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Main Title: Fatalism, Faith and Fear: A case study of self-care practice among adults with type 2 diabetes in urban Malaysia.

Key words: Diabetes Mellitus Type 2, Self-care, Qualitative research, Case Study, Adult Nursing.

What does this paper contribute to the wider global clinical community?

- Fatalism, faith and fear influence the way the Malaysian population with type 2 diabetes manage self-care and respond to health professional consultations
- Structured self-care programmes for type 2 diabetes are required in Malaysia and should focus on building patients' feelings of self-efficacy

Abstract:

Aim: An exploration of self-care and self-care support in patients with type 2 diabetes in urban Malaysia

Background: The prevalence of type 2 diabetes in Malaysia and associated long-term and life changing complications is increasing. With effective self-care and self-care support severe complications of the condition can be avoided or reduced. Prior to this study no evidence existed about Malaysian patients' management of the condition or support for self-care from the health care system.

Design: A single embedded qualitative case study.

Methods: Semi-structured interviews with 18 patients with type 2 diabetes aged 28 - 69 years, health care professionals (n=19), observations (n=13) of clinic appointments from two urban settings in Malaysia and a documentary analysis. Recordings were transcribed verbatim, field notes were made during observations and the data analysed and synthesised within and across case using Framework analysis.

Findings: Three main themes explained self –care and self-care support in Malaysia: fatalism, faith, and fear. Patients were fatalistic about developing diabetes – they perceived it as inevitable because it is so common in Malaysia. However, faith in God, coupled with fear of the consequences of diabetes, motivated them to engage in self-care practices. The fear was largely induced by diabetes health care professionals working in overcrowded clinics, and stretched thinly across the service, who used a direct and uncompromising approach to instil the importance of self-care to avoid severe long term complications.

Conclusion: This study provided important insight on how people in Malaysia developed diabetes, their responses to the disease, and the approach of health care professionals in supporting them to engage with self-care.

Relevance to clinical practice: Any future development of self-care programmes in Malaysia needs to recognise the factors that motivate patients to self-care, and include components that build self-efficacy.

Introduction

The prevalence of diabetes mellitus (types 1 and 2) is escalating rapidly worldwide, especially in developing and newly industrialised countries, with more than 170 million people predicted to have the condition (Rugayah, 2007) by 2025 in the Southeast Asia region (Mutlu et al., 2015). Thought to be a result of the economic development, increasing obesity, more sedentary and unhealthy lifestyles, and urbanisation of countries in this region, this will also have cost implications for health care (Whiting, Guariguata, Weil, & Shaw 2011). This increase is apparent in Malaysia where numbers are reaching epic proportions with 17% (3.5 million) of the population currently reported to have the condition (Ahmed 2015-18). Urban areas such as Kuala Lumpur and Selangor recorded the highest prevalence of type 2 diabetes with up to 128,000 cases compared to other states in 2012 (Malaysian Ministry of Health, 2012). People with poorly controlled diabetes type 2 are at risk of severe health complications such as lower limb amputation due to ulceration (4.3%), stroke (3.4%) and chronic renal failure (1.6%) (Letchuman et al., 2010). Malaysia is reported to have the highest numbers of patients with diabetes associated renal failure in the world (Williams, 2010). This pattern of increasing prevalence has occurred despite health promotion measures and improvements to services initiated by the Malaysian Government in 2008.

Effective self-care is key in the avoidance of these conditions related complications to which there are four key elements: diet modification, physical exercise, adherence to medication, and self-monitoring blood glucose (Funnell et al., 2010). Success in self-care largely depends on the ability and willingness of the patients to carry out complex and multifaceted self-care activities (Evangelista & Shinnick, 2008). However, the evidence, internationally, has consistently found that patients find aspects of self-care for diabetes type 2 challenging, in particular adherence to recommended physical activity and dietary regimes. A questionnaire based study set in East Jerusalem identified that 84% (n=230) were physically inactive and 64.3% did not follow a low fat or low sugar diet (Daoud, Osman, Hart, Berry, & Adler, 2015). In a Bangladesh Health Sciences Hospital, patients (n=500) completed structured questionnaires, 28.2% reported problems with self-care and non-adherence to exercise and diet was reported at 33.2% and 44.8% respectively (Saleh, Mumu, Ara,

Hafez, & Ali, 2014). A study conducted in the United States (US) measured physical activity in 406 type 2 diabetes patients through a self-report questionnaire and found only 34% exercised, and 9% to a level that would be clinically beneficial (Thomas et al 2004).

Focusing on the Asian region, a similar pattern is evident in the literature. In Taiwan, a National Health Interview Survey found that only 21.8% of 764 participants adhered to meal plans and 40% performed exercise regularly (Chang et al., 2005). In the same study adherence to medication varied and depended on the number of medications and types of treatment used. Patients taking oral hypoglycaemic agents had better adherence (70.8%) than patients with insulin injections (9%) (Chang et al., 2005). These findings are similar to an international review of studies on adherence to medication in three cardiovascular conditions, including diabetes - 58% patients achieved 80% adherence to their diabetes related medication (Cramer, Benedict, Muszbek, Keskinaslan, & Khan, 2008).

Ineffective self-care has consistently been argued to be the main reason for related health complications of type 2 diabetes in Malaysia (Chan, 2005; Ramli & Taher, 2008; Rampal et al., 2008; Mafauzy et al., 2011). Evidence exploring why this is the case is limited but a study of 126 patients with type 2 diabetes found that 80% had not followed diet recommendations, 54% were physically inactive and only 4% tested their blood glucose regularly (Tan & Magarey, 2008). However, in contrast with studies in other countries Malaysian patients had better adherence to insulin treatment than oral hypoglycaemic agents, although adherence rate was still only 46%. These studies suggested that poor glycaemic control in type 2 diabetes patients in Malaysia was due to poor adherence to self-care activities. The reasons for this are not clearly understood due to lack of research in this area. Therefore, the research question this paper addresses is 'What are the self-care practices and support of Malaysian patients with type 2 diabetes?'

Methods

Design

A qualitative case study design (Yin, 2014) was used to support an in-depth exploration of self-care in patients with type 2 diabetes in Malaysia and the available self-care support. Case study design has been utilised successfully in previous studies to guide the in-depth exploration of service user perspectives of self-care and the investigation of a condition specific service delivered in a real life context (Lyte, Milnes, Keating, & Finke, 2007).

Study setting

The study settings were three outpatient clinics: one in primary care and two in secondary care in Malaysia. The sites were chosen based on their high population of patients with type 2 diabetes. Clinics in these case study sites were staffed by nurses/healthcare educators, medical specialists, medical officers, assistants, with the addition of pharmacists and nutritionists in case study three. Care for each patient was between a doctor and a diabetes educator who counselled patients in self-care, conducted investigations, screened for complications and managed foot ulcers caused by diabetes. The sites were chosen to illustrate diversity in the management of the clinics and inequity in numbers of specialist staff across these sites.

Sampling and recruitment

Purposive sampling was used to identify potential participants. Health Care Professionals (HCPs) who were involved in the care of patients with diabetes type 2 were identified by reviewing the clinics' organisational charts and snowball sampling. Sampling aimed to target a maximum variation in HCPs involved in the care of patients with type 2 diabetes, they were seen as a multi-disciplinary team each with specific expertise in the care of this condition. Patients with type 2 diabetes were approached and recruited via the HCPs with support from the clinics' administrators and diabetes educators. Patients over 18, had a diagnosis of type 2 diabetes and were able to understand and communicate in Malay, English, or both were eligible to take part.

Ethical considerations

The study was approved by the Ethical Committee of the Faculty of Medical Human Sciences, University of Manchester (ID 12238) and Malaysian Medical Research Ethical Committee (MREC) (ID NMNR 12-792-13253).

Data collection

Multiple methods were chosen to address the research question and gain a full and inclusive perspective; interviews with key stakeholders in self-care facilitated in-depth exploration of a range of perceptions, observations of clinic situations allowed us to gain a more in-depth view of available self-care support in real time and analysis of documents provided contextual comparisons. In summary we conducted:

- Face to face semi-structured interviews with patients and health care professionals (for example diabetic educators, physicians, pharmacists, nutritionists, general nurses, nurse manager and medical assistants) conducted in Malay or English
- Observation of clinic consultations between patients and HCPS
- Analysis of documents relevant to the delivery of self-care support in type 2 diabetes at each case study site, as well as policies, guidelines and health education posters published by the Ministry of Health website identified as influential to self-care support.

Patients and HCPs were offered the choice of taking part in both an interview and observation, or an interview only. Most interviews were conducted at the clinics, and two were conducted in a quiet corner in the cafeteria, as preferred by the participants. Extracts from the interview topic guides can be seen in Box 1

Insert Box 1 here

Interviews took approximately 30-60 minutes. Interviews were audio recorded and detailed field notes made afterwards. Interviews were conducted in Malay, transcribed in Malay then the transcripts were translated into English to facilitate analysis and reporting. Seven translated transcriptions of early interviews were discussed with the research team, who are native English speakers.

Observations were recorded in note form guided by an observation schedule. Areas observed included the context, who was involved, the structure, and interactions in the consultation.

