

Teachable moments: Potential for behaviour change among people with Type 2 Diabetes and their relatives

Illness perceptions of type 2 diabetes.

Qualitative studies

Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design/Methodology	Findings
Murphy & Kinmonth (1995)	To explore patients' understanding of type 2 diabetes	UK	<p>People with type 2 diabetes</p> <p>N=46</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: mean=8.2</p> <p>Age: mean=66 years</p> <p>Gender: 24 men, 22 women</p> <p>Occupation: 16 non-manual, 30 manual</p> <p>Treatment: 14 diet only, 29 diet + tablets, 3 insulin</p> <p>Diabetes complications: 6 retinopathy, 6 cataract, 10 neuropathy, 2 renal problems, 1 small vessel ischemia, 1 impotence</p>	Exploratory qualitative, interviews	<p><i>Orientation towards diabetes:</i></p> <p><u>Focusing upon symptoms:</u> participants discussed diabetic control in terms of symptom avoidance; in the absence of symptoms there was no risk of complications, some even denied they had type 2 diabetes; they engaged in temporary behaviour adjustments in response to symptoms.</p> <p><u>Focusing upon complications:</u></p> <p>These participants prioritised the avoidance of complication, irrespective of symptoms.</p>

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					<p><i>Perceived seriousness of diabetes:</i></p> <p><u>Serious but not for me:</u> due to lack of symptoms or complications, medical advances and perception of type 2 diabetes as a serious in older people.</p> <p><u>Serious but I can control it:</u> serious effects are avoidable</p> <p><u>Serious for me:</u> pessimistic about own prognosis</p>
Dietrich (1996)	To investigate attitudes of people with diabetes toward their disease and its treatment	USA	<p>People with type 2 diabetes</p> <p>N=7</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: range: 5 weeks – 40 years</p>	Exploratory qualitative study, general interview guide approach, open ended interviews, naturalistic content analysis	<p>Negative feelings at the time of diagnosis (shock, panic, fear) and denial.</p> <p>Participants were afraid of diabetes.</p> <p>Feelings of inferiority and loss</p>

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			<p>Age: range: 37-81</p> <p>Gender: 100% female</p> <p>Education: 9th grade (1), 10th grade (1), high school (4), vocational school (1)</p>		<p>of control over one's life.</p> <p>Borderline diabetes was not taken seriously.</p> <p>"Not feeling sick means not being sick"</p>
Hernandez, Antone & Cornelius (1999)	To determine how First Nations clients with type 2 diabetes perceive and live with their diabetes	Canada	<p>People with type 2 diabetes</p> <p>N=10</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: 2 to 32 years</p> <p>Age: 32 to 75</p> <p>Gender: 6 females, 4 males</p> <p>Marital status: 6 married, 1 widowed, 1 separated, 1 divorced, 1 living common-law</p> <p>Diabetes treatment: 1 on diet only, 4 on oral agents, 5 on insulin</p>	Exploratory qualitative, grounded theory, interviews	<p><i>Having diabetes:</i> denying diabetes, minimizing thoughts and feelings about diabetes, and normalizing life so it is the same as it was before the diagnosis of type 2 diabetes.</p> <p>Concerns about loss of freedom, mortality and complications.</p> <p>Lack of type 2 diabetes knowledge but no interest in receiving information.</p>

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					<p><i>Turning point:</i> events that help people recognise their diabetes and move past the denial stage.</p> <p><i>Science of one:</i> diabetes is part of their lives, rooted in daily habits</p>
Alcozer (2000)	To investigate the explanatory models of diabetes from the perspective of Mexican American women with type 2 diabetes?	USA	<p>People with type 2 diabetes</p> <p>N=20 Mexican Americans</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: mean = 6 years (range: 14 months – 20 years)</p> <p>Gender: 100% female</p> <p>Age: mean = 33</p> <p>Education: 10% <12th grade, 60% high school, 20% college/tech school, 10% college graduate</p> <p>Marital status: 18 partnered, 2 married</p>	Exploratory qualitative study, open-ended interviews, observations, thematic and pattern analysis	<p>Five thematic categories:</p> <p>Defining diabetes: <i>borderline</i> or <i>glucose intolerant</i> meant “sugar in my urine” and it “wasn’t so bad”. <i>Diabetes</i> meant “sugar in my blood” and was described as “scary because of all the damage”</p> <p>Getting diabetes: heredity and eating too many sweets were identified as the main causes of diabetes</p>

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			<p>Income: mean = \$22 000</p> <p>BMI: mean = 26.4</p>		<p>Having diabetes: described as having high sugar and as a confusing illness</p> <p>Describing diabetes: the description was linked to the definition of the illness (borderline or diabetes)</p> <p>Insulin was regarded as a consequence and a symptom: needing insulin is a symptom of diabetes and insulin causes complications</p> <p>Taking care of diabetes: Treatment was views as congruent with knowledge of symptoms. Type of self-care: 30% used blood glucose monitors; 100% followed a specific diet; 55% engaged</p>
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					in physical activity; 5% joined a support group
Jayne & Rankin (2001)	To demonstrate the application of Leventhal's Self-regulation model with a group of Chinese immigrants with type 2 diabetes	USA	<p>People with type 2 diabetes</p> <p>N=30 Chinese immigrants</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: 19 had been aware of it for 10 years or less</p> <p>Age: range 46-80 years</p> <p>Gender: 17 (57%) men</p> <p>Length of time in USA: average 13 years</p> <p>Education: 18 (62%) less than high-school; 5 (17%) college;</p> <p>Marital status: 23 (77%) married</p> <p>Living arrangements: 13 (45%) lived with more than 3 adults</p> <p>Employment status: 7 homemakers, 7 employed, 10 retired.</p>	Non-experimental, exploratory, qualitative, interviews: the questions addressed each of the components of the SR model	<p><i>Cause of type 2 diabetes</i></p> <p>23 (74%) indicated eating behaviour as a cause of type 2 diabetes.</p> <p>10 related type 2 diabetes to heredity.</p> <p>30% mentioned stress and depressing</p> <p>7 did not know</p> <p>100% blamed themselves for developing type 2 diabetes.</p> <p><i>Identity</i></p> <p>Some of the participants experienced symptoms of increased thirst, fatigue, weight loss, frequent urination</p>

