*Journal of Endocrinology, Metabolism and Diabetes of South Africa* 2020; 25(3):51–56
https://doi.org/10.1080/16089677.2020.1817281



JEMDSA
ISSN 1608-9677 EISSN 2220-1009

ARTICLE

# Perceptual systems of the self-management of students living with diabetes mellitus: an IQA approach

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**Introduction:** Diabetes mellitus (DM) is a chronic metabolic disease defined by elevated blood glucose levels over a long period of time. One in 10 people are living with DM.
**Objective:** The main purpose of this investigative study was to gain knowledge regarding the perceptions of students' self-management living with diabetes mellitus at a tertiary institute.
**Methods:** The Interactive Qualitative Analysis (IQA) was used to construct and describe a cognitive mind map of students' perceptions of their self-management living with DM.
**Results:** An analysis of the participants' mind map representing students living with DM revealed eight main components (affinities), namely: Social awareness and acceptance, Food available on campus, Keeping insulin cool, Independent lifestyle, Adjusting by cooking, Hurdles in the academic environment, Causes of changing blood sugar and Adapting to effects of changing blood sugar.
**Conclusion:** The final perceptual system was an informative representation of the self-management of students living with DM. The system reflects barriers to compliance with self-management facing students living with DM. The system produced four recognisable loops or cycles, namely the Ignorance loop, the Revision loop, the Developing loop and the Self-management loop. These loops created pathways through the system for the students living with DM to find a way to better self-management.

**Keywords:** DM, interactive qualitative analysis, self-management of diabetes, university

## Introduction

Diabetes mellitus (DM) is currently known as the epidemic of the century. The global DM statistics grew phenomenally from 1980 to 2017 and show a 393.5% increase from 108 million people diagnosed with either Type 1 (T1DM) or Type 2 (T2DM) to 425 million people. With this trend the International Diabetes Federation (IDF) estimates an increase to 629 million people living with DM by 2045.[1]

Many complications, inter alia the loss of vision, kidney failure, heart attacks, strokes, loss of lower limbs and death, are attributable to DM. DM is ranked seventh on the World Health Organization's (WHO) death statistics with almost half of the deaths of people younger than 70 years in 2016.[2]

In Africa, 3.1% of adults (between 18 and 99 years old) live with DM, accounting for 516 million people of the total population in 2017 and 0.258% of the children (between 0 and 18 years old) live with the disease, accounting for 50 600 people of the total population.[3]

In 2019, 5.4% of the South African adult population was diagnosed with DM, a total of 1 826 100 out of 33 762 000. The DM epidemic in South Africa is worsening with an increase of diagnosed patients and deaths as a result of DM complications between 1997 and 2015.[4] With 25 070 deaths out of 55 290 000, DM was ranked as the second highest cause of deaths in South Africa in 2015, accounting for 0.04% of the population.

## Diabetes mellitus

The American Diabetes Association (ADA) describes DM as a chronic disease pertaining to continuous raised blood glucose levels as a result of either defective insulin secretion or an impairment of insulin action or both.[3–7] There are two main types of DM, namely Type 1 DM (T1DM) and Type 2 DM (T2DM). T1DM is found mostly in children aged 0–18 years old and is defined as the failure to produce insulin in the body. The T2DM individual's pancreas does secrete insulin, but the body does not use the insulin as it should. This also known as insulin resistance.[3,8] Over a period of time various complications are caused by DM.[9] These complications include, amongst others, cardiac problems and stroke, high blood pressure, loss of vision and other problems related to the eyes, renal problems, nervous system disease, the loss of limbs due to amputations, diseases of the teeth, complications during pregnancy and other difficulties.[9] Finally, DM could be caused by various factors, including disturbances in the metabolism of carbohydrates, fat and protein.[10] DM cannot be described by one definition alone. The various components and factors relating to DM need to be examined.

## Self-management

Self-management is a term referring to the ability of an individual to manage his/her treatment, physical symptoms and psychosocial consequences together with the lifestyle changes and characteristics of living with a chronic disease.[11]

As the mortality rates associated with DM rise, the prevalence of DM appears likely to double by 2030.[12] Adjustments to lifestyle, such as eating more healthily, daily exercise and monitoring of blood glucose levels, delay the advancement of DM.[13] The WHO added that individuals living with DM need to adjust to a healthy lifestyle that consists of dieting, monitoring and

maintenance of blood glucose levels, and adherence to medicine usage.[14] Forouhi et al. contributed to the self-management practice of DM by advising weight loss, monitoring the intake of carbohydrates and fibre, restricting cholesterol, and avoiding saturated fats, trans fats and sodium.[15] Finally, individuals with DM are required to enhance their tactics towards individual, family and social practices to improve self-management of DM.[16]

## Problems university students face according to literature

The main stressors for students when transitioning to independence are assuming the responsibility of caring for themselves, facing conflicts with parents and realising DM.[17] The main goal students with DM tend to aim for is the independent management of their DM by assuming the burden of self-care. Some of the factors formulated by Babler and Strickland that are inherent in the task of achieving independence are the fear of needles and forgetting to inject insulin.[17]

This article focuses on one issue, namely describing and investigating self-management of students living with DM at a tertiary institute.

## Method

Interactive Qualitative Analysis (IQA) data were collected during a focus group with students, selected from a constituency representing students living with DM on the NWU Potchefstroom campus. An ethical application was submitted to the Health Research Ethics Committee (HREC) of the NWU Potchefstroom campus. The researcher obtained ethical approval for the study from HREC on 19 November 2018 (ethics number NWU-00124-17-A1).

The IQA process that was used in this study consisted of a focus group and additional participants' Affinity Relationship Tables. The processes followed by the researcher, the specific protocol as well as documentation used was developed by Northcutt and McCoy.[18] 'IQA as a qualitative methodology is grounded in systems theory whose primary purpose is to present the meaning of a phenomenon in terms of elements (affinities) and the relationships among them.'[18]

The IQA data-collection tool – the focus group – assisted the participants to describe and label their experiences. The results of the focus group were conceptualised in a mind map (a composite picture of the system) of the participants and formed a systematic representation of how the group understood the specific problem or phenomenon.

The system, or mind-map, entails the affinities or categories of meaning and the perceived perceptual relationships amongst the affinities.[18] The IQA focus group was used to identify the affinities, each of which was well documented as part of the focus group protocol, according to the prescribed methods of Northcutt and McCoy. In the focus group the participants expand their meaning on each affinity. Affinities are like the quantitative concept of elements, or variables.

The idea of rigour that is used in the IQA refers to a specific procedure for both data collection and analysis.[18] The purpose of the IQA was to draw a picture of the system, or mind map, by means of the System Influence Diagram (SID) that is a representation of the perceptual topography of the mind map of the group of participants with regard to the phenomenon. Theoretical coding is aimed at the establishment of the perceived cause and effect relationship, or influences, amongst all the affinities of the system.

The participants in the focus group, and the additional participants in this study, analysed the nature of the relationships amongst the affinities according to the guidelines published by Northcutt and McCoy.[18] The results of these relationships could either have been A → B (A influences B), A ← B (B influences A) or A <> B (no relationship).

The study proceeded as follows:

> Phase 1: The IQA research design offered a series of tools to support and articulate the problem to the researcher. It helped to identify constituencies for the focus group, and to state a research question that is applicable to the problem statement.
>
> Phase 2: The focus group was formed by individuals who shared a common experience, lived in a common structure and had the same background pertaining to the phenomenon. The main concept of the IQA was to allow the participants of the constituency to define their meaning and the range of affinities of the phenomenon and to articulate how these affinities are linked in their perception of the phenomenon.
>
> Phase 3: There are two main parts in the last phase of the IQA. They are the results and analysis, and interpretations and implications that will be discussed by the researcher using all the data from the participants.

We therefore report on:

- naming and describing the elements of the system; and
- explaining the relationships between the elements of the system.[19]

The results from the relationships of the Affinity Relationship Tables (ART) of all the participants were tallied in the Combined Theoretical Code Frequency table.

The SID Assignment Protocol was used to allow the researcher to identify all the relationships and to determine what the basic flow of the system will be, from primary driver to primary outcome.[19] The Cluttered SID was built first, but consisted of saturated links between the affinities. However, it was wide-ranging and rich and thus difficult to interpret.[19] The next step was the Uncluttered SID where all the redundant links were removed. It then represented the simplest possible form.

The Pareto Protocol was applied to the system, the mind map, and results in the final Uncluttered Reconciled SID. In the final Uncluttered Reconciled SID all the vague relationships were resolved and the optimal numbers of relationships for the SID were determined. The Pareto Protocol specifies that the minority of the relationships in any system will account for the majority of the variation within the system.[19] Only one relationship could be used in the ART and thus the relationships with the highest amount of frequencies were used in the SID Assignment Protocol. The other relationships might have a significant impact on the final system and were reconciled according to the stipulations of the Pareto Protocol.[18]

## Results

All participants who took part in this investigation were well suited to the study. The focus group consisted of 13 participants consisting of 9 females and 4 males. Their ages ranged between 19 and 28. There were 11 participants diagnosed with T1DM and 2 participants diagnosed with T2DM. The participants spent between 1 and 9 years on campus among themselves and were diagnosed with DM between the ages of 4 and 18 years.

The final results constructed by the focus group can be seen in Table 1. Table 1 consists of the final eight affinities produced by the participants and the descriptions allocated to each affinity in their own words.

The results of the Detailed ARTs are in correspondence in a Combined Theoretical Frequency table. The purpose of the Detailed ART was to indicate the relationship between affinities. All the affinities received arbitrary numbers for the processing of the data.

The information of all 13 participants was tallied and the product was the Combined Theoretical Frequency table. The affinities at first were randomly ordered and numbered during the focus-group activities and were then sorted to be added to the Combined Theoretical Frequency table.

The researcher used the information from the Combined Theoretical Code Frequency table and following the Systems Influence Diagram (SID) Assignments protocol the researcher created the SID or mind map of the students' perceptual system of their self-management living with DM.

After following the Pareto Protocol the result was the Cluttered SID (see Figure 1), the first version of the SID that was developed.[18]

After following the rest of the Pareto Protocol the Uncluttered SID (see Figure 2) was formed.[18]

The Pareto Protocol was applied to the system to determine the optimal number of relationships in the composite system and to assist in resolving all the ambiguous relationships and the Uncluttered Reconciled SID was developed as seen in Figure 3.

The final SID was developed as seen in Figure 4.

**Table 1:** Affinities and descriptions

| Name of the affinity | Definition of the affinity |
|---|---|
| Food available on campus | There is not sufficient diabetic-friendly food available on campus |
| Keeping insulin cool | It is a 'drag' to keep insulin cool for up to 14-hour stretches, every day or trying |
| Causes of changing blood sugar | Almost everything contributes to blood sugar variation |
| Adapting to the effects of changing blood sugar | You have to understand the causes and effects and learn to counter it |
| Social awareness and acceptance | If society was better educated about diabetics, it would be much easier to manage my life |
| Hurdles in academic environment | The academic community has to be more accommodating |
| Adjusting by cooking | Learn, adjust, adapt in order to meet your personal health requirements (make it interesting) |
| Independent lifestyle | Accepting your condition and taking responsibility towards a healthy life |

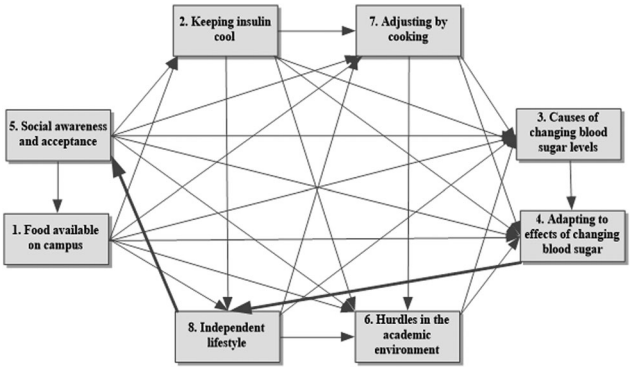


**Figure 1:** Cluttered systems influence diagram.

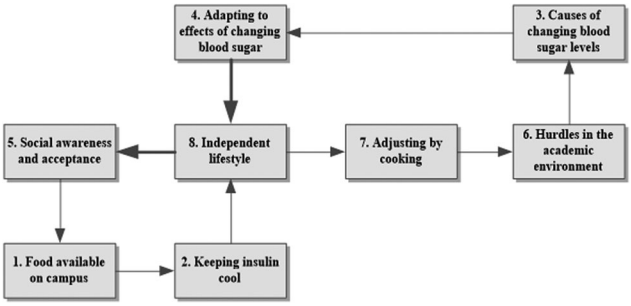


**Figure 2:** Uncluttered systems influence diagram.

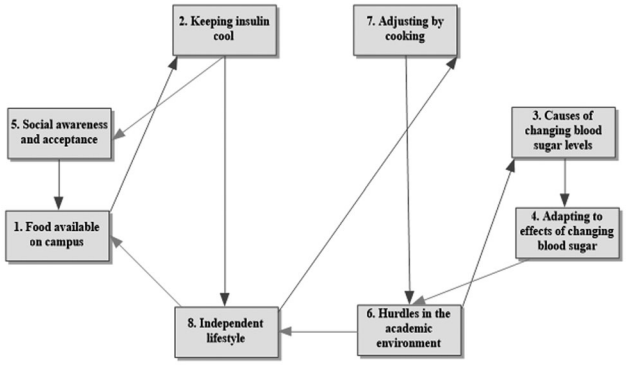


**Figure 3:** Uncluttered reconciled systems influence diagram.

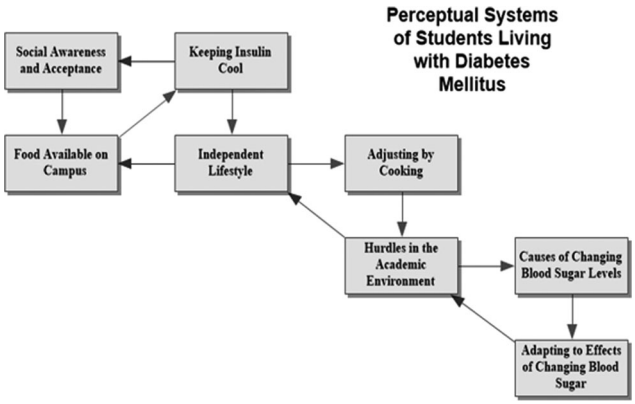


**Figure 4:** Final composite systems influence diagram.

## Discussion

The system can be seen as a pathway beginning with Social awareness and acceptance and ending with Adapting to effects of changing blood sugar levels. Affinities, or elements, can be seen as either positive or negative. One affinity's experience can influence and change the experience of the next affinity.[18]

In Figure 4 the primary driver, named Social awareness and acceptance, can be found at the top left of the figure. The primary outcome, named Adapting to effects of changing blood sugar, can be found in the bottom right corner. The secondary drivers can be found at the bottom left and in the middle of the figure. They are Food available on campus, Keeping insulin cool and Independent lifestyle. The secondary outcomes are found in the top right and in the middle. They are Adjusting by cooking, Causes of changing blood sugar and Hurdles in the academic environment.

Part of the IQA was the exercising of the system. The researcher exercised the system and cast scenarios by presuming given states of the drivers and investigated the expected results, which is known as prospective scenarios. The opposite or reverse exercise was also done and is known as the retrospective scenario. In the retrospective scenarios the states of some of the outcomes were presumed. The system was then examined to see what states of the drivers produced these outcomes. The third scenario was the impact of a factor outside the system that influenced the system at a given point and is known as the extra systematic scenario.

A prospective scenario will be used, in this article, as an example of how to exercise the system (as seen in Figure 5). In this scenario the researcher will look at the prospect of what if the *Social awareness and acceptance* was a *positive driver* and it did not influence the self-management of the student as the social environment will be informed. Then the researcher will explore what the result will be on the primary outcome, *Adapting to the effects of changing blood sugar*.

Social awareness and acceptance is the primary driver of the system. A positive Social awareness and acceptance will have a positive impact on the rest of the system, the self-management of students living with DM on campus. It is assumed that the rest of the system's affinities are all neutral. If the other affinities were negative, then the positive influence of Social awareness and acceptance would not be able to overturn for example the Hurdles in the academic environment. The community as a Social awareness and acceptance factor could have been positive and would be well educated on the self-management tasks of a student living with DM, but because the Hurdles in the academic environment is still negative and beyond the student's control, the system will stay negative.

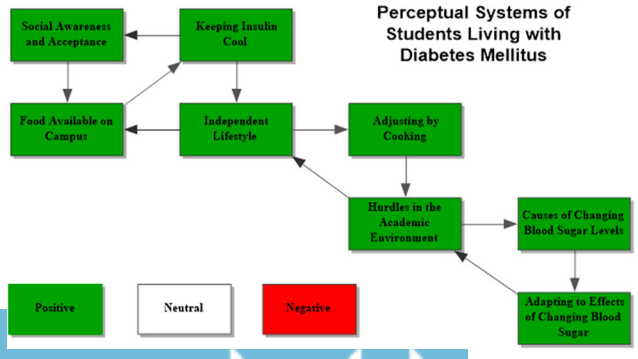


Figure 5: Optimal self-management for students living with DM.

Better education regarding DM will lead to people in the student's social environment asking more relevant questions on DM. Frustrating questions, such as 'can you eat that?', will be eliminated and questions concerning changing blood sugar levels and how to counter these will instead be asked. This will result in the student living with DM feeling supported and cared for.

Injecting insulin in public draws a negative reaction. In the ideal situation, injecting insulin would be acceptable and understood by the public in the same way as someone using an inhaler for asthma.

Testing, i.e. pricking and doing a blood test to check blood glucose levels, has caused people to cringe as they do not like the idea of blood. For students living with DM a community with ideal understanding of the consequences of not testing will encourage the student to engage in self-management tasks.

Living with DM is not something students advertise to the public. Consequently, students with DM on campus do not know about each other and cannot communicate with each other. Knowing other students with DM will result in positive interactions between students living with DM.

In an ideal world where everyone understood DM, the burden of educating the public about DM would not be the responsibility of the student with DM. In such an ideal scenario the DM student would live life without the stress of having to educate those around him/her on aspects of DM.

Students at tertiary institutions are under pressure to be socially active. The ideal for a student with DM is to know that you do not have to pretend to make others feel comfortable, and that you can be yourself around your peers.

### *Food available on campus*

If the perfect world existed, the Food available on campus would be a positive factor and the student living with DM would have better self-management skills in the university environment. There would be less unhealthy food on campus and more DM-friendly food options for the student living with DM to choose from and increase self-management. 'People are uninformed (management) and thus order/provide unhealthy/inappropriate foods.'

### *Keeping insulin cool*

The positivity towards the Food available on campus will then influence Keeping insulin cool. 'What you eat on campus (healthy or not) then determines how your blood sugar will be, in turn affecting how much insulin you'll need (influencing how much you bring).'

### *Independent lifestyle*

The student can now enhance his/her Independent lifestyle as the task of being independent becomes easier to maintain when the insulin is kept cool and managed through the daytime when he/she is active on campus. 'It just teaches you to take the steps of responsibility and to be independent and check up on yourself.' This makes the student more independent.

### *Adjusting by cooking*

Self-management becomes easier when a student has a positive factor in Adjust by cooking. Because the student is more independent, he/she either has an easy task of cooking for himself/herself when there is time, or the food available on campus is healthy enough to not need to cook for oneself. 'Adjusting by cooking helps one to be more independent by being able to manage one's diabetes better.'

### *Hurdles in the academic environment*

There are Hurdles in the academic environment when the student gets a positive effect on the Social awareness and acceptance. The hurdles, such as food available on campus and managing hypoglycaemia or hyperglycaemia in public, are eliminated by either having healthy food options or reacting to fluctuations in blood sugar in the moment as there is no judgement from the social groups. 'If one decides to cook then they can avoid hurdles like having high ketones during the school day. Cooking my own meals means controlled sugar levels and therefore better academic performance.'

### *Causes of changing blood sugar*

With a positive flow coming from Hurdles in the academic environment the Causes of changing blood sugar is handled in a positive way and not in a negative way as 'when experiencing stress in the academic environment, it directly influences your blood sugar levels'. Some causes will not be present as they are eliminated by previous positive influences like Food available on campus. Other factors driven by internal factors like emotions that cause fluctuations will be handled positively, because of positive factors such as a positive Independent lifestyle.

### *Adapting to effects of changing blood sugar*

Adapting to effects of changing blood sugar becomes positive when the Causes of changing blood sugar are positive. 'If the cause of your blood sugar rising/dropping is within your control then steps to counter the effects should be taken.' When the Causes of changing blood glucose are positive via elimination or better management, then Adapting to the effects of changing blood sugar becomes less complicated, because the self-management has increased through the positive system. 'Understanding why hypos occur at night helps one adapt to the effects of changing blood sugar, e.g. practising emotional self-control.'

## Conclusion

Social awareness and acceptance was identified as the primary driver of the system with Adapting to effects of changing blood sugar levels as the primary outcome to self-management living with DM.

The system produced four recognisable loops or cycles, namely the Ignorance loop, the Revision loop, the Developing loop and the Self-management loop.

The students experienced Social awareness and acceptance as a negative aspect in their daily lives as they have limited power over the stigma surrounding DM. Social and awareness plays a significant role in the lives of students living with DM as it influences self-management of DM.

The perceptual system might not be a complete representation of self-management of DM but rather a system reflecting barriers towards compliance with self-management. However, it shows a significant but unknowing shift in terms of independence towards changing and adapting to DM.

The model can be used by universities across the globe to get a better understanding of the perceptions of students living with DM. Management in the cafeterias and other providers of food on campus can use the model to change their meal plans to include the dietary needs of students living with DM. Manufacturers can use the model to develop a way for students to keep their insulin at an optimal level for as long as possible and to be as comfortable as possible. The structures and management on campus have the power to increase awareness of DM. They can use the model to enforce the belief that a change in stigma and awareness can assist in the self-management and quality of life of students living with DM. Accommodation for students living with DM can be achieved if faculties used the model to change the academic environment for the better. Healthcare providers can use the model to educate themselves on perceptions that students living with DM have and to communicate misunderstandings to students diagnosed with DM. Students living with DM or recently diagnosed with DM can use the model and results to enhance their knowledge with regard to self-management of DM. Postgraduates can use the model to build their study around or increase study on the topic.

A few limitations were identified in the study, but none that compromised the integrity of the research process or the results and conclusions. Limitations such as working with students, the number of participants and the timeframe of the focus group were present but did not limit the study. This study opens the way for any future investigations of students living with DM. More constituencies can be brought in and be compared with this model, for example, adults who had to make it through university living with DM.

This study was the first to be undertaken on the perceptions of students' self-management living with DM. It helps by providing new information on the format of a system and model to the benefit of universities and students regarding DM. This study gives a small view into the daily lives of students living with DM on campus and how they deal with self-management.

*Acknowledgements* – Dr Danny McCoy is thanked for his assistance in the process to complete the Pareto Protocol. Financial assistant from MUSA and the North-West University for study bursaries.

*Disclosure statement* – No potential conflict of interest was reported by the authors.

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**Received: 10-06-2020 Accepted: 28-08-2020**