Data analysis

Within case analysis followed by cross case analysis was conducted as described by Yin (1994). Analysis of the interview and observation data was guided by the Framework method. This method is frequently used in the management and analysis of qualitative health care related data and particularly useful in research that involves multi-disciplinary teams and service users (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The first stage of Framework involved familiarisation with the data through listening to the interview recordings and reading field and observation notes and documents. This process led to the development of a thematic framework (Ritchie & Lewis 2009). Indexing followed – data were indexed against the relevant categories on the Framework. The final stage was charting, mapping and interpreting the transcripts to identify recurrent themes. Finally, cross-case analysis was conducted in which the themes, subthemes and categories that emerged from the interview data, documents and observation field notes were compared and contrasted to identify similarities, differences and patterns. This paper will present key themes that

emerged from the data that explain self-care and self-care support behaviour in the study sites: fatalism, faith and fear.

Findings

Between November 2012 and June 2013, 49 eligible patients were identified and approached to take part in the study. Of the 49 approached, 18 patients took part, 13 of these in both an interview and an observation, and five in an interview only. A total of 39 health care professionals, medical and non-medical were invited to take part in the study. Twenty agreed to take part: ten for both an interview and observation, and ten for an interview only (Tables 1 and 2). Self-care education for patients was mainly delivered by diabetic educators and general nurses as identified by participants themselves.

Insert Table 1 and 2 here

Three themes emerged from the data that encapsulated the response of participants to being diagnosed and living with type 2 diabetes: Fatalism, Faith and Fear. Type 2 diabetes is very common in Malaysia due, to a large extent, to valued dietary customs that involve the consumption of rich, sugary food. Participants perceived that it was inevitable that they would develop diabetes, because most people eventually did. However faith in – and love of - God, coupled with fear of the consequences of diabetes motivated them to engage in self-care practices. The fear was largely induced by diabetes health care professionals working in overcrowded clinics, and stretched thinly across the service, who used this direct and uncompromising approach to instil the importance of self-care to avoid severe complications of the disease.

Fatalism – *inevitability of developing Type 2 Diabetes*

Rice, noodles, coconut milk and fried food, rich in carbohydrates and saturated fat, are staple foods in Malaysia. Not surprisingly perhaps, around 30% of the Malaysian population are defined by the Ministry of Health Malaysia as overweight or obese (Ministry of Health Malaysia, Academy of Medicine Malaysia, 2015), a known contributing factor to the development of type 2 diabetes. As one participant pointed out:

“It is the culture. Malay culture. I was raised eating a heavy breakfast, with coconut milk rice, fried rice, or fried noodles. That is the breakfast routine in my family. We never had cornflakes, toast or oats... We got used to that routine.” (Patient 10)

Due to the high prevalence of diabetes in Malaysia, being diagnosed with the disease was viewed as both inevitable and 'normal' by all participants. For some, it was normalised to the extent that it was not seen as dangerous to health:

"There are many people in Malaysia with diabetes. It has become sort of normal to have diabetes. Diabetes is not like people having AIDS. But diabetes...People here just said, "Okay...that's fine if you have diabetes". So we just have to control it. That's all. People accept it as a normal condition, as a lot of people in Malaysia have it."(Patient 5)

Most participants did, however, recognise that they needed to control their disease, mostly through changes to their diet. Which is not to suggest that they found it easy, many didn't, as Patient 10 (above) continues:

"So, when the doctor or nurse asked me to change my breakfast to cornflakes or oats, it becomes very awkward." (Patient 10)

However, there were participants who had no intention of changing their diet, believing that they could eat normally and take medication to regulate their blood sugar. Their poor adherence to dietary guidance reflected their fatalistic attitude to the normality of diabetes within their community, but also the invisibility of the disease:

'At first, when I was told that I have diabetes, of course I felt worried. But after a while, I got used to it and everything went back to normal. It feels like I don't have any illness. Because, I don't see the seriousness of this illness. Thus, we just live our lives as normal, and the same as before we had diabetes. I think it is okay...just eat as normal. If we get sick, we have medication.' (Patient 13)

Self-care was considered unimportant by a few participants because they claimed that they were healthy and did not experience any symptoms; most, however, were motivated to change their lifestyle due to their relationship with God, and fear of the consequences of diabetes.

The evidence of a fatalistic attitude and the seeming low priority of diabetes to patients compared to daily life, work and family situations was also apparent in interviews with diabetic educators:

'when patients come for consultations, they don't immediately tell me about their diabetic problem, but start by talking about their personal problems and their family situation. Only then do they talk about their problem with diabetes. '(Diabetic Educator 7)

Some diabetic educators were reported to have diabetes type 2 themselves and many were described by health care professionals as perceiving diabetes type 2 as less dangerous than other diseases, with potential consequences the disease underplayed:

'They (other HCPs) usually see diabetes as a simple problem and they do not explore it further. This is because they usually hear about other diseases such as cancer which they think is more dangerous...then only they would bother. But diabetes ..they usually think that is a common problem and just an ordinary disease' (General Nurse 1).

