

# SELF-MANAGEMENT EXPERIENCES OF PERSONS LIVING WITH DIABETES MELLITUS TYPE 2

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## ABSTRACT

Diabetes mellitus (DM) type 2 is a progressive disease that has the potential of negatively affecting virtually all the systems of the body, causing debilitating and life-threatening complications if blood glucose levels are not controlled. A high level of self-management is required in order to control blood glucose levels and prevent or delay the onset of complications, which may have severe physical, psychological and financial implications for the individuals and their families. As no research on the experiences of persons living with DM type 2 was previously conducted in Nelson Mandela Bay, South Africa, a qualitative, descriptive, exploratory and contextual study was conducted between January and April 2009. Nineteen participants were purposively sampled from both the private and public health care sectors. The following themes emerged from the data collection: persons living with DM type 2 experience a wide range of emotions on initial diagnosis; gradually they experience an acceptance and acknowledgment of their condition; persons living with DM type 2 have definite opinions on the concept of self-management; persons living with DM type 2 acknowledge both positive and negative factors that influence self-management, and they expressed views on how professional nurses can assist them in achieving self-

management. Recommendations included the following: persons diagnosed with DM type 2 should take a leading role in decisions regarding management of their condition; an ongoing patient education process should include periodic reinforcements of lifestyle management; qualified diabetes nurse educators should be employed at health care facilities, both in the public and private sector; and finally, specialised courses covering all areas of management of DM type 2 should be more readily available to health care workers.

**Keywords:** empowerment model, diabetes mellitus type 2, professional nurses, self-management

## INTRODUCTION AND BACKGROUND INFORMATION

The incidence of non-infectious diseases is steadily increasing globally with diabetes mellitus (DM) type 2 playing a significant role in this growth. Diabetes mellitus has a higher incidence in Africa than was previously thought, with an estimated South African prevalence rate of 6.5% for adults aged 20–79, an estimated 1.9 million people (SEMDSA, 2012:1). The wide-ranging complications of DM type 2 include cardiovascular diseases, nephropathy, retinopathy and neuropathy, which all contribute to the high mortality rates of people with the condition (Shrivastava, Shrivastava & Ramasamy, 2013:1).

DM was the direct cause of 8.2% of deaths around the world in 2011, a figure that is 'similar in magnitude to the combined deaths from several infectious diseases that are major public health priorities' (International Diabetes Federation, 2012). The condition, if not adequately controlled, can have serious negative effects on quality of life both of the persons living with DM type 2 and of their families. For example, in South Africa, the majority of non-trauma-related amputations can be linked to uncontrolled DM type 2 (Butler, 2011:41).

Most diabetes-related deaths occur in low-income and middle-income countries (Shrivastava et al., 2013:1). A high incidence of DM type 2 can lead to direct and indirect adverse economic effects such as absenteeism due to health issues and premature withdrawal from the labour market for those whose health is seriously affected. It is imperative that measures are taken to address this issue to ease the burden of soaring health costs on the economy, particularly in developing countries where economic gains are being reversed by rising health costs (Hu, 2011:1249).

Rising health care costs affect the management of chronic conditions such as DM type 2. South Africa has both public and private health care sectors with 84% of South Africans making use of the public sector and 16% accessing the private sector with private medical insurance or medical aid schemes (Centre for Development and Enterprise, 2011:5). However, some people make use of both sectors depending on their individual circumstances. The various medical aid schemes have their own rules, so each scheme differs in how claims are handled. Diabetes mellitus is one of

the conditions recognised as a Prescribed Minimum Benefit (PMB) condition by the *Medical Schemes Act 131 of 1998* (Council for Medical Schemes [s.a.]). Therefore, all treatment required for the management of the condition must be funded by the medical aid, but this is not necessarily the latest treatment or technology.

Traditionally, management of chronic diseases used the authoritative medical model with the medical practitioner as an authority figure, dictating the terms of treatment to the patient. The main focus of disease management was to 'get patients to change', which was not very effective (Funnell & Anderson, 2004:124). The focus of chronic disease management has changed to a self-management model where the person living with DM type 2 has to take responsibility for making lifestyle choices, such as dietary management, glucose monitoring, exercising, management of acute complications and normal health management.

