Clinical implications

Supporting turning points could be made easier by a patient-centred approach and the themes in this study seem to be crucial in the turning point transition. These themes are core expressions, which not only describe particular issues of interest when someone has come to the moment where a turning point in self-management occurs, but can also be identified by a diabetes specialist nurse as an important step towards self-management and illness integration. Diabetes educational programmes have previously focused on diabetes knowledge more than on patients' experiences of living with the disease.⁴⁰ Patients also express that professionals use a compliance-expecting approach based on a traditional biomedical view of diabetes management.⁴¹ To support turning point transitions and illness integration, a focus on personal

understandings of illness (i.e. what people living with diabetes feel and consider as most important to take control over in their disease management) is an alternative way in which to counsel people with diabetes that could be more successful.^{42,43}

Many people with diabetes express the wish to change their lifestyle, but their motivation and willpower may be decreased due to barriers and situations that undermine their intentions for changed behaviour.⁴⁴ Motivational interviewing (MI) is another widespread method of exploring people's motivation for change.⁴⁵ It is a method that strengthens self-efficacy, where patients are seen as equal and autonomous, and should be respected for their well-informed choices. It is important to examine and solve patients' ambivalences for change.⁴⁵ We consider that motivational interviewing – despite national guideline recommendations stating that MI does not affect HbA_{1c} after 6–12 months⁴⁶ – would be a useful method in supporting illness integration and turning points in self-management among people with diabetes.^{34,45,47–49}

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Declaration of interests

There are no conflicts of interest declared.

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