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					<p>or blurred vision while other had no symptoms.</p> <p>Perception of severity was related to acuteness of symptoms and the presence of complications.</p> <p>Without symptoms the diagnosis came as a surprise.</p> <p>Type 2 diabetes resulted in being labelled as different and was described as a social disease</p> <p><i>Consequences</i></p> <p>77% feared becoming blind or having body limbs amputated.</p> <p><i>Timeline</i></p> <p>50% said type 2 diabetes is a long term condition.</p> <p>Some expected it to be cured.</p>
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					13 people did not answer the question.
Jezewski (2002)	To develop a culturally specific explanatory model (EM) of type 2 diabetes from the perspective of Mexican Americans living along the United States-Mexican border.	Mexico	<p>People with type 2 diabetes</p> <p>N=22</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: average =14 years, range: 1 to 45 years,</p> <p>Age: average=53, range: 29 to 77,</p> <p>Gender: 18 women and 4 men</p> <p>Education: average = 6 years, range: 0 to 14</p> <p>Income: average \$865, range \$390 to \$4,000.</p>	Descriptive qualitative, grounded theory, interviews, focus groups	<p><i>Cause:</i> susto (a scare or fright) or strong anger. Being overweight, heredity, lack of exercise, diet and not taking care of oneself were also viewed as contributing to the development of type 2 diabetes.</p> <p><i>Symptoms:</i> visual problems, fatigue, weakness, headaches, dry mouth, weight loss.</p> <p><i>Treatment:</i> traditional remedies and herbs; regulation of diet was seen as important but there was lack of knowledge and adherence to diet regimen. Fear that</p>

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					<p>insulin causes blindness and leads to addiction. The importance of regular exercise was recognised but there was variation in how the interpretation of need for exercise.</p> <p><i>Social significant:</i> only participant was ashamed of her diabetes. The rest shared the diagnosis and sought support from family members.</p>
Egede & Bonadonna (2003)	To explore what diabetes means to African Americans and the role of fatalism in self-management	USA	<p>People with type 2 diabetes</p> <p>N=39 African Americans</p> <p>DEMOGRAPHICS:</p> <p>Gender: 22 men, 17 women</p> <p>Age: mean=48 years</p> <p>Duration of diabetes: mean=13 years</p>	Qualitative exploratory, Gender-specific focus groups, ISAS paradigm	<p><i>Meaning of diabetes:</i> as a death sentence; as an inherited disease they have no control over; uncontrollable; generational curse and the only way to get rid of this curse is to deny the existence of the disease; loss of</p>

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					<p>normalcy and suffering.</p> <p><i>Illness experience:</i> individuals with long-standing disease, friends or relatives with diabetes, disability from diabetes or poor social support appeared to be more fatalistic.</p> <p><i>Coping response:</i> regret for not being informed earlier of lifestyle changes that may have helped avoid diabetes; focused on preventing their children and relatives from developing diabetes</p> <p><i>Religious or spiritual beliefs:</i> having diabetes as predestined and having complications is independent of</p>
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					one's personal efforts.
Peel, Parry, Douglas & Lawton (2004)	To explore the emotional reaction of newly diagnosed patients in Scotland at the time of diagnosis	Scotland	<p>People with type 2 diabetes</p> <p>N=40</p> <p>DEMOGRAPHICS</p> <p>Diabetes duration: within past 6 months</p> <p>Age: mean=48, range: 21-77 years</p> <p>Gender: 19 women, 2 men</p> <p>Socio-economic status: 12 non-manual class III, 13 manual class III , 5 is class IV-V</p> <p>NB: the provided demographics do not add up to the number of participants</p>	Exploratory qualitative, in-depth interviews, thematic analysis	<p>The route to diagnosis affected emotional reactions towards type 2 diabetes:</p> <p><i>1. Suspected diabetes route to diagnosis:</i> symptoms => suspected diabetes => visit to GP and subsequent diagnosis: many said they did not experience shock when diagnosed</p> <p><i>Illness route:</i> Feeling ill => health service contact and subsequent diagnosis: sense of relief; compared type 2 diabetes to other illnesses they might have been diagnosed with.</p> <p><i>Routine route to diagnosis:</i> absence</p>

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					of symptoms => routine testing => diagnosis: for some, type 2 diabetes formed a wider pattern of ill health so it did not require an emotional reaction; worry about the interaction between type 2 diabetes and other illness they have; others were glad it was identified.
Ali, SM (2006) (PhD thesis)	To explore the perspectives of the Malays with type 2 diabetes and their understanding of diabetes	Malaysia	<p>People with type 2 diabetes</p> <p>N=18</p> <p>DEMOGRAPHICS</p> <p>Gender: 9 male, 9 female</p> <p>Age: range 15-75</p> <p>Employment: retired, 2 teachers, 2 students, postman, part-time tour guide, food business, international relations,</p>	Exploratory, qualitative, semi-structured interviews, grounded theory	<p><i>Nature of type 2 diabetes:</i></p> <p>Salient disease, “no symptoms, no problem”; lack of knowledge of type 2 diabetes and its complications</p> <p><i>Perceived seriousness/severity</i></p> <p>Some perceived type 2 diabetes as serious when other</p>