Faith – Diabetes as a test from Allah

The majority of participants in this study were Muslim. When asked how they reacted to a diagnosis of diabetes, most said they had accepted it positively as a test from Allah. They believed that they needed to try their best to look after their bodies and keep praying for forgiveness and a cure from Allah:

"I considered this disease as a test from God. To this point I have been healthy, so I believe that God may want to test me by giving me this illness. But the test doesn't mean that we just accept it without doing anything to treat it. As humans, we also need to try to find a way to manage and cure it if possible." (Patient 13)

Most participants recognised that poor diet control had resulted in diabetes and blamed themselves because they were unaware of the consequences of their actions. Feelings of disappointment and awareness of the need for lifestyle modifications following their diagnosis were factors that increased participants' motivation to self-care.

"Before being diagnosed with diabetes, my lifestyle was not very healthy. I was a heavy smoker. I think, in terms of physical activities I don't have much of a problem. But the most important thing that contributed to my problem was, I was not really looking after my diet." (Patient 10)

Health care professionals discussed how common it was for patients to perceive a diagnosis of diabetes as fateful, particularly the older generation, and that this was the reason for patients not engaging or being motivated to partake in self-care.

' Patients with type 2 diabetes who were older gave less attention to their self-care. Might be, the younger patients think that they are still young and they don't want to get any complication so, they will more concerned on self-care. Usually, older patients with type 2 diabetes will already get the complication so, most of them had given up and just accept the disease as their fate. Most of these patients don't have motivation to really look after themselves very well' (HCP 3).'

Conversely patients (mean age 48) reported that their faith counterbalanced fatalism about being diagnosed with diabetes, and motivated patients to make lifestyle changes to respond to this 'test from God'. Participants also believed that God would give them guidance to self-manage their disease, illustrated by the next quote:

"We have to believe that this is all from Allah. Always believe...Ask for help from Allah, He is the one that gave us this illnesses and will give us relief. Despite our confidence and belief in the power of Allah, this does not mean that we can do anything we like. That is wrong. Allah asked us to make an effort to make ourselves better. I am already 66 years old; my turn will come anytime [to die]...Only Allah knows when. As humans we can't do anything.' (Patient 2)

Although the preceding quote from a patient concludes with fatalism about when life will be taken away, this did not lead to participants passively waiting for their 'turn' or time to die. God expects them to take care of themselves and attempt to overcome their disease. As powerful a motivation for changing their lifestyle in response to God's test, however, was fear of the consequences of diabetes.

Fear – patient anxiety and self-care support

Despite being perceived as a prevalent condition that patients saw as inevitable, feelings of fear dominated patients' approach to self-care. They described diabetes as a devastating disease that causes destruction to the body. Fearful of the complications of diabetes, some participants described 'living in fear'. Such negative connotations were often linked to interactions with healthcare professionals. Patients described scare strategies used by health care professionals to

increase their motivation to self-care effectively and reduce the risk of serious complications – a topic frequently discussed.

'When the doctor told me that I have diabetes, I actually didn't know what it was. The nurse told me that diabetes is 'sweet urine'. They (the HCPS) also showed me pictures of people with the leg being cut off because of diabetes. Then I knew diabetes was dangerous. It made me scared.' (Patient 12)

I had a discussion with the doctor. He said that this illness is serious. It can cause damage to my kidneys, I will have problems with wound healing, there are people who lose their limbs and if it affects my eyes, I could go blind' (Patient 2)

Despite their seeming readiness to self-care effectively, patients described a lack of knowledge, detailed information and guidance from HCPS about self-care practices.

They (HCPS) said that if I don't want to end up with dialysis, I need to look after my condition very well. I actually don't know what to do. They just told me that I can't eat much rice as it will cause my blood sugar to rise because rice contains sugar. But I don't know how much I should eat every time.' (Patient 12)

Feelings of being scared and uncertain were also contextualised within the day to day self-management of diabetes, particularly around diet control.

"I felt scared, especially with respect to diet. I was afraid to eat sweet drinks or food and I also reduced the amount of food that I ate. I felt worried about eating whatever food. I was afraid that if I ate more that my sugar level would increase" (Patient 7)

Taking insulin injections is part of my daily routine, I need to take it four times a day. Sometimes I do feel stressed and ask myself, how long do I have to live my life like this? Sometimes I do not take the insulin because I am too lazy to inject myself. But when I check my sugar level and it is high, I feel regret and scared. So I have no choice. (Patient 8)

Other participants were more accepting of their condition describing the need to change in order to enjoy life.

'I just accepted it. It does not totally cutting down on everything that I used to eat. I still enjoy eating, although everything has been cut to half the amount. I think it really depends on the individual, what they actually want in their life. If they think that they want to enjoy life then...they have to change' (Patient 9).

Written information collected for the documentary analysis, such as leaflets and posters, also focused on potential health complications and included graphic photographs of previous cases of leg or foot ulcers.

