Diet modification challenges faced by marginalized and non-marginalized adults with Type 2 Diabetes: A systematic review and qualitative meta-synthesis

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Introduction:

The rates of diabetes mellitus have increased dramatically in the past decades, with over 2.4 million Canadians and 24 million Americans living with the disease, representing approximately 8% of the general population of each country.1, 2 More than 90% of adults with diabetes have type 2 diabetes mellitus (T2DM), which correlates with increased age, body weight, and family history.1 In industrialized countries, the prevalence, morbidity and mortality rates of diabetes are higher among indigenous peoples,3 immigrants,4 non-immigrant ethnic minorities5 and people of low socioeconomic status.6, 7

T2DM causes several wide-ranging complications, and when blood sugar levels are uncontrolled, diabetic complications can negatively affect all aspects of a person’s quality of life.8, 9 People with type 2 diabetes who are unable to control their condition through medication, diet, and exercise often experience multiple, interconnected complications which affect their physical, emotional, practical, and social well-being. Uncontrolled blood sugar levels contribute significantly to both the short- and long-term complications associated with diabetes. The short-term consequences of uncontrolled diabetes include dizziness, restlessness, confusion or cognitive dysfunction, headaches, weakness, anxiety, depression, and nausea, among others; these often impair daily functioning.8, 9 The long-term effects of uncontrolled T2DM include a greatly increased risk of cardiovascular disease, kidney failure, damage to eyesight and hearing, foot damage, nerve damage, a decline in mental health status, and an increase in overall mortality.8, 9
While there is no consensus as to the ideal diet for type 2 diabetes, there is ample evidence that modifying diet by limiting the intake of red meats, balancing macronutrients, eating regularly, and controlling caloric intake and weight gain offers one of the most effective ways to maintain glycemic control. Appropriate diet modification, clinically individualized to each patient’s treatment goals and preferences, correlates with a lower risk of diabetes related morbidity and mortality. As a result, alongside medication adherence and consistent physical activity, many clinical care guidelines recommend diet modification. Despite the known importance of diet modification and the proliferation of self-management interventions to encourage diet modification, many adults with type 2 diabetes struggle to adopt and maintain a clinically recommended diet. Available country-based data show low adherence and sub-optimal diet quality among people with type 2 diabetes.

This systematic review and qualitative meta-synthesis examines recent published qualitative research to provide evidence that answers the following research questions: What barriers do people with type 2 diabetes experience when trying to modify their diets? How does social marginalization affect the experience of diet modification? We chose to focus our analysis on the differential challenges faced by people who are socially marginalized and those who are not as marginalized. This analytic decision reflects the differential health outcomes and prevalence of diabetes in marginalized groups and corresponds to the available literature: nearly two-thirds of qualitative studies regarding diet modification for people with diabetes describe the experiences of research participants identified by the author as socially marginalized.

We conducted this study using an intersectional theoretical lens to guide our understanding of the significance of social marginalization. Our interpretive lens views each person with diabetes as living within a specific social context shaped by their unique perspective, situation, and access to (or deprivation from) certain resources. The social, economic, and political environments of people with diabetes, including the effects of race, class, and gender identities, play a critical role in mitigating or magnifying existing challenges to diet modification. Recognizing the artificiality of categories of social identification, but still requiring a way to categorize included papers for the purpose of the systematic review, we use each author’s identification of participants as marginalized. We recognize that individual participants may experience their identities differently, and that participants in studies where the author does not identify marginalized identities within the sample may still experience social marginalization.

Our analysis reveals that while all people with diabetes experience common challenges when modifying their diets, social marginalization can magnify the experience of common challenges and introduce new challenges. While we did identify some challenges characteristic of specific types of marginalization, we caution readers from making a causal link between particular aspects of identity and specific diet modification challenges, as members of groups do not share all the same experiences. For example, two people with diabetes may both identify as female
senior citizens who are first-generation Bangladeshi immigrants. However, due to their particular social supports, financial resources, education, and health care experiences they may have very different experiences when trying to adapt their diet to fit diabetes guidelines.

Methods:

We conducted a literature search on April 1, 2015 using OVID Medline, EBSCO Cumulative Index to Nursing and Allied Health Literature (CINAHL), ISI Web of Science Social Sciences Citation Index (SSCI) for studies published from January 1, 2002 to April 1, 2015. We chose to limit the search to papers published since 2002 to balance comprehensiveness with manageability. We limited our search to high-income countries where health care and food and diabetes education are available to most of the population, choosing the regions of Canada, USