

Illness perception of adolescents with well-controlled type 1 diabetes mellitus

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Abstract

In this study, to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus in South Africa, semi-structured interviews were conducted with nine, purposively selected adolescents (mean = 13.9 years; median = 12). Themes that emerged from the thematic analysis include the following: accepting diabetes and the diabetes care plan as part of their lives; viewing diabetes as manageable and as their responsibility; and the important role of gaining information on diabetes and diabetes management. These perceptions contributed to adherence to diabetes care plans and should be explored and developed among adolescents with type 1 diabetes mellitus to improve their diabetes management.

Keywords

adherence, adolescents, diabetes mellitus, illness perception, qualitative methods

Introduction

Type 1 diabetes mellitus, one of the most emotionally and behaviourally challenging chronic diseases (Compas et al., 2012; Hagger et al., 2016), usually presents during childhood, with 79,000 children worldwide estimated to develop type 1 diabetes mellitus annually (Patterson et al., 2014). Individuals diagnosed with type 1 diabetes mellitus must adhere to a complex, multicomponent care plan (Gonzalez et al., 2016), which can be challenging, especially during adolescence (Compas et al., 2012; Hunter, 2016). This is a critical transition period in diabetes management when adolescents should accept more responsibility for their diabetes management (Hunter, 2016) but are also endeavouring to establish autonomy during a time of physiological transformation (Hunter, 2016; Wiebe et al., 2014). Research has indicated that adherence to diabetes care plans usually deteriorates during adolescence (Hilliard et al., 2013; King et al., 2014).

Effective therapy modules exist, but their essential components include balancing insulin dosing with frequent blood glucose monitoring, attention to diet and complying with an exercise program (Borus and Laffel, 2010; Hunter, 2016). Successful implementation of and consistent adherence to an intricate and demanding care plan presents a

challenge to even the most motivated adolescent (Borus and Laffel, 2010). A considerable amount of research has been done with adolescents living with type 1 diabetes mellitus and concomitant poor treatment outcomes. Inadequate adherence has been strongly linked to an increased risk of microvascular complications (retinopathy and nephropathy) (Lung et al., 2013). Furthermore, poor management has been associated with psychological disorders, including anxiety (Herzer and Hood, 2010) and depression (Buchberger et al., 2016). The barriers to effective disease management among adolescents with type 1 diabetes mellitus include a phase of psychological turmoil and peer pressure, a lack of knowledge and understanding of care plans and potential health complications, fatigue from adhering to a diabetes care plan and experiencing physical changes with greater insulin resistance during puberty (Borus and Laffel, 2010; Datye et al., 2015; Lotstein et al.,

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2005). Yet, while adolescents often adhere poorly to diabetes care plans, some succeed in complying with the required protocol (Hilliard et al., 2013). Psychosocial factors reported to be associated with good metabolic control (HbA1c levels) include coping strategies (Graue et al., 2004) and perceptions of their condition, also referred to as illness perceptions (Broadbent et al., 2011).

As adolescents endeavour to make sense of their condition, they develop beliefs that will guide and influence their management thereof (Petrie and Weinman, 1997). Illness perceptions are defined as a collection of beliefs about an illness (Petrie et al., 2007; Petrie and Weinman, 2012) acquired through experiencing or being subjected to an ailment and by personal interpretation of information gathered (Hagger and Orbell, 2003). The Common-Sense Model of illness representations (Petrie and Weinman, 1997) is widely used in diabetes research and entails five dimensions, namely, (1) perceived cause, (2) consequences (beliefs about effects and impact), (3) control/cure (beliefs about curability and controllability), (4) timeline (course and duration) and (5) identity ascribed to illness (Petrie et al., 2007; Petrie and Weinman, 1997, 2012). Chronically ill patients' philosophies about their illnesses prognosticate self-care behaviour shape illness-related outcomes (Mc Sharry et al., 2011) and have been shown to be independently associated with adherence to treatment and metabolic control in people living with type 1 diabetes mellitus (Broadbent et al., 2011; Hagger and Orbell, 2003).

Research exploring the relationship between illness perceptions and diabetes outcomes among adolescents has been limited in South Africa, known for its culturally diverse population. Furthermore, previous international studies have yielded contradictory results (Fortenberry et al., 2014). A number of qualitative studies have explored the experiences of adolescents living with diabetes (see Ferrari et al., 2018; Koller et al., 2015; Schur et al., 1999), but little qualitative research concerning illness perceptions of adolescents was found. Furthermore, gaining a deeper understanding of illness perceptions of adolescents who manage their diabetes well can provide valuable information to possibly improve the adherence of those who are living with uncontrolled diabetes. The aim of this study is first to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus and second, to explore how these illness perceptions help them to manage their diabetes.

Methods

Rationale for a qualitative design

There has recently been a significant increase in quantitative research into illness perception, especially since the development of validated psychometric instruments to measure this construct. These instruments include the

Illness Perception Questionnaire (IPQ; Petrie et al., 1996), the revised version of the IPQ (IPQ-R; Moss-Morris et al., 2002) and the Brief Illness Perception Questionnaire (B-IPQ; Broadbent et al., 2006). However, this research is the first of its nature to explore the above objectives in the South African context, specifically focusing on adolescents with well-controlled diabetes. A qualitative approach with a subtle realist perspective was used to gain a better understanding of adolescents' illness perceptions and how it helps them to manage their diabetes. This approach assumes that we can only know reality from our own perspective of it (Cohen and Crabtree, 2006). Open-ended, semi-structured interviews were used as this allowed participants to introduce and discuss the issues they perceive to be significant (Ritchie and Lewis, 2009).

Participants

The gatekeeper was the Centre for Diabetes and Endocrinology (CDE) in Houghton and Parktown, Gauteng province region of South Africa. Prospective participants were informed by the CDE of the background to the study and the voluntary nature of participation. Purposive sampling was done to select participants who conformed to the sampling criteria, namely, they had to be aged 12–18 years; had been diagnosed with type 1 diabetes mellitus more than 12 months previously; were an enrolled patient of the abovementioned CDE; and to have had maintained an HbA1c of 64 mmol/mol or less during the preceding 12 months. Although ISPAD (International Society for Pediatric and Adolescent Diabetes) prescribes an HbA1c of 58 mmol/mol, it was decided, in consultation with a team of medical experts to also include participants with an average HbA1c up to 64 mmol/mol. This was done to allow more participants to take part and is still within the prescribed guidelines of the CDE (2015). The researchers excluded individuals who were currently undergoing psychotherapy and those suffering from another chronic medical condition that could impact diabetes management.

Participants who indicated interest in taking part in the project were screened and interviewed after obtaining consent. As information on eligibility to take part in the study was communicated clearly to participants, all participants who were screened were allowed to take part and there were no participants who dropped out. Recruitment and data collection ceased when ongoing analysis of the data confirmed that no new information or insight was forthcoming. Data saturation was reached after seven interviews but two more interviews were conducted to ensure that no new data emerged. The final sample consisted of five male and four female adolescents between 12 and 18 years (mean = 13.9 years, median = 12). Three participants were Afrikaans speaking and six were English speaking. The median age at diagnosis was 9.7 years, ranging from 5 to

12 years. The average HbA1c level of the participants was 55 mmol/mol (SD=0.68).

Biographical information and pseudonyms of participants

Charles is a 16-year-old boy who has been diagnosed 4 years ago. Anna is a 12-year-old girl, 1 year after diagnosis. Susan is 15 years old, living with diabetes for 10 years. John is a 16-year-old boy who has been diagnosed 5 years ago. Matthew is 12 years old, living with diabetes for the past 7 years. Frank, also 12 years of age, has been living with diabetes for the past 3 years. Both Sylvia and Peter are 12 years old and have been living with diabetes just more than 1 year. Finally, Linda is the eldest of the participants being 18 years old, living with diabetes for the past 6 years.