Observational data reinforced patient descriptions of HCPs focus on disease related complications, their use of photographs and explicit descriptions of complications in consultations. An extract from observation notes from a consultation between a diabetic educator and patient describes health promotion advice alongside the use of a photograph to demonstrate a severe foot ulcer:

'Mrs A was told to wear proper shoes and to inspect her feet for any signs of blisters or skin breaks every night before bed. Mrs A just kept quiet and listened to the diabetic educator's explanation. In addition, Mrs A was shown a picture of a bad foot ulcer and warned about the possibility of facing the same problem if she did not properly control her sugar level and did not look after her feet. Mrs A looked worried and said 'that is the thing that I worry about the most' (Observation)

There was evidence from all sources of difficult and non-therapeutic relationships between health care professionals and patients, compounded by overcrowded clinics and few diabetic educators with a broad remit, stretched thinly across the service.

'Like what you saw here in this clinic, we are too overloaded. We are only able to focus on important things like their medication and their health status at that time. We don't have enough time to ask them clearly what is actually the reason for their failure to manage their diabetes. What is happening at home? We don't have enough time to ask. Patients also sometimes feel uncomfortable telling us because they feel that we are not friendly. We are too rushed' (Diabetic Educator 10)

It is important to note exceptions to fear tactics suggesting that other approaches to health promotion were not only possible, but desirable. Several HCPs described the value of listening to patients, building relationships, and empathising with them to encourage behaviour change and self-care:

'When we listen to them, they are more positive towards us. So we can help them in the management of their diabetes. We try to put ourselves in their personal situation and be part of their family, so they can follow our advice and what we ask them to do. They will follow our instruction...to check their glucose level, for instance. I do not frighten them and not to treat them...no. I just want them to know their responsibility towards their own life. That's all. So far, we can. We need to make the patients appreciate their body.' (Diabetic Educator 5)

Discussion

The aim of this study was to explore approaches to self-care and self-care support in a Malaysian population where disease related complications are rising. Findings described here revealed an approach to self-care that is influenced by a fatalistic attitude to the disease balanced by willingness to self-manage due to a strong faith in God and fear of disease related complications. Fear of complications was mostly instilled by health care professionals who often used scare tactics to deliver health promotion messages, the merits of which will be debated below. We will also suggest complementary approaches to health promotion for patients with diabetes in the Malaysian context.

Participants in this study were fatalistic about their diagnosis of diabetes due to the high prevalence of the disease in the population and perceived inevitability of developing it sooner or later. Diabetes fatalism has been described as 'a complex psychological cycle characterised by the perception of despair, hopelessness, and powerlessness' (Walker et al., 2012 p. 2). In Walker et al's US study, 378 patients with diabetes were assessed for diabetes fatalism using previously validated scales. Fatalism was found to be negatively correlated with all aspects of self-management including medication adherence and following dietary advice. In another study, Egede and Bonadonna (2003), researched the association between self-care management and the concept of fatalism in African-American participants with type 2 diabetes. Again, diabetes fatalism was conceptualised by the participants in every aspect of the disease, including their understanding and experience of diabetes, and their style of coping. A fatalistic attitude led to ineffective diabetes self-management behaviour and poor adherence to self-care. Whilst participants in our Malaysian study were fearful about the consequences of diabetes, and reported that they found self-care difficult, they did not however exhibit despair, hopelessness and powerlessness. This may in part be explained by their strong religious beliefs and compulsion to respond to their diabetes a test from God and fear of complications. It is unclear whether participants in Walker et al and Egede and Bonadonna's studies had a similar level of belief.

The impact of religious belief on self-care behaviours has been researched in a number of studies. For example a study by Samuel-Hodge et al. (2000) of 70 African-American women with type 2 diabetes used focus groups to explore participants' perspectives of facilitators to self-care, and found religious beliefs and faith to be the most common coping mechanisms. They found that faith had a positive influence on self-care practices and that 'reliance on God' provided them with strength to cope with 'a complicated life' and dealing with diabetes. Confidence in the power of God to help participants find a cure for their disease encouraged them to engage with self-care (Samuel-Hodge et al., 2000). This finding is similar to reports of self-care from our Malaysian sample who responded positively to what was seen as a test from God, and who believed that God would support them in their self-care behaviours. Other studies suggested, however, that religious beliefs sometimes have a negative effect on self-care. Gomersall et al. (2011) and (Bai et al 2009) ,for example, reported that participants who rely solely on God to cure the disease become more passive in self-care. This is perhaps why faith in God was not the only motivating factor for our sample. Scare tactics by health care professionals appeared to carry equal weight.

This strength of belief in God and impact on patient's views of both their diagnosis and self-care behaviours was not acknowledged in the interviews with HCPs, observations or documents analysed. Yet religious belief have been cited by patients as helping them to cope with long-term conditions, as it encourages positive thinking which can result in improved quality of life (Puchalski, 2001). Lifestyle behaviours, such as culture and religion, are key influences on the quality of health (Bandura, 2004). Understanding the power of religious belief in the success or failure of self-care, and the need to integrate spirituality into self-care support and written guidelines, might lead to a more holistic and culturally competent approach to care (Puchalski, 2001) in Malaysia.

Scare tactics, often referred to as fear appeals or theories, are commonly used in health promotional activities, but have been found to be more effective when combined with messages that aim to increase patients' self-efficacy (Tannenbaum et al., 2015) (Witte & Allen, 2000). HCPs in this study seemed to adopt a fear appeal approach to motivate patients to adhere to their long-term treatment regime. To some extent this was working with patients who described being fearful of complications as a reason they looked after and monitored their diabetes. However, in some cases constant feelings of fear and being a failure, seemed to prevail over learning and practising effective self-care. These findings were echoed in a study conducted in China where fear and worries about control and complications predominated feelings of patients with type 1 and 2 diabetes (Tak-Ying

Shiu & Yee-Man Wong, 2002). Fear can develop from feelings of powerlessness and loss of control (Jeon et al 2010) and has been found to inhibit self-care behaviours (Brundisini et al 2015) increasing the potential for complications to occur.

Interestingly, health promotion campaigns based on scare tactics such as the 1980s HIV/AIDS campaign and current, graphic anti-smoking messages on cigarette packages have been cited as highly successful in the western world. This may be because risk assessment, health outcome expectancy and self-efficacy, are predictors of health behaviour change (Schwarzer, 2004) . In our study the risks of poor self-care to patients was made very clear through vivid descriptions of complications, but for patients health outcome expectancy was less clear with feelings of fatalism and faith in God leaving patients feeling less in control or self-efficacious in self-care. Therefore, although scare tactics could be a useful component of interventions that support the development of self-care skills, self-efficacy in managing long-term conditions is needed for patients to change their behaviour.

Self-care support based on scare tactics and instilling fear – communicated in a sometimes seemingly aggressive manner by HCPs in this study - raises some important ethical and practice issues. This approach can only be justified if it leads to desired behaviour change and is not psychologically damaging. While there is evidence of success of a ‘fear appeals’ approach in public health campaigns such as anti-smoking, (Tannenbaum et al., 2015) evidence for success in individual behaviour change in long-term conditions , such as diabetes, is scant (Harvey & Lawson, 2009). Our study highlights the need to review fear appeal tactics used in self-care support in Malaysia. It may be useful or could hinder patient self-care and understanding. Insight into patient’s beliefs about their condition and their level of disease self-efficacy could moderate its use and support a more patient-centred approach, that has gained popularity in recent years (McCormack and McCance 2016).

Conclusion

This study is the first in Malaysia to explore self-care and self-care support in patients with type 2 diabetes. A strength of the study is the case study design which allowed exploration of diabetes self-care from multiple perspectives. The patient population was varied, with similar numbers of men and women, a variety of backgrounds and ages. A limitation however was the HCP sample. The aim of recruitment of HCPs was to obtain balanced numbers of participants from each professional

background and role. This was to ensure that the interpretations made did not lean towards one HCP perspective. However, the researcher faced difficulties in recruiting HCPs, particularly doctors. The researcher was also unable to recruit an equal number of dieticians and pharmacists to the study, as there were only two of each involved in the diabetes management at each of the clinics. It is anticipated that the limited numbers of doctors, dieticians and pharmacists recruited to this study may have restricted understanding of the self-care issues in type 2 diabetes in Malaysia from their point of view. This limitation notwithstanding, the study does; however, provide important insight into the reasons that people develop diabetes in Malaysia, their responses to the disease, and the approach of health care professionals to promoting self-care. With this knowledge, it is possible to design self-care programmes that are tailored to this population and their unique needs.

Relevance to clinical practice

Shiu and Wong recommended that HCPs work with patients' to increase their feelings of self-efficacy and consequently increase feelings of control. The association between self-efficacy and improved self-management of diabetes has also been found to be consistent across race/ethnicity and levels of health literacy (Sarkar, Fisher, & Schillinger, 2006). Health behaviour theory helps to explain why self-efficacy is such an important concept in successful self-care. For instance, social cognition, the theory that self-efficacy beliefs work with outcome expectations, perceived contextual barriers and facilitators to regulate motivation, behaviour and well-being (Bandura, 2004). There was some evidence in this study of a few health care professionals taking this more person-centred approach to health promotion, which is promising. Any future developments of structured self-care programmes should be informed by health behaviour theory related to health promotional activities and in particular focus on self-efficacy beliefs. More immediately health care professionals can influence the development of patient self-efficacy in self-care through:

- Developing more positive health expectations through emphasising that Type 2 diabetes is not inevitable and complications can be prevented or modified
- Include faith based organisations, where religious belief is prominent in the culture, to support patients in overcoming perceived barriers to successful self-care
- Take a more person centred approach in consultations to balance fear tactics with improving self-efficacy to change behaviour

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References

- Ahmed., N (2015-18) National Health and Morbidity Survey (Online)
<http://www.iku.gov.my/index.php/berita/179-nhms-2015-faq> Accessed Sept 2017
- Bandura, A. (2004). Health Promotion by Social Cognitive Means. *Health Education & Behavior*, 31(2), 143-164. doi: doi:10.1177/1090198104263660
- Bai, Y., Chiou, C., & Chang, Y. (2009). Self-care behaviour and related factors in older people with Type 2 diabetes, (8), 3308–3315. <https://doi.org/10.1111/j.1365-2702.2009.02992.x>
- Brundisini, F., Vanstone, M., Hulan, D., Dejean, D., & Giacomini, M. (2015). Type 2 diabetes patients' and providers' differing perspectives on medication nonadherence : a qualitative meta-synthesis. *BMC Health Services Research*. <https://doi.org/10.1186/s12913-015-1174-8>
- Chan, G. C. (2005). Type 2 diabetes mellitus with hypertension at primary healthcare level in Malaysia: are they managed according to guidelines? *Singapore Medical Journal*, 46(3), 127–31.
- Chang, H. Chiou, C. Lin, Ph, D. (2005). A population study of the self-care behaviors and their associated factors of diabetes in Taiwan : results from the 2001 National Health Interview Survey in Taiwan, 40, 344–348. <https://doi.org/10.1016/j.yjmed.2004.06.012>
- Cramer, J. A., Benedict, Á., Muszbek, N., Keskinaslan, A., & Khan, Z. M. (2007). The significance of compliance and persistence in the treatment of diabetes, hypertension and dyslipidaemia: a review. *International Journal of Clinical Practice*, 62(1), 76–87. <https://doi.org/10.1111/j.1742-1241.2007.01630.x>
- Daoud, N., Osman, A., Hart, T. A., Berry, E. M., & Adler, B. (2015). Self-care management among patients with type 2 diabetes in East Jerusalem. *Health Education Journal*, 74(5), 603-615. doi: doi:10.1177/0017896914555038
- Egede, L. E., & Bonadonna, R. J. (2003). Diabetes self-management in African Americans: an exploration of the role of fatalism. *The Diabetes Educator*, 29(1), 105–15.
- Evangelista, L. S., & Shinnick, M. A. (2008). What Do We Know About Adherence and Self-care? *J Cardiovasc Nurs*, 23(3), 250-257. doi: 10.1097/01.JCN.0000317428.98844.4d
- Federation, I. D. (2009). *Diabetes Atlas* (4th ed.). International Diabetes Federation.
- Funnell, M. M., Brown, T. L., Childs, B. P., Haas, L. B., Hoseney, G. M., Jensen, B., . . . Weiss, M. A. (2010). National Standards for Diabetes Self-Management Education. *Diabetes Care*, 33(Suppl 1), S89-S96. doi: 10.2337/dc10-S089
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13, 117-117. doi: 10.1186/1471-2288-13-117
- Gomersall, T., Madill, A., & Summers, L. K. M. (2011). A metasynthesis of the self-management of type 2 diabetes. *Qualitative Health Research*, 21(6), 853–871.