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			<p>staff nurse, 3 housewives, unspecified part-time work, 2 in the government sector.</p>		<p>members of the family have suffered from it.</p> <p>All of the participants were aware of the severity of type 2 diabetes.</p> <p>Some of them believed that Allah gave them the illness and he will cure it. People who believed in fate were less worried.</p> <p>Participants used traditional medicines to self-manage their condition.</p>
<p>Macaden & Clarke (2006)</p>	<p>To explore the experiences of South Asian people with type 2 diabetes in the UK</p>	<p>UK</p>	<p>People with type 2 diabetes</p> <p>N=20 South Asian participants</p> <p>DEMOGRAPHICS</p> <p>Not reported</p>	<p>Exploratory, qualitative, grounded theory, focus groups</p>	<p><i>Cause</i></p> <p>Cold weather, worrying too much, having eaten too many sweets, fate</p> <p><i>Severity</i></p>

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					<p>Depended on whether or not they are on insulin, the number of tablets they take and the frequency of hospital visits.</p> <p><i>Control</i></p> <p>Control was external and they relied on health care professionals</p>
Naemiratch & Manderson (2006)	To explore lay perceptions of people with type 2 diabetes and their families about diabetes.	Thailand	<p>People with type 2 diabetes</p> <p>N=33</p> <p>DEMOGRAPHICS</p> <p>Gender: 17 men, 16 women</p> <p>Age: mean=54.7, range 31-80 years</p> <p>Education: 32 basic education, 1 without basic education</p> <p>Religion: 29 Buddhist, 4 Muslim</p>	Ethnographic study, interviews, conversational methods	The nature of type 2 diabetes was described in terms of visibility and invisibility but not in terms of symptoms but in terms of impact on daily life. An invisible form of type 2 diabetes may have symptoms but they do not affect daily activities. These perceptions affected self-management.

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					Participants associated type 2 diabetes with control but they were ambivalent whether they control the disease or the disease controls them.
Lawton, Ahmad, Peel & Hallowell (2007)	To explore understanding of diabetes and its causation among Pakistani and Indian and Scottish type 2 diabetes patients.	Scotland	<p>People with type 2 diabetes</p> <p>Pakistani and Indian sample N= 32</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: range 1-30 years</p> <p>Age: mean=59, range 33-78 years</p> <p>Gender: 15 males, 17 females</p> <p>Ethnicity: 23 Pakistani, 9 Indian</p> <p>Religion: 22 Muslims, 1 Christian, 4 Hindus, 5 Sikhs</p>	Exploratory qualitative, repeat interview design, grounded theory	<p><i>The role of self in the onset of diabetes: <u>Pakistani and Indian sample:</u> type 2 diabetes was perceived to be caused by external contextual factors that the respondents had no control over.</i></p> <p><i><u>White sample:</u> the causes of diabetes were linked to participants' personal lifestyle</i></p> <p><i><u>Attributing blame:</u></i></p> <p><i><u>Indian and Pakistani sample:</u> externalised responsibility for type 2 diabetes</i></p>

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			<p>White Scottish sample – N=32</p> <p>DEMOGRAPHICS</p> <p>Age: mean=56, range 36-77 years</p> <p>Gender: 15 men, 17 women</p>		<p>development; perceived the disease to be inevitable (heredity) or caused by contextual factors such as unhealthy lifestyle in response to the Western culture (food availability) and stress associated with arriving and living in a foreign country, and with British medication</p> <p><u>White sample:</u> internalised blame for their type 2 diabetes; Associated it with their personal “unhealthy” lifestyle; perceived themselves as responsible for developing type 2 diabetes; genetic predisposition did not suffice as an explanation.</p>
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<p>Finucane & McMullen (2008)</p>	<p>To identify the cultural values, traditions, and perceptions of diabetes risk and self-care among Filipino Americans in Hawaii with type 2 diabetes</p>	<p>USA</p>	<p>People with type 2 diabetes N=15 Filipino Americans</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: range from less than a year to over 5 years</p> <p>Age: mean=50.7, range 33-60</p> <p>Gender: 12 female</p> <p>Education: 1 completed 8th grade, 2 high school, 5 college or two-year degree, 7 four-year college degree, 1 more than four-year degree</p> <p>Income: 7 <\$50 000, 1 >\$50 000, 7 refused to answer</p>	<p>Exploratory qualitative, two rounds of focus groups (same participants), qualitative theme analysis</p>	<p>Participants reported feelings of shame, humiliation and guilt about having diabetes.</p> <p>Some people believed that they deserve diabetes because they have done something bad. They viewed diabetes as punishment.</p> <p>Participants were aware of the diabetes risk factors such as family history, diet, physical activity.</p> <p>They had limited understanding of the problems diabetes can cause to major organs.</p> <p>Most patients did not associate diabetes with feelings of dread but they associated</p>
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					with negative emotions.
Péres, Franco & Santos (2008)	To explore feelings and emotional reactions of women after the diagnosis of type 2 diabetes	Brazil	<p>People with type 2 diabetes</p> <p>N=8</p> <p>DEMOGRAPHICS</p> <p>Gender: 100% female</p> <p>Age: range: 49-76 years old</p> <p>Education: 8 less than 4th grade of basic education</p> <p>Income: 5 below two minimum salaries</p> <p>Occupation: 8 housewives</p>	Descriptive, exploratory, semi-structured interviews	<p>Immediately after type 2 diabetes diagnosis women felt anger, rage, sadness, fear, shock and fright.</p> <p>They described diabetes as a disease that doesn't cause any pain or affect people much.</p>
Cullen & Buzek (2009)	To assess type 2 diabetes knowledge, perceptions, risk factor awareness, and prevention practices among African American and Hispanic families with a history of diabetes.	USA	<p>Relatives of people with type 2 diabetes</p> <p>Adolescents and parents with a family history of diabetes: N=39 parents and 21 adolescents</p> <p>DEMOGRAPHICS</p>	Descriptive, interviews, open-ended questions	<p><i>Diabetes knowledge:</i> 52% of adolescents and 56% of parents reported high blood sugar as a cause of diabetes; knowledge about insulin was much lower for parents</p>