Ethical considerations

Several measures were implemented to verify the ethicality of this research. Before the study was conducted, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) granted ethical approval for this study (NWU-HS-2016-0066). The participants comprised a physically and potentially psychological vulnerable set of individuals due to their diagnosis (type 1 diabetes mellitus) and their age (minors). The researchers were fully cognisant of the sensitive and emotional nature of the exploratory inquiry, and the rights and prerequisites of the individual were therefore considered at all times. Steps taken to avoid participant stress included conducting interviews in a safe and familiar place, providing participants with a low-carb snack and having access to medical staff and a psychologist should it be necessary. Interviews proceeded once the researchers had obtained independent informed written consent from both the parents and the participants. Participants were guaranteed confidentiality and anonymity which was ensured using participant codes, storing consent forms separately from the code list, storing all data generated securely and making sure that no statement would be used in a way that would identify any specific participant. Each participant received a summary of the findings, as well as positive individual feedback regarding their illness perceptions and how they aided in managing their diabetes well.

Data generation

Open-ended, semi-structured interviews were conducted between October 2015 and August 2016. The interviews were conducted at the site at which the participants normally received their treatment (CDE, Parktown). The researchers scheduled the interview sessions to coincide with the participants' regular visits to the CDE. Three parents requested that the interviews be conducted at their

homes in Johannesburg, South Africa. The three interviewers were fully bilingual. With the participants' consent, the interviews were audio-recorded and lasted an average of 45 minutes. An interview agenda was adhered to, ensuring consistency across the interviews. Interview questions were not formulated based on any existing model of illness perception but was focused on gaining a better understanding of how the perceptions of adolescents influence their management of diabetes. Interviewers also wrote notes and reflections on the day of the interviews.

Data analysis

All the audio recordings were transcribed verbatim by the interviewers. The research team checked each transcript against the recordings for accuracy. Thematic analysis using an inductive (data-driven) approach was used to analyse the data. Thematic analysis is a method of identifying, analysing and reporting patterns or themes within data (Braun and Clarke, 2006). Inductive reasoning was then applied as an open-ended exploration to identify categories and themes in the data (Braun and Clarke, 2006). The transcripts were imported into Atlas.ti, a qualitative data management software application, to facilitate data coding. Data were analysed following the six steps described by Braun and Clarke (2006), namely, immersion in data to become familiar with its breadth, developing initial codes, searching for themes, reviewing themes, naming and defining themes and finally, reporting the outcomes. A co-coder also independently analysed the data, divergent findings were discussed and consensus was reached in discussions with the researchers and a panel of medical experts. Thus, this qualitative study drew on the concept of investigator triangulation by sharing data collection and data analysis between researchers drawn from various disciplinary backgrounds (research psychology, clinical psychology and general practice in the health psychology domain), again increasing the trustworthiness of the analysis. The researchers had a strong positive psychology stance and were constantly aware of their possible influence on the analysis process and kept reflective journals about their own process to ensure it does not impact the analysis.

To encourage high-quality research, this study was subjected to Lincoln and Guba's (1985) criteria for establishing trustworthiness, namely, credibility, confirmability, dependability and transferability. Credibility was accomplished by the use of the gatekeepers at the CDE. They ensured that the participants who were recruited were able to make meaningful contributions to this study. Sufficient participant quotations are provided to support the findings (see 'Results' section), which are deemed credible because they are grounded in data rather than in assumptions or conjectures, thus also establishing confirmability. To achieve dependability, two researchers deciphered the data individually and independently, after which a consensus was

achieved regarding the reliability of the research and its saturation. Good contextualisation included a rich description of the methodology, context and research process, contributing to transferability.

Results

Thematic analyses of the participants' responses to the first aim of the study (What are the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus?) yielded four dominant themes, namely, (1) living with diabetes becomes a way of life, (2) managing diabetes leads to being different, (3) acknowledgement of potential negative health consequences and (4) recognising diabetes as manageable. The second aim of the study (How does these illness perceptions contributed to the effective management of the participants' diabetes?) yielded three further themes, namely, (1) procurement of adequate knowledge, (2) embracing accountability by complying with obligatory management protocol and (3) acceptance of lot/fate. The motive themes are illustrated by verbatim examples from the nine participants.