- Harvey, J. N., & Lawson, V. L. (2009). The importance of health belief models in determining self-care behaviour in diabetes. *Diabetic Medicine*, *26*(1), 5-13. doi: 10.1111/j.1464-5491.2008.02628.x
- Jeon, Y.-H., Kraus, S. G., Jowsey, T., & Glasgow, N. J. (2010). The experience of living with chronic heart failure: a narrative review of qualitative studies. *BMC Health Services Research*, *10*(1), 77. <https://doi.org/10.1186/1472-6963-10-77>
- Letchuman, G. R., Nazaimoon, W. M. W., Mohamad, W. B. W., Chandran, L. R., Tee, G. H., Jamaiyah, H., Faudzi, Y. A. (2010). Prevalence of Diabetes in the Malaysian National Health Morbidity Survey III 2006 The Malaysian National Health Morbidity Survey III (NHMS, *65*(3), 173–179.
- Lyte, G., Milnes, L., Keating, P., & Finke, A. (2007). Review management for children with asthma in primary care: a qualitative case study. *Journal of Clinical Nursing*, *16*(7b), 123-132. doi: doi:10.1111/j.1365-2702.2005.01542.x
- Mafauzy, M., Hussein, Z., & Chan, S. P. (2011). The status of diabetes control in Malaysia: Results of DiabCare 2008. *Medical Journal Malaysia*, *66*(3), 175–181.
- McCormack, B. and McCance, T. (2016) *Person-centred Practice in Nursing and Healthcare*. Oxford: Wiley-Blackwell
- Ministry of Health Malaysia, Academy of Medicine Malaysia, M. E. & M. S. and D. M. (2015). *Clinical Practice Guidelines for the Management of Type 2 Diabetes Mellitus*. No Title (5th Edition). Kuala Lumpur. Retrieved from http://www.mems.my/file_dir/1227958176570683150bafb.pdf
- Mutlu, F., Bener, A., Eliyan, A., Delghan, H., Nofal, E., & Shalabi, L. (2015). *Projection of Diabetes Burden through 2025 and Contributing Risk Factors of Changing Disease Prevalence: An Emerging Public Health Problem* (Vol. 5).
- Puchalski, C. M. (2001). The role of spirituality in health care. *Proceedings (Baylor University. Medical Center)*, *14*(4), 352-357.
- Ramli, AS; Taher, S. (2008). Managing Chronic diseases in the malaysian primary health care - a need for change. *Malaysian Family Physician*, *3*(1), 7–13.
- Rampal, L., Rampal, S., Azhar, M. Z., & Rahman, A. R. (2008). Prevalence, awareness, treatment and control of hypertension in Malaysia: A national study of 16,440 subjects. *Public Health*, *122*, 11–18.
- Ritchie, Jane & Lewis, J. (2009). *Qualitative Research Practice: A Guide for Social Science Students and Researchers* (2nd ed.). Sage Publications.
- Rugayah, B. (2007). Diabetes epidemic in Malaysia. *Malaysian Diabetes Association*, (9), 1–8.
- Saleh, F., Mumu, S. J., Ara, F., Hafez, M. A., & Ali, L. (2014). Non-adherence to self-care practices & medication and health related quality of life among patients with type 2 diabetes: a cross-sectional study. *BMC Public Health*, *14*(1), 431. doi: 10.1186/1471-2458-14-431

- Samuel-Hodge, C. D., Headen, S. W., Skelly, A. H., Ingram, A. F., Keyserling, T. C., Jackson, E. J., ... Elasy, T. A. (2000). Influences on day-to-day self-management of type 2 diabetes among African-American women: spirituality, the multi-caregiver role, and other social context factors. *Diabetes Care*, *23*(7), 928–933.
- Sarkar, U., Fisher, L., & Schillinger, D. (2006). Is Self-Efficacy Associated With Diabetes Self-Management Across Race/Ethnicity and Health Literacy? *Diabetes Care*, *29*(4), 823-829. doi: 10.2337/diacare.29.04.06.dc05-1615
- Schwarzer, R. (2004). Modeling Health Behaviour Change: The Health Action Process Approach (HAPA). Retrieved March 25th, 2009, from <http://userpage.fu-berlin.de/~health/hapa.htm>
- Tak-Ying Shiu, A., & Yee-Man Wong, R. (2002). Fears and worries associated with hypoglycaemia and diabetes complications: perceptions and experience of Hong Kong Chinese clients. *Journal of Advanced Nursing*, *39*(2), 155-163. doi: 10.1046/j.1365-2648.2002.02255.x
- Tan, M. Y., & Magarey, J. (2008). Self-care practices of Malaysian adults with diabetes and sub-optimal glycaemic control. *Patient Education & Counseling*, *72*(2), 252–267.
- Tannenbaum, M. B., Hepler, J., Zimmerman, R. S., Saul, L., Jacobs, S., Wilson, K., & Albarracín, D. (2015). Appealing to fear: A meta-analysis of fear appeal effectiveness and theories. *Psychological Bulletin*, *141*(6), 1178-1204. doi: 10.1037/a0039729
- Thomas, N., Alder, E., & Leese, G. P. (2004). Barriers to physical activity in patients with diabetes. *Postgraduate Medical Journal*, *80*, 287–291.
- Whiting, D. R., Guariguata, L., Weil, C., & Shaw, J. (2011). IDF Diabetes Atlas: Global estimates of the prevalence of diabetes for 2011 and 2030. *Diabetes Research and Clinical Practice*, *94*(3), 311-321. doi: 10.1016/j.diabres.2011.10.029
- Walker, R. J., Smalls, B., Hernandez-tejada, M.. (2012). Effect of diabetes fatalism on medication adherence and self-care behaviors in adults with diabetes. *General Hospital Psychiatry*, *34*(6), 598–603. <https://doi.org/10.1016/j.genhosppsy.2012.07.005>
- Witte, K., & Allen, M. (2000). A Meta-Analysis of Fear Appeals: Implications for Effective Public Health Campaigns. *Health Education & Behavior*, *27*(5), 591-615. doi: doi:10.1177/109019810002700506
- Williams, M. E. (2010). Diabetes CKD/ESRD 2010: A progress report? *Seminar in Dialysis*, *23*(2), 129–133.
- Yin, R., . K. (2014). *Case Study Research Design and Methods* (5th ed.): Sage London.