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			<p>Age: not specified adolescents: (ninth and tenth graders)</p> <p>Gender: adolescents: 71% female; parents: 95% female</p> <p>Ethnicity: adolescents: 43% African American, 57% Hispanic; parents: 49% African American; 51% Hispanic</p> <p>BMI: 33% of the adolescents and 79% of the parents had BMI>25</p>		<p>(18%) and unknown by adolescents</p> <p><i>Diabetes risk factors:</i> 74% of parents and 25% of the adolescents identified family history as a risk factor. 26% of the parents and 10% of the adolescents identified being overweight as a risk factor. Age and gender were unknown risk factors by both groups.</p> <p><i>Diabetes risk perception:</i> 78% of parents reported their risk correctly. 59% felt their children were at risk.</p> <p><i>Diabetes prevention practices:</i> 72% of parents and 62% of adolescents reported eating healthily as a</p>
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					prevention strategy. 49% of parents and 42% of adolescents reported being active as a prevention strategy. Losing weight was not acknowledged.
Pijl, Henneman, Claassen, Detmar, Nijpels & Timmermans (2009)	To explore the perceptions of causes, risk and control with regard to diabetes and the role of family history among people at an increased risk for type 2 diabetes	The Netherlands	<p>Relatives of people with type 2 diabetes</p> <p>N=9 people with family history of diabetes</p> <p>DEMOGRAPHICS</p> <p>Affected relatives: 1 to 4 among first- and second-degree relatives</p> <p>Age: mean=67, range 62-72</p> <p>Education: approx. a quarter were highly educated</p>	Exploratory, qualitative, semi-structured interviews	<p><i>Causal beliefs</i></p> <p>Genetic predisposition, unhealthy food, lack of physical activity, stress, alcohol intake, age; a combination of genetic predisposition and unhealthy lifestyle.</p> <p>The role of genetics was very pronounced “diabetes runs in the family”.</p> <p>Some people had incoherent thoughts about the causes of diabetes.</p>

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					<p>Behaviour factors were perceived to influence the onset or the course of diabetes.</p> <p>One participant talked about "inherited lifestyle".</p> <p><i>Perceived risk</i></p> <p>4 (9) participants perceived a slightly higher risk when comparing themselves to people of the same age.</p> <p>Some people with family history of diabetes did not perceive themselves to be at risk.</p> <p>Despite risk awareness, a lot of people did not worry about getting diabetes.</p>
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					<p><i>Perceptions of control</i></p> <p>Most of the participants were unaware of the ways to prevent diabetes.</p> <p>Participants with family history of diabetes who believed that genetics cause diabetes, felt that they could not prevent it.</p> <p>Those with family history who saw behaviour factors as causes of diabetes believed they can prevent it.</p>
Al-Qazaz, Hassali, Shafie, Sulaiman & Sundram (2011)	To explore type 2 diabetes patients' experience and knowledge about diabetes	Malaysia	<p>People with type 2 diabetes</p> <p>N=12</p> <p>DEMOGRAPHICS</p>	Exploratory qualitative study, semi-structured interviews, thematic content analysis	<p>Only a few of the participants knew if they have type 1 or type 2 diabetes.</p> <p>All of them knew the name of the</p>

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			<p>Duration of diabetes: range: 1 to more than 6 years</p> <p>Gender: 8 male, 4 female</p> <p>Age: range 45 to over 63</p> <p>Race: 8 Malay, 2 Indian, 2 Chinese</p> <p>Education: 2 primary, 8 secondary, 2 university</p> <p>BMI: 1 normal, 8 overweight, 3 obese</p>		<p>drugs used for treatment.</p> <p>Genetic factors were the main cause identified, followed by dietary habits and lack of exercise</p>
Everett (2011)	To explore patients' perceptions of type 2 diabetes among people in Oaxaca, Mexico.	Mexico	<p>People with type 2 diabetes</p> <p>N=18</p> <p>DEMOGRAPHICS</p> <p>Age: 24-67 years</p> <p>Gender: 4 men, 14 women</p>	Exploratory qualitative study, interviews, open-ended questions	<p>Although some participants mentioned diet, lifestyle, obesity and family history as risk factors for diabetes, the majority placed emphasis on strong emotions (anger, fear) and traumatic events as the main causes of type 2 diabetes.</p> <p>Patients had no concerns about privacy or stigma</p>