Theme 1: living with diabetes becomes a way of life

The majority of the participants recognised that type 1 diabetes mellitus was an integral part of their daily lives:

It's a way of life. What else? (Charles)

Can't really be ashamed of something that's part of me. (Susan)

However, it was evident from the data that this perception was shaped over time. The participants described their association with diabetes management as difficult at first, but as time progressed, they acquired an understanding of how to manage their diabetes. With a better understanding, well-controlled management became a habit:

You brush your teeth in the morning. You have to bath. It's the same thing as that. (Charles)

It's just routine action [...] you automatically do. (Matthew)

As such, the identity and management of type 1 diabetes mellitus could not be separated from the individual, since it had become a routine component of his or her daily life. There was no concord between the participants themselves, especially among the younger adolescents, regarding the label they attached to type 1 diabetes mellitus, with some reporting: 'condition', 'illness' or 'disease'. Yet, diabetes and its management were perceived not just as sheer habit, but an integral part of self, 'something that's in you' (Anna).

Theme 2: managing diabetes leads to being different

The majority of the participants perceived themselves as being different because they had to adhere to a care plan, unlike people without type 1 diabetes mellitus:

I am not similar to other people who have a normal pancreas. Other children can eat whenever they want. I must first prepare myself. (Matthew)

I am different. (Anna)

This perception is supported by the participants' experiences of various situations in which they were treated differently from their peers and the wider community due to their diabetes care plans. Some participants mentioned that one way of coping with this 'being different' is denial:

I just wanna pretend that I'm normal. Like pretend it's not there. (Charles)

However, it was evident from both the interviews and the inclusion sample criterion of well-controlled type 1 diabetes mellitus that these participants were actively involved in managing their diabetes, not indicating avoidance behaviour. Yet, sometimes they wanted to experience being 'normal' and conform to ordinary conventional behaviour, for example, in social settings regarding their diet restrictions, even though they acknowledged the negative health consequences (theme 3) and the implications (e.g. high blood sugar) of indulging in a typical 'normal' adolescent lifestyle.

Theme 3: acknowledgement of potential negative health consequences

The participants uniformly acknowledge that type 1 diabetes mellitus could have negative health consequences:

You know what it does to people. You know what it has done to people. You know that it can do it very likely to you. (Peter)

The participants understood that uncontrolled type 1 diabetes mellitus could cause serious damage to the human body. For example, consequences that were reported included the following: 'into coma' (Frank), 'complications are like your eyesight, your circulation in your feet' (Susan), 'losing weight' (Linda) and admitting that such damage could have fatal consequences:

If I don't manage it properly it could kill me in the end. (Charles)

More specifically, the participants realised that these negative outcomes went hand in hand with poor diabetes management. 'You don't want the trouble that comes with

diabetes not managed well' (Peter). However, in some participants, this perception elicited fear:

If it's high I then get a bit of a fright. Then I give insulin because [...] I don't wanna compromise my future. (Susan)

It makes you scared. It makes you feel what could happen so it keeps you in line. (Peter)

The experience of emotional distress and fear (as seen from the above quote) motivated this group of adolescents living with well-controlled diabetes to stay within the diabetes care plan. The illness perceptions of adolescents living with type 1 diabetes mellitus regarding possible negative health consequences are interlinked with themes 5 and 6. Nonetheless, the knowledge of the complications that might arise due to poor management enabled the participants to appreciate the benefit of managing their diabetes well.

Theme 4: diabetes is manageable

Despite the specific diabetes care plan, the majority of the participants perceived type 1 diabetes mellitus to be manageable:

It is manageable. (Charles)

It is not the most difficult thing to manage. (John)

This perception was regarded as a most positive aspect of diabetes when compared to, for example, '*much better like say a cancer patient*' (Susan). Consequently, some even perceived themselves to be fortunate because diabetes, however inescapable, was manageable. The participants also perceived managing diabetes well as being beneficial for the future in terms of avoiding negative health consequences (theme 3) and, for some participants, buying time for a future cure:

If I control it now maybe if a cure comes out and then I can do it, but if I don't, I can't use that cure because maybe one limb of mine will be gone. (Sylvia)

The data indicated that this illness perception might have developed over time as the participants began to perceive, acknowledge and accept that it was part of their lives (theme 1), and as they gained adequate knowledge about how to manage their diabetes (theme 5) and were empowered by hands-on experience. Although type 1 diabetes mellitus was perceived as manageable, some participants acknowledge that crisis situations were inevitable, '*You gonna get highs and you gonna get lows*' (Susan). Yet, due to the fact that diabetes was perceived as manageable, some of the participants experienced guilt if they failed to manage it well, especially in view of the fact that diabetes calls for specific management (theme 6):

I always think it's my fault that it's high. Maybe I have eaten something or I haven't injected enough. (Anna)

Theme 5: procurement of adequate knowledge

The most prominent repetitive theme in the dataset was the imperative procurement of adequate knowledge. By incorporating it as a way of life (theme 1) and having come to the conclusion that type 1 diabetes mellitus is manageable (theme 4), the participants understood and acknowledged that they had a duty to acquire adequate knowledge of the management of their diabetes. Furthermore, the participants perceived acquiring such knowledge as a vital obligation:

Without knowledge you're pretty much dead. (Peter)

In addition, knowledge of the complications (theme 3) that poor management might generate helped the participants to appreciate the benefit of managing their diabetes well. This procurement of adequate knowledge thus empowered the participants living with type 1 diabetes mellitus to not only manage their diabetes well but also to proceed with self-confidence.

Theme 6: embracing accountability to comply with the specific management protocol

By understanding the beliefs of the participants, which include that, although type 1 diabetes mellitus is manageable (theme 4), poor management of type 1 diabetes mellitus could generate negative health consequences (theme 3) that should be avoided, it was evident that these philosophies helped, in a specific way, to promote rigorous adherence to their management. The majority of the participants perceived that they had to adhere to a specific diabetes care plan:

It's not grey areas. It's only black and white. (Charles)

You have to do it every day. (Anna)

Also, the majority of the participants specifically regarded the diet they had to observe as essential and obligatory, '*to only eat the appropriate food*' (Matthew). Furthermore, the participants perceived this management approach to be non-negotiable, '*I just have to manage it properly*' (Linda). This theme clearly links with theme 5, namely, admitting that adequate knowledge is essential.

In general, discipline, maturity and responsibility are perceived to be vital if one is to comply with the obligatory management protocol:

Don't try and make excuses and be lazy [...] I would recommend to them to take care of it [type 1 diabetes mellitus], cause it's taking care of your health. (Charles)

Nobody else can decide for you when to eat this or that or when to inject [...]. You yourself must decide how you are going to do it. (John)

Becoming more disciplined, responsible and mature will have a positive impact on them as individuals and on their health in the future:

It's a win-win situation, because I'm more grown up and ready for everything [...] it will help me in the future. (Peter)

By embracing accountability to comply with specific management protocol, the participants integrated the management of their disease into the nucleus of their daily being (theme 1).

Theme 7: acceptance of lot/fate

The participants acknowledged that acceptance of their illness helped them to manage their diabetes well:

Ok, this is something I have; this is something I am going to have to live with, so I might as well just get used to it and make the best of it. (Susan)

With the majority of the participants, it was evident that this perception was also shaped over time. Initially, it was not easy to come to this conclusion, but as time progressed, they gained insight and a better appreciation of how to manage their condition, and they succeeded in incorporating its management into their daily lives (theme 1). The acknowledgement that they were indeed different but their ability to come to terms with it also helped them to accept their disease:

No point in me whining and complaining, feel bad like why people gonna look at me funny. It's just no point. (Charles)

As time passed, the participants accepted that *'it is what it is, you can't change it'* (Susan) and *'I'm gonna live with it'* (Anna). Furthermore, they recognised that diabetes and the management thereof held negative as well as positive consequences:

It's like everything in your life [...] it's got its ups and downs. (Susan)

Subsequently, by accepting responsibility (theme 6) *'it's on you to make yourself better'* (Linda) and that their fate is in their own hands will provide them with a future:

I understand that if maybe there's no cure it will be for [...] with me for the rest of my life. So if I learn now, I won't struggle later. (Sylvia)

Discussion

The merit and contribution of this study is that it is considered by the researchers to be the first South African

exploratory study of illness perception among adolescents with well-controlled type 1 diabetes mellitus. In addition, the findings illustrate how illness perceptions can create a positive framework that aids the management of type 1 diabetes mellitus.

Research concerning the barriers to effective disease management among adolescents with type 1 diabetes mellitus yields contradictory results. Barriers to management include psychological turmoil, peer pressure and lack of knowledge about care plans and potential health complications (Borus and Laffel, 2010; Datye et al., 2015; Lotstein et al., 2005). However, the findings of this study illustrate that adolescents with well-controlled type 1 diabetes mellitus can develop illness perceptions that can help them to embrace living with diabetes. The participants were empowered by managing their diabetes well and thus gained confidence about the future. Although the perception of being different can be disturbing and problematic for adolescents, the participants had accepted the fact that due to their diagnosis and care plan, they were dissimilar to their peers. The findings highlighted the fact that the participants understood and accepted that they had a duty to acquire sufficient knowledge regarding the management of their diabetes and acknowledged that potential negative outcomes went hand in hand with poor diabetes management.

The first goal of this study was to explore the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus. Although there is perplexity among the participants regarding the identity of type 1 diabetes mellitus (is it an illness, disease or condition?), a distinctive conclusion manifested, namely, that well-controlled adolescents view it as a way of life. Research on illness centrality (Helgeson and Novak, 2007) showed that the extent to which adolescent females define themselves in terms of their illness is most problematic when the illness is perceived in highly negative terms, but this group of adolescents identifies diabetes as an integral part of their existence and a permanent relationship to acknowledge rather than to oppose. This quality has thus far not been identified or explained in diabetes research.

Furthermore, the adolescents seldom reacted to the desire to pretend that they were 'normal'. They were supported by the (fear-inducing) knowledge that negative health outcomes went hand in hand with poor diabetes management, making an obligatory management protocol compulsory. The perceived severity of bad outcomes motivated them towards greater adherence. This acceptance of consequences is supported by a study done by Gaston et al. (2012), in which better blood glucose monitoring was associated with acknowledging the danger of uncontrolled diabetes.

Previous research has underlined that patients who believe that their diabetes is variable and unpredictable might show little motivation to reduce their blood sugar levels and sustain good control (Mc Sharry et al., 2011). By contrast, the findings indicate that although some participants acknowledge that crisis situations were inevitable,

they still perceived type 1 diabetes mellitus to be manageable and thus strove to maintain good control. Although previous research has established that questions concerning long-term outcome beliefs are not valuable because the large majority of patients consider their diabetes to be a chronic condition with no known cure (Huston and Houk, 2011; Scholes et al., 2013), the timeline beliefs between the participants in this study varied. Although some of them believed that there was no cure and had accepted their lot, other participants seemed to be optimistic – they had accepted their fate, but they also believed that controlling diabetes well was a way of buying time while awaiting a potential cure. This contradicts previous research, which stressed that waiting for a potential cure was associated with poorer glycaemic control (Scholes et al., 2013).

Although an inductive approach was adopted for this study, the findings signified both similarities and differences between the broad dimensions of the Common-Sense Model of illness representations (Petrie and Weinman, 1997). Research has emphasised that illness perception dimensions of identity, consequences and control are significantly correlated with well-controlled type 1 diabetes mellitus across studies (Gaston et al., 2012; Griva et al., 2000; Nouwen et al., 2009). For example, in Griva et al.'s (2000) study of adolescents and young adults (15–25 years) with type 1 diabetes mellitus, 30 percent of the variances in HbA1c were attributed to these three dimensions.