As diabetes patient education evolves, the emphasis is changing from the medical model in which the physician takes a leadership role to models, such as the Empowerment Model, which give the person living with DM type 2 a leading role. Making use of the Empowerment Model in diabetes patient education assists in informing patients and allowing them to take a leading role in decision-making regarding the management of their condition, enhancing the level of self-management achieved and encouraging the growth of personal responsibility (Funnell & Anderson, 2004:124).

## STATEMENT OF THE RESEARCH PROBLEM

Persons diagnosed with DM type 2 will face an uncertain future if they are unable to achieve optimal levels of self-management. In order to provide the assistance required, it is important to explore and describe the experiences of persons living with DM type 2 and identify their needs related to self-management. The following research question was addressed in this study:

- What are the experiences of persons living with DM type 2 related to self-management?

## PURPOSE OF THE STUDY

The purpose of this study was to explore and describe the experiences of persons living with DM type 2 related to self-management.

## DEFINITIONS OF KEY TERMS

### Diabetes mellitus type 2

The metabolism and utilization of glucose, fat and protein in persons living with DM type 2 are disturbed by either insulin deficiency or insulin resistance (Levene and

Donnelly, 2008:6). DM type 2 results mainly from insulin resistance and is typically, but not exclusively, found in older persons.

## Empowerment Model

The Empowerment Model demonstrates the process in which a person living with a chronic condition is educated and encouraged to take personal control of the management of their condition.

## Professional nurse

A professional nurse is someone who has undergone training as set down by the South African Nursing Council, and who has met the requirements for registration as a professional nurse and practices comprehensive nursing in the manner and to the level prescribed as an independent practitioner in their own right while accepting full responsibility and accountability for their actions (*Nursing Act No.33 of 2005*).

## Self-management

Self-management in DM type 2 comprises self-monitoring of blood glucose, dietary control, adjustment of insulin dose to actual needs/correct administration of medication, weight control and regular exercise. The concept of self-management also involves the interrelationships between these activities and the ability to implement appropriate changes when required (Sigurdardottir, 2005:301).

## RESEARCH METHODOLOGY

This section discusses the research design and methodology as applied in the study.

### Research Design

A qualitative, descriptive, exploratory and contextual framework was utilised for this study, which was conducted in Nelson Mandela Bay, an industrial metropolitan area in the Eastern Cape Province of South Africa.

### Research population and research site

The research population included persons living with DM type 2 and who had accessed either public or private health care facilities in the Nelson Mandela Bay.

## Sampling method

Purposive sampling was used to select persons living with DM type 2 from both private and public health care facilities in Nelson Mandela Bay. Criteria for inclusion included: participants must have been diagnosed with DM type 2 for a minimum of six months; participants were required to be able to communicate in English; participants needed to be between 40 and 75 years; and finally, participants must have accessed private or public health care facilities in Nelson Mandela Bay. A specialist physician and diabetes nurse educators were approached to assist with the identification of participants. They were willing to refer patients, with their consent, to take part in this research study. As the health care professionals who referred the patients work in both public and private sectors, it was possible to obtain access to participants from a wide range of economic, social and cultural backgrounds, which provided rich data for analysis.

## Data collection

Semi-structured individual interviews were utilised for data collection. The researcher conducted the interviews at the home of each participant. The interviews were recorded using a tape recorder and later transcribed verbatim. Data collection continued until data saturation was achieved (n=19). Reflective journals in which the participants further elaborated on their experiences of living with DM type 2, as well as field notes added to the richness of the data.

## Data analysis

The resulting data were analysed and coded using Tesch's method of thematic analysis allowing for a structured organisation of data to take place (Creswell, 2003:192). Tesch's method of thematic analysis includes careful reading of transcriptions, identifying topics and assigning codes to the topics. Coding allows insight into the data that may not have been obvious at first glance and allows sorting into categories and identification of themes (Moule & Goodman, 2009:354). Themes that are repeated throughout the data collection process are used to provide the story told by the participants about their experiences. An independent coder assisted with identifying themes separate to those of the researcher. This assisted in the cross-validation of themes, while also enhancing the trustworthiness of the study (Polit & Beck, 2008:406).

## Trustworthiness

The trustworthiness of the study was ensured through addressing the constructs of credibility, transferability, dependability and confirmability (Polit & Beck,

2008:537). Credibility was ensured by encouraging frank descriptions by participants of their experiences of living with DM type 2. Transferability was ensured by the descriptions of participant characteristics, the research setting and the research process. Dependability was ensured by documenting each stage of the research process. Themes and sub-themes identified during the data analysis process were confirmed by discussion with the independent coder. An expert panel consisting of a specialist physician with a special interest in diabetes, two diabetes nurse educators and an academic with a PhD focusing on the management of DM type 2, critiqued the above constructs of the study, thus enhancing its trustworthiness.

## Ethical considerations

In order to ensure the safety and well-being of participants, it is imperative that the ethical principles of autonomy, beneficence and justice are applied at each stage of the research process (Streubert & Carpenter, 2011:61). Before commencing the research process, ethical approval was given by the Ethics Committee of a local university. Informed consent was sought from the participants prior to commencing each interview (Polit & Beck, 2008:168). The procedure and implications of the study were explained carefully to each participant, giving them the option of withdrawing if they so wished. Confidentiality was maintained at all times by identifying interview transcripts and tapes by number and keeping the personal details of the participants separate, and accessible only to the researchers. Special mention of the measures to ensure confidentiality was made in the informed consent form. Each participant was asked for permission, both verbally and on the informed consent form, for the interviews to be recorded by tape recorder.

## FINDINGS

In the study group of 19 persons living with DM type 2, the gender division was 13 female and six male. The age range of the participants was from 44 to 74 years. There was a wide range of time periods since first diagnosis for each participant. One participant had been diagnosed eight months prior to the interview, while others had been living with DM type 2 for up to 30 years. Fourteen participants made use of private health care facilities, while three used only public health care facilities. Two participants had experienced both private and public health care services due to their socio-economic situations.

## Thematic analysis

During the research process, the following themes were identified. A discussion on each theme, together with verbatim statements from the transcripts of the interviews will follow.

- Persons living with DM type 2 experience a wide range of emotions on initial diagnosis.
- Persons living with DM type 2 gradually experience an acceptance and acknowledgement of their condition.
- Persons living with DM type 2 have definite opinions on the concept of self-management.
- Persons living with DM type 2 acknowledge both positive and negative factors which influence self-management.
- Persons living with DM type 2 expressed views on how professional nurses can assist them in achieving self-management.

### Persons living with DM type 2 experience a wide range of emotions on initial diagnosis

The emotional reactions that most of the participants described are similar to the descriptions given by Kubler-Ross (2003: 51) on experiencing and adjusting to loss, such as shock, anger, denial and anxiety. The typical initial reaction described by most of the participants was shock and horror. 'And I got quite a shock when I was diagnosed with diabetes.' Anger is a common feature in response to loss and leads to revolt against the situation. One participant in this study described his anger on diagnosis as he had witnessed others dealing with DM type 2 and he did not want to be in the same position. 'So yes, it made me feel very angry and also, not understanding anything about diabetes, all you've seen is some of your family members have suffered from diabetes and the dire consequences that they found themselves in.'

Denial occurs when a person living with DM type 2 does not or cannot assimilate all the implications of the initial diagnosis of DM type 2 and refuses to admit the severity of the condition. 'The diagnosis was six years ago and I think I'm still in denial, and I think probably the whole thing is that you don't perceive it as being related to yourself.'

Several participants expressed some form of fear and anxiety in facing the future as a diabetic. 'It also brings you very close to, or reminds you quite a bit about mortality.'

### Persons living with DM type 2 gradually experience an acceptance and acknowledgment of their condition

Most participants in this study have reached a stage of acceptance of the condition and of the required changes in lifestyle. However, it is not an easy journey to acceptance and most participants acknowledged that they had had some difficulty in reaching

that level. 'You've got to acknowledge your illness. You've got to! If you don't acknowledge your illness, things won't go right, it will go wrong.' The importance of a change in personal attitude is emphasised in the following quotation: '[A]s far as I'm concerned it's more, you've got to take control of it and handle it.'

Achieving the goal of self-management does not come easily or quickly, as shown in the following quotation: '[S]elf-management to me has only come over the years.'

## **Persons living with DM type 2 have definite opinions on the concept of self-management**

People living with DM type 2 have to take responsibility for the management of the condition due to the particular lifestyle changes required. A participant stated, it's a total life-changing scenario and it takes a lot of working on ... you have to accept that and adapt your life and your lifestyle to the change that you have to go through'. Those with a strong internal locus of control fare better in making the lifestyle changes that are required.

The participants acknowledged the importance of self-discipline in achieving optimal self-management, often feeling that it is their own fault if problems with blood sugar levels arise. 'it's to have the will to do that right, ... if you let it run away with you, you've got problems'. Some participants admitted that they did not have the required self-discipline to implement all that they had learnt. 'And it's quite sad because I know about everything. I know what's right.' Self-discipline is often related to dietary issues as some participants felt that the correct diet was boring and could become repetitive and repulsive 'You kind of get sick of the TLCs (the tomatoes, lettuces and cucumbers). It becomes repulsive, because it is a repetitive type of diet.'

## **Persons living with DM type 2 acknowledge both positive and negative factors that influence self-management**

A positive attitude and an acceptance were regarded by the participants as basic prerequisites for self-management of DM type 2. However, there were negative aspects that affected their ability or inclination to implement strategies, which would assist in improving their levels of self-management.

Participants experienced both positive and negative levels of support from family and friends. One participant with a positive experience stated, 'well, I mean your families are supportive'. However, some participants experience a lack of support from both family members and from friends who were often insensitive to their needs as diabetics. 'I hate it when I go anywhere and people force you.'

There are occasions when people are simply uninformed and will give support when they realise the truth of the situation. Lack of support often is experienced



as related to diet because the person living with DM type 2 may be coerced into eating something that they should not eat as they do not wish to offend someone. A participant tried to avoid coercion, stating, 'and I mean some of the ladies were upset with me at some of our meetings'.

Participants experienced both positive and negative aspects adhering to a medication regime. Some expected the doctor to take the lead. 'You comply with the medication because that's what the doctor prescribed. He should be superior in knowledge.' Other participants were willing to take a more active role in managing dosages, stating: 'You must be prepared to change it yourself, to manage your own diabetes, if you don't do that, you're sunk.'

In order to be able to follow an exercise regime or to increase the level of physical activity enjoyed by the persons living with DM type 2, they must have the mental and physical ability to be able to carry out the activities. All participants in the study were aware of the importance of exercise and some made the most of every opportunity they had to exercise. However, others were not so successful. One participant experienced frustration at not being able to do yoga, which she loved, due to problems with her knee and shoulder: 'Dr J said he doesn't want me to do it.' Another participant who lived in a township described how she made the opportunity to exercise on a daily basis by walking around her garden for half an hour each morning. 'Every day I wake up in the morning, I get up and take a walk, every day – five days.' However, some participants found it difficult to summon up the self-discipline to exercise.

Some participants were grateful that they had adequate funding for the various aspects of diabetes care, such as medication and a correct diet. Other participants experienced this negatively due to financial constraints. 'Now you only have one visit allowed a year, so if you have to go again it's another four or five hundred rand out of your pocket.' This was often linked to medical aid issues as some medical aids limit the type of medication the patient may utilise. State hospitals and clinics also had a limited range of medication and supplies available for persons living with DM type 2: 'And a couple of times I went to Provincial and that Outpatients hasn't changed in 45 years, exactly the same.' Affordability of a correct diet varies according to the socio-economic status of the patient: it can be very expensive for people who don't have a lot of money'.

## **Persons living with DM type 2 expressed views on how professional nurses can assist them in achieving self-management**

Most participants had strong feelings on the ways in which professional nurses can assist them in achieving self-management. They felt that nurses needed to be informed about all aspects of DM type 2 themselves, stating, 'get the facts right themselves first, because a lot of them haven't got a clue'. DM type 2 is a highly complex

condition that requires intensive management. They noted that the professional nurse is in a position to play an important role as patient educator and advocate: 'your nurse is in the front line in any medical scenario'.

Some participants felt that professional nurses were sometimes insensitive about the timing and manner in which information is presented: 'educating a person at the right place when he's ready for it, not when the nurse is ready for it'.

Unfortunately, due to large patient loads, nursing staff become less available to the individual patient as experienced by some of the participants in this study. Participants felt that not all nurses are aware of the importance of acknowledging the gains they made as they learnt more about their condition. '[E]very step in achieving control over his glucose levels is a massive achievement for every patient, and he should be recognized for that.'

Participants felt that nurses should be encouraged to promote self-management by implementing diet and exercise strategies themselves. A participant felt that nurses had the potential to be an example to the patients in their care if they could be seen to carry out their own advice. He felt that it was difficult to heed advice to lose weight, for example, given by someone who was very overweight. 'They are often so big. Makes you wonder why they don't take their own advice.'

Participants experienced a widely diverse range of availability and access to topical and current information regarding DM type 2. Access to information for assisting in the self-management of DM type 2 was regarded as vitally important by participants. Some participants felt that the clinics at the state hospitals should have information available as it may be more difficult for those patients utilising the facilities to have access to relevant information sources. The information provided should be culturally sensitive and relevant to the various cultural groups making use of the facilities. 'I think if there was pamphlets or information to educate people on how to control it and what to do, they wouldn't get to the problem of losing limbs and stuff.'

There is a wealth of information available for anyone wishing to research the topic of DM type 2: 'What can help is, especially in OPD clinics is reading material that is freely available for people to read. When I go to Dr P, he's always got nice articles, brochures that you can read, so that must be more available to the poorer people.' However, persons living with DM type 2 are often not aware of what information is available or how to access the information they require.

## DISCUSSION OF FINDINGS

The identified themes show that persons living with DM type 2 experience numerous challenges along the road to achieving optimal self-management of their condition. These challenges range from emotional issues to practical considerations in improving their health status. In order to provide a holistic service and encourage high levels

of self-management, nurses need to have an understanding of the experiences of persons living with DM type 2.

The emotions experienced by participants were often overwhelming in the initial period after diagnosis. The pattern of emotions, described by Kubler-Ross as the 'cycle of grief', can be applied to many other situations and are not limited to a reaction to death or dying but also to loss (Bolden, 2007:237). The grief and denial experienced after such a diagnosis are normal and the person should be allowed to deal with the conflicting emotions with support and understanding (McClain, 2010:49). The time-frame required for the person to go through the grieving process will vary from person to person (McDowell, Matthews & Brown, 2007:45). As emotions and feelings affect each aspect of one's life and could have a profound effect on the later achievement of optimal self-management, all health care workers have to be aware of the possible impact of the diagnosis on the mental status of the individual.

People generally are positive about their health and do not realise that there is a connection between their current behaviour and developing a chronic condition later in life (Shrivastava et al., 2013:2). When diagnosed with a condition such as DM type 2, people are often overwhelmed and bewildered by the range of lifestyle changes required for achieving optimal self-management and may react in an extremely negative manner. However, as time passes, most people become accustomed to the changes and manage to deal with the negative emotions, ultimately leading to a level of acceptance, making them more open to taking personal responsibility for their condition.