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					associated with diabetes.
Hughes, Keith, Byars & Wiginton (2012)	To determine the issues and perceptions of persons newly diagnosed (within last 3 months) with type 2 diabetes.	USA	<p>People with type 2 diabetes</p> <p>N=16</p> <p>DEMOGRAPHICS:</p> <p>Duration of diabetes: mean =2.6 weeks</p> <p>Age: mean=48.4</p> <p>Gender: 7 men, 9 women</p> <p>Ethnicity: 7 Hispanic, 8 White, 1 other</p> <p>Marital status: 11 married, 1 separated, 3 single, 1 cohabitating</p> <p>Education: 6 no high school, 10 high school or college/university degree</p> <p>Employment: 4 full-time, 1 part-time, 3 seasonal, 8 retired or unemployed.</p> <p>Doing chores: 16</p>	Exploratory qualitative, interviews, post-it notes, cognitive mapping	<p>The words most commonly associated with “living with diabetes” were:</p> <p>Eat (diet, food, sweets, sugar, meal, carbs)</p> <p>Diabetes (complications, sick, amputation, death)</p> <p>Negative emotions (scared, worried, lonely, anger, fear, sad, stress, terrible)</p>

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			<p>Exercise: 5 don't exercise</p> <p>Special diet: 11</p>		
Pistulka, Winch, Park, Han & Kim (2012)	To explore illness experience of Koreans with type 2 diabetes and hypertension	USA	<p>People with type 2 diabetes</p> <p>N=12</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: 8 years</p> <p>Age: mean=55.9</p> <p>Gender: 8 women, 4 men</p> <p>Education: 12 high school, 5 college</p> <p>Occupation:</p> <p>Insurance: 2 uninsured</p>	Cross-cultural, qualitative descriptive inquiry design, interviews, ethnographic semi-structured questioning	<p>Type 2 diabetes was perceived as undermining one's social image:</p> <p>Lack of control was connected with type 2 diabetes;</p> <p>People with diabetes were perceived to have a certain type of personality and a character weakness as they lack discipline;</p> <p>A public diagnosis may affect the future of the offspring as diabetes is genetic and this may make children less "marriageable";</p> <p>Participants kept their diagnosis a secret;</p>

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					Revealing the diagnosis evoked shame, guilt and regret.
Baggio, Santos, Sales & Marcon (2013)	To identify how people suffering from type 2 diabetes, re-hospitalised due to uncontrolled glucose, perceived the disease, and the reasons that led to hospitalization.	Brazil	<p>People with type 2 diabetes</p> <p>N=7</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: 2-21 years</p> <p>Gender: 4 males, 3 females</p> <p>Age: males: 47 to 71; females: 18 to 36.</p> <p>Education: 2 illiterate, 5 had four to eleven years of schooling</p> <p>Occupation: 3 retired, 2 unemployed, 1 babysitter, 1 tractor driver</p>	Descriptive qualitative study, semi-structured interviews, thematic analysis	<p>Participants had a very negative conception of type 2 diabetes.</p> <p>They identified heredity and lifestyle as primary causes.</p> <p>They also recognised the complications resulting from type 2 diabetes</p>
Gordon, Walker and Carrick-Sen (2013)	To understand the knowledge and perceptions of type 2 diabetes and to explore preferable educational strategies in the non-diabetic offspring of	UK	<p>Relatives of people with type 2 diabetes</p> <p>N=6 offspring of patients with type 2 diabetes</p> <p>DEMOGRAPHICS</p>	Exploratory qualitative study, semi-structured one-to-one interviews, thematic framework analysis	<p><i>Risk:</i> Three participants believe their risk is the same as the general population</p>

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	<p>patients with the disease.</p>		<p>Age: 21-38</p> <p>Gender: 4 male, 2 female</p> <p>Weight status: 2 obese, 2 overweight, 2 healthy weight</p> <p>Education: mixture</p> <p>Work background: most were from working or lower middle class</p> <p>Ethnicity: White</p>		<p>and three believed it was higher.</p> <p>There was no correlation between perceived risk and weight status.</p> <p><i>Loading the dice:</i> those who believed to be at increased risk examined different lifestyle and family risk factors. Those who believed to be at the same risk as the general population offset negative lifestyle factors with positive behaviours.</p> <p><i>Denial and postponing inevitability:</i> several participants believed type 2 diabetes develops in older people and it doesn't concern them right now.</p>
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					<p><i>Knowledge:</i> type 2 diabetes was associated with “sugar levels” and “balanced”.</p> <p>Knowledge of biological mechanisms and long-term consequences was poor. Type 2 diabetes was associated with increased weight and poor diet. Knowledge may be associated with accurate risk perception.</p> <p><i>Inheritance:</i> the majority believed family history is a risk factor but were unsure how significant it is</p> <p><i>Lifestyle knowledge:</i> described a close association between weight</p>
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					and risk of type 2 diabetes.
Nguyen (2014)	To explore illness representations (Leventhal's model) of Vietnamese type 2 diabetes patients	USA	<p>People with type 2 diabetes</p> <p>N= 23 Vietnamese Americans</p> <p>DEMOGRAPHICS:</p> <p>Age: mean=64.7, range: 43 to 83 years</p>	Descriptive ethnography design, face-to-face semi-structured interviews, field notes.	<p><i>Labelling of diabetes:</i></p> <p>Type 2 diabetes was labelled as a disease with sugar in the urine. If this symptom was not present, the presence of type 2 diabetes was denied. Symptom-oriented self-management behaviour.</p> <p><i>Perceived causal mechanism</i></p> <p>Diet (eating too much rice), family history and stress were identified as main risk factors.</p> <p><i>Perceived consequences</i></p> <p>The lack of pain was associated with low perceived</p>