The second objective of this study was to explore how these illness perceptions help adolescents to manage their diabetes. Disease can be described as a catastrophe affecting the very existence of an individual with consequential psycho-social outcomes (Lewko et al., 2007). It is conceivable, taking the adolescence developmental phase into account, that especially adolescents living with type 1 diabetes mellitus might experience difficulty in coming to terms with the idea of living with a disease. Some of the participants were found to acknowledge the actuality of their illness and even succeeded in identifying some long-term positive consequences of their chronic illness, which in return encouraged effective management. This acceptance was formed over time, without a clear specific timeframe or end point. Taking the demographic information of the participants into account, the average disease duration had been 4.1 years. However, it was evident from the data that, as time progressed, insight into and appreciation of how to manage diabetes were developed, which in return helped to facilitate acceptance. Furthermore, by accepting living with diabetes as a way of life, the participants also recognised and acknowledged that they had a responsibility to acquire adequate knowledge about the management of their diabetes. This is strongly supported by other studies that showed that a lack of knowledge was associated with poorer treatment adherence. By empowering adolescents from the onset of the disease with more knowledge of how to manage their diabetes, we might help adolescents to come to terms with it much sooner.

Although this study provides insight into the illness perceptions of adolescents living with well-controlled diabetes, it should be noted that the study included participants with limited demographic variation. The majority of the participants were from an urban, socio-economically moderate income bracket, able to afford a private medical insurance and thus able to access treatment via the private health sector, while the reality within the South African context is that many people living with type 1 diabetes mellitus are dependent on the public health sector to receive their diabetes treatment due to socio-economic factors. Furthermore, the inclusion criteria sample was purposely aimed at adolescents between 12 and 18 years, yet the study did not synchronise the distribution between the age span – the majority of the participants were 12 years. This aspect might have limited the study in terms of obtaining more prolific data. Notwithstanding these limitations, this study sheds light, from a new perspective, on people who successfully adhere to treatment and lays the foundation for future innovative research that focuses on positive approaches and mindsets to be nurtured and encouraged, rather than only on what contributes to poor management outcomes.

Conclusion

This study provides new information about the illness perceptions of adolescents with well-controlled type 1 diabetes mellitus in South Africa, as well as insight into how these perceptions aid effective management. The findings will be of use for diabetes-related healthcare experts who can constructively use the conclusions to look beyond just the care plan and develop these underlying perceptions of adolescents with type 1 diabetes mellitus to improve their diabetes management. However, suggestions for future research include expanding the demographic variation of participants to also include rural areas and investigating the development of illness perceptions within this group. This would require a longitudinal study exploring how illness perceptions develop during the period of adolescents. Furthermore, conducting focus groups with adolescents with well-controlled diabetes can provide valuable information on the development of their thoughts about diabetes, as well as the mechanisms involved in the developing of illness perceptions, which can inform possible interventions to increase adherence. This will help to better understand why for some adolescents, experiencing emotional distress and fear debilitates them not to adhere to the diabetes care plan, while it motivates others to develop alternative beliefs which aids in diabetes management.

Clinical implications

Adolescents should be made aware of their own illness perceptions and be challenged to change illness perceptions to facilitate adherence. Developing clinical interventions to

address cognitive or behavioural features linked to perceptions regarding diabetes adherence could improve diabetes outcomes. Also, the illness perceptions might be connected with or linked to numerous other challenges during adolescence, including acquiring greater competencies in diabetes numeracy (e.g. insulin dosing; Mulvaney et al., 2013) and improving socio-emotional aptitudes (Fortenberry et al., 2014).

The findings illustrate how illness perceptions might create a positive framework that facilitates the management of a chronic illness. This is supported by the review done by Yi-Frazier et al. (2012) demonstrating clear evidence of the impact of a positive psychological framework on the daily management and health outcomes of people with diabetes. It is recommended that research regarding people living with type 1 diabetes mellitus should equally focus on the positive aspects (Jaser et al., 2014) as opposed to focusing only the areas that need improvement. Clinicians and researchers should appreciate the availability of measurements of wellness (Vázquez et al., 2009) and specifically focus on identifying positive areas in addition to addressing deficits during diabetes adherence interventions.

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