Participants in this study described that when they experienced a deeper understanding of the need and reasons for change, it became easier to implement lifestyle changes regarding diet, exercise and medication. However, it must be borne in mind that continuing education and support are required to maximise the benefits (Shrivastava et al., 2013:2). Some participants who felt that they had been following a healthy diet could not understand why they were then confronted with the diagnosis of DM type 2. Others admitted that they did not follow a healthy diet due to various factors, ranging from cost, convenience, simple likes or dislikes or laziness. Emotional reactions to diagnosis may lead to eating disorders, further complicating the issue of self-management of DM type 2 (Young-Hyman & Davis, 2010:686). The best type of eating plan for anyone living with DM type 2 is a personal plan drawn up by a dietitian, taking into account the lifestyle of the patient. However, patient education regarding diet is not limited to an eating plan but includes such factors as reading labels and measuring portions (Beebe & Schmitt, 2011:126). Making persons living with DM type 2 more aware of the cause and effect of their actions regarding lifestyle changes will help deepen their understanding of the various aspects of self-management (Shrivastava et al., 2013:3; Chlebwoy, Hood & LaJoie, 2010:899).

Exercise may be regarded as the most important lifestyle change required, but the most difficult to implement (Johnson, Mundt, Soprovich, Wozniak, Plotnikoff

& Johnson, 2012:455). Some people are more naturally disposed to exercise while others will do anything to avoid it. Although the guidelines for self-management emphasise the importance of exercise, the majority of persons living with DM type 2 remain inactive. Some participants were very open to exercise as a change in lifestyle but others were not so receptive. All, however, recognised the importance of exercise in the management of DM type 2.

Participants also experienced problems related to their medication regime. Remembering to take the medication timeously was often a problem and some felt uncomfortable if they needed to adjust the dosage according to their blood glucose levels. Dosage adjustment becomes particularly confusing when a patient has a number of co-morbid conditions such as hypertension, renal impairment and cardiac conditions (Hunt, Kreiner & Brody, 2012:453).

All participants acknowledged the importance of self-discipline in achieving optimal self-management and, as a result, often felt guilty if they encountered problems with blood glucose control. Persons living with DM type 2 with a strong internal locus of control usually have the required self-discipline to implement necessary lifestyle changes, while those with an external locus of control find it difficult to do so (Macaden & Clarke, 2010:145).

Nursing staff are not always knowledgeable about the implications of the management of DM type 2. They may also be insensitive about the timing and manner in which information is presented as well as not being available and approachable. The patient education process should be regarded as a partnership and the nurses dealing with these patients must be aware of the 'powerful influence' they may have on the 'beliefs and attitudes of their patients' (Dunning, 2003:231). Education programmes must not be done on a once-off basis but must be a continuing process to give periodic reinforcement to the lifestyle modification that needs to take place (Shrivastava et al., 2013:3). Regular follow up and support groups are some of the essential factors that have been shown to encourage the growth of personal responsibility in the self-management of DM type 2 (Dunning, 2003:231).

## LIMITATIONS OF THE STUDY

The study was limited to persons living in the Nelson Mandela Bay urban and suburban area. There is no input from persons living with DM type 2 who reside in outlying semi-rural areas. Another limitation of this study is that participants were not insulin dependent as it focused on persons living with DM type 2, most of whom make use of oral medication. As this is a contextual study, transferability of data is only possible in health care facilities of a similar context.

## RECOMMENDATIONS

The following recommendations may be made as a result of this study:

### Recommendations for nursing practice

Professional nurses need to allow persons living with DM type 2 to take a leading role in decisions regarding the management of their condition. Periodic reinforcement of lifestyle modifications should be part of an ongoing patient education process. Ideally, qualified diabetes nurse educators should be employed at healthcare facilities, both in the public and private sector, to facilitate the training of persons living with DM type 2 and for other staff members. However, the reality of the healthcare situation in South Africa makes this difficult to implement. Therefore, management of DM type 2 should be an important focus in continuous professional development programmes for nursing staff.

### Recommendations for nursing education

Specialised courses covering all areas of management of DM type 2 must be made more readily available for health care workers.

### Recommendations for future research

A similar study may be done with input from persons living in semi-rural areas with limited access to available health facilities

## CONCLUSION

As DM type 2 is a highly complex condition, persons living with the condition need to take responsibility for their own self-management with the aim of achieving good blood glucose levels and preventing the onset of life-threatening complications. Research findings in this current study provide a deeper understanding of the experiences of persons living with DM type 2, thus enabling nurses and other health care workers to better care for such patients in achieving optimal self-management.

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