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					<p>threat. Knowledge about the pathophysiology of complications was medically inadequate. Type 2 diabetes also affected quality of life.</p> <p><i>Timeline trajectory</i></p> <p>Curability was used interchangeably with diabetes management. Most of the participants views type 2 diabetes as a life-long condition with an unlikely cure.</p> <p><i>Controllability</i></p> <p>Western oral medicines were perceived as important for diabetes control; participants believed they can feel it if glucose levels are abnormal; diet modification and</p>
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					<p>home remedies were also perceived as effective in controlling diabetes symptoms.</p> <p><i>Adaptive and coping decisions</i></p> <p>Spirituality was seen as a means to coping and dealing with complications.</p>
<p>Yilmaz-Aslan, Brzoska, Bluhm, Aslan & Razum (2014)</p>	<p>To explore illness representations among Turkish migrants with type 2 diabetes</p>	<p>Germany</p>	<p>People with type 2 diabetes</p> <p>N=24</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: range 6 months to 35 years</p> <p>Gender: 54% female</p> <p>Age: range 39-73 years</p> <p>Education: 29.1% no formal education, 54.2% school education of 2-5 years, 16.7% 9 or more years</p>	<p>Exploratory qualitative, semi-structured interviews, constructivism</p>	<p><i>Timeline</i></p> <p>Type 2 diabetes was perceived as cyclical and permanent. Patients preferred not to think about the course of their condition.</p> <p><i>Consequences</i></p> <p>Physical: worse health status, body changes</p> <p>Psychosocial: social isolation (sometimes voluntary), loss of contacts,</p>

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			<p>Duration of stay in Germany: 8-46 years</p>		<p>discrimination, loss of social functioning abilities, changes in social role</p> <p>Financial</p> <p>Older men underestimated the seriousness of type 2 diabetes.</p> <p><i>Causal attributions</i></p> <p>Low physical activity, diet, insufficient care for oneself, aging, heredity, environment (e.g. poor working and living conditions), immigration, stress, family problems, fate.</p> <p><i>Identity and coherence</i></p> <p>Type 2 diabetes was associated with physical symptoms. Described as invisible, non-</p>
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					<p>disturbing due to the absence of pain. However, they underlined the complexity and unpredictability of type 2 diabetes and its impact on daily life.</p> <p><i>Control</i></p> <p>Through own behaviour by means of physical activity and diet change.</p> <p>Through powerful others – doctors and God.</p> <p>Type 2 diabetes was also described as uncontrollable.</p> <p>Some patients exercised control only when needed (i.e. when it gets worse)</p> <p><i>Emotional representations</i></p>
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						Fear of complications
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Quantitative studies

Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design	Measure(s)	Results
Scollan-Koliopoulos, O'Connell & Walker (2007)	To test the hypothesis that the ways in which family members with type 2 diabetes viewed controllability, consequences and stigma of diabetes would be positively related to target	USA	People with type 2 diabetes N=123 DEMOGRAPHICS Duration of diabetes: mean=8.85 years Gender: 59 women, 59 men Age: range 41-90	Hypothesis testing, surveys	Recollections of family illness perception questionnaire Revised illness perception questionnaire Summary of diabetes self-care activities survey	Perceptions of control in family members were associated with perceptions of control participants (p=.03) Recollections of family members' social and general consequences were associated with participants' own representations of

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Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design	Measure(s)	Results
	patients' perceptions of controllability, consequences and stigma		Ethnicity: 9 Hispanic, 103 Non-Hispanic Race: 29 Black, 74 White, 4 Asian, 7 More than one race Education: 3 9 th grade or lower, 29 12 th grade or GED, 7 graduate technical, 33 some college/trade, 50 4-year college Income: 9 below \$20 000, 19 between \$40 000 and \$59 000, 31 over \$70 000.		Demographic questions	social and general consequences (p=.01 and p=.05, respectively).
Searle, Norman, Thompson & Vedhara (2007)	To assess the illness representations of type 2 diabetes patients and their partners	UK	Patients with type 2 diabetes and their relatives N=164 DEMOGRAPHICS Age: mean and range: patients 67 (32-86); partners: 67 (33-87). Gender: 97 male, 67 female	Cross-sectional, questionnaires at baseline and at 12 months	Revised illness perception questionnaire (IPQ-R) Personal models of diabetes interview (PDMI)	<i>Diabetes representations:</i> There were significant differences for 2 of the 12 illness representations: patients scored lower on the illness coherence dimension, indicating poorer understanding of type 2 diabetes than

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Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design	Measure(s)	Results
			<p>Ethnicity (% White European): 95% patients, 97% partners</p> <p>Duration of diabetes: mean=8.8 years, range 6 months to 38 years</p> <p>Diabetes medication: 107 oral, 37 insulin</p> <p>BMI: mean=31.5</p> <p>Number of years living together/married: mean=35.6, range 2-64</p> <p>Occupation: patients: 54 retired, 10 professional, 32 semiskilled manual, 4 unemployed. Partners: 47 retired, 5 professional, 38 semiskilled manual, 10 unemployed.</p> <p>Age they left school: patients: 28 at 14 yrs, 32 at 15 yrs, 25 at 16 yrs, 15</p>			<p>partners (p<.01). Patients scored higher on personal control than partners (p=.009).</p>

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Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design	Measure(s)	Results
			at other age; partners: 24 at 14, 37 at 15, 24 at 16, 15 at other age Comorbidity in last 6 months: 31% arthritis, 11% asthma, 11% nervous disorders, 12% angina, 6% MI, 43% hypertension, 9% other heart trouble, 6% stroke, 6% cancer			

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Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design	Measure(s)	Results
Wallymahmed, A. (2007) (PhD thesis)	To explore illness perceptions in people with type 2 diabetes	UK	People with type 2 diabetes N=66 DEMOGRAPHICS Duration of diabetes: >12 months	Cross-sectional	Illness Perception Questionnaire (1 strongly agree – 5 strongly disagree)	Over 68% of patients could not decide about the chronicity of their type 2 diabetes. Participants were undecided whether type 2 diabetes is caused by external or internal factors. The most commonly identified different risk factors were diet, stress, heredity and own behaviour. Other factors included: virus, pollution, state of mind, chance, other people, and poor medical care. <i>Means for IRs:</i> Identity: 3.85 Consequences: 2.57 Control: 2.68 External: 3.43 Internal: 2.98 Timeline: 2.62
White, Smith, Hevey & O'Dowd (2009)	To examine the relationship between psychological and social factors and	Ireland	Patients with type 2 diabetes and their relatives N=153 patients N=74 relatives	Cross-sectional study	Diabetes knowledge questionnaire (DKQ)	<i>Diabetes knowledge:</i> patients and relatives scored a similar number of correct items (67% and 64%, respectively)

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	diabetes outcomes in people with type 2 diabetes and their family members.		<p>DEMOGRAPHICS</p> <p>Relationships: 47.9% wives, 19.2% husbands, 16.4% daughters, 5.5% sons, 5.5.% sisters, 2.7% partners, 1.4% mother, 1.4% nephew</p> <p>Gender: patients: 56.2% male; relatives: 27.4% male</p> <p>Age: patients: mean=59.1; relatives: mean=51.8</p> <p>Marital status: patients: 71.2% married, 12.4% single, 11.1% widowed, 5.2% separated</p> <p>Education: patients: 2.7% no formal; 38.7% primary; 16% junior certificate, 24% leaving certificate, 16%</p>		<p>Social support questionnaire-6 (SSQ6)</p> <p>The 12-item well-being questionnaire (W-BQ12)</p> <p>Illness perception questionnaire-revised (IPQ-R)</p>	<p><i>Social support:</i> Relatives have a similar number of people for support but they are less satisfied with the support they receive ($p < .001$)</p> <p><i>Well-being:</i> The mean general well-being scores for patients and relatives were similar (24.94 and 24.59). Relatives experience lower positive well-being ($p = .03$)</p> <p><i>Illness perceptions:</i> Cause according to patients and relatives: diet (71.1% and 81%), heredity (52.3% and 53.7%), aging (50.4% and 48.5%), own behaviour (49% patients) and stress (40% relatives). Relatives of people with good control were more likely to perceive chance/bad luck to be a</p>

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Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design	Measure(s)	Results
			undergraduate, 2.7% postgraduate; relatives: 0% no formal; 23.2% primary; 18.8% junior certificate, 37.7% leaving certificate, 15.9% undergraduate, 4.3% postgraduate SES: patients: 21.6% I and II, 25.5% III and IV, 10.5% V and VI, 26.8% housewife, 10.5% retired, 5.2% unemployed			cause of type 2 diabetes. Relatives perceived type 2 diabetes as cyclical more than patients did. Relatives perceived the consequences of type 2 diabetes to be more serious than patients. Patients perceived type 2 diabetes to be more personally controllable than relatives did ($p < .001$). Relatives perceive they have significantly less understanding about type 2 diabetes than patients. No difference in emotional distress between patients and relatives.
Calvin, Quinn, Dancy, Park, Fleming, Smith & Fogelfeld (2011)	To explore perceived risk for diabetes complications among urban African American adults (18-75 years)	USA	People with type 2 diabetes N=143 African Americans DEMOGRAPHICS	Exploratory, descriptive, correlational, cross-sectional	Risk Perception Survey-Diabetes Mellitus 12-item Well-being Questionnaire	Mean score of risk perception for diabetes complications = 2.58 (range 1-4). >50% did not perceive their health to be at moderate or high risk

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Author and year	Study aim(s) as relevant to the current review	Country	Participants (number and characteristics)	Design	Measure(s)	Results
	old) with type 2 diabetes		Duration of diabetes: 1.95 years Age: 52.8 Gender: 53.1% women Family history of diabetes: 85.3% First-degree relative with diabetes: 69.2% Education: 12.2 years Monthly income: between \$499 and \$2100 or more History of hypertension: 70.6		Illness Perception Questionnaire (IPQ-R) Blood gas analyser for A1C Blood pressure	for having complications, with the exception of heart attack, vision problems, and high blood pressure. 65% did not see diabetes as a permanent condition
Hajos, Polonsky, Twisk, Dain & Snoek (2011)	To explore across countries the extent to which physicians understand Type 2 diabetes patients' perceptions of seriousness, worries about complications, emotional distress,	France, Germany, UK, Italy, the Netherlands, Spain, Sweden, USA	People with type 2 diabetes N=1609 DEMOGRAPHICS Duration of diabetes: mean=6.5 Age: mean=51.4 Gender: 41% female	Cross-national survey	Perceived seriousness Diabetes-related distress: worried, afraid, overwhelmed, would benefit from psychological support, angry Worries about complications: eye damage, kidney	Perceived seriousness differed by country (p<.001) Mean perceived seriousness = 2.4 Mean diabetes distress= 6.9 Worries about complications: mean=3 Worries about complications were

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	and needs for care improvement.				damage, cardiovascular complications, leg problems, foot sensitivity disorders, sexual disorders, amputations.	significantly and positively related to perceived seriousness and emotional distress.
Scollan-Koliopoulos, Walker & Rapp III, (2011)	To test if type 2 diabetes patients with and without family history of type 2 diabetes have different illness representations	USA	<p>People with type 2 diabetes N=100 (50 with family history, 50 without family history)</p> <p>DEMOGRAPHICS Age: range 21-90 (mainly 71-80 years) Race: 19 Black, 53 White, 2 Asian, 6 Mixed race Income: clustered below \$15 000 and over \$70 000. Education: 1 8th-9th grade, 19 12th grade, 8 technical, 23 some college/trade, 29 4-year college</p>	Hypothesis testing, surveys.	Illness Perception Questionnaire-Diabetes Version Summary of Diabetes Self-care Behaviour (SDSC)	Type 2 diabetes patients with family history of diabetes were more likely to perceive diabetes as distressing, upsetting, causing fear, anger, anxiety and worry. They also reported less understanding of diabetes and feeling it is unpredictable. The difference between people with and without family history of diabetes were detected on scores of personal control (p=.001), treatment control (p=,001), emotional representations

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						(p=.048) and illness coherence (p=.043)
Dimitraki & Karademas (2014)	To examine the relation between certain illness representations and the physical and psychological well-being of persons with type 2 diabetes mellitus and their spouses	Greece	<p>Patients with type 2 diabetes and their relatives N= 84 couples (168 individuals) DEMOGRAPHICS: Duration of diabetes: 14.94 years Age: patients: 64.65 years, spouses: 62.83 years Gender: patients: 55 women, 29 men. Marriage duration: 27.39 years Education: patients: 62% nine year mandatory education or less; 16.70% high school; 21.30% higher education. Spouses: 63.1% mandatory education or less; 25% high school; 11.9% higher education</p>	Hypothesis testing, questionnaires, Actor-Partner Independence model (APIM)	Illness Perception Questionnaire (IPQ-R) General Health Scale from the RAND 36-item health survey The Hospital Anxiety and Depression Scale	Female patients reported high levels of anxiety and depression. The direction of interaction between patient and spouse illness representations may depend on the strength of personal perceptions as well as on the ways that each person evaluates partner reactions and understanding of type 2 diabetes. Spouses were more anxious when they perceived illness as serious (p<0.01)

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van Esch, Nijkamp, Cornel & Snoek (2014)	To explore patients' illness representations	The Netherlands	<p>People with type 2 diabetes N=546</p> <p>DEMOGRAPHICS</p> <p>Duration of diabetes: 241 <5yrs, 115 5-10yrs, 187>10yrs.</p> <p>Age: mean=63.6</p> <p>Gender: 272 men, 274 women</p> <p>Domestic situation: 180 living alone, 350 cohabiting</p> <p>Education: 336 low, 186 high</p> <p>Ethnic background: 311 Dutch, 157 Surinamese South Asian, 72 other</p> <p>Family history of diabetes: 155 no, 189 first- or second-degree relatives, 202 first-and second-degree relatives</p> <p>Treatment: 334 diet and/or tablets, 208 insulin</p>	Cross-sectional survey	Illness representations questionnaire (Likert 1-strongly disagree, 5-strongly agree)	<p>Patients had strong beliefs about the chronicity of type 2 diabetes (M=4) and the effectiveness of controlling it by own behaviour (M=3.60) and by medication (M=3.67). They reported good understanding of type 2 diabetes (M=3.48). They did not perceive type 2 diabetes as unpredictable (M=2.74). They did not report major consequences (M=2.49) and emotional impact (M=2.49). Most endorsed causes of type 2 diabetes:</p> <ul style="list-style-type: none"> Heredity-61.3% Ageing-49.4% Diet – 44.5% Stress-40.4% Lack of exercise-37.4% Chance/bad luck-36.7% Own behaviour-25.3% Family problems-22.9% Altered immunity-21.6%

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			<p>Complications: 280 yes, 246 no</p>			
<p>Woolthuis, de Grauw, Cardol, van Weel, Metsemakers & Bierman (2013)</p>	<p>To investigate how the route to diagnosis of type 2 diabetes (through screening versus clinical symptoms) affects illness perceptions of patients and their partners.</p>	<p>The Netherlands</p>	<p>Patients with type 2 diabetes and their relatives N=109 patients N=109 relatives DEMOGRAPHICS Patients: screening and clinical, respectively Age: 61.4 and 59.3 Gender: 42 male and 22 female Education: primary 8 and 10; secondary 59 and 14; tertiary 8 and 8 Employment: employed 24 and 9; homemaker 13 and 6; unemployed 9 and 5, retired 30 and 11 Diagnosis <6 months ago: 16 and 7 Partners: screening and clinical, respectively</p>	<p>Cross-sectional</p>	<p>The brief illness perception questionnaire (Brief IPQ) The revised illness perception questionnaire (IPQ-R)</p>	<p>Screening group was less likely to identify lifestyle as the cause and more likely to believe that heredity plays a causal role. Partners of screening detected patients, in comparison to partners of clinically diagnosed patients, perceived type 2 diabetes as a more serious disease and they also perceived greater consequences for their own life. Partners perceive type 2 diabetes to be more serious than patients do</p>

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			<p>Age: 61.6 and 56.9 Gender: 35male and 10 male Education: primary 9 and 5; secondary 53 and 21; tertiary 13 and 5 Employment: employed 26 and 8; homemaker 22 and 12; unemployed 3 and 4, retired 25 and 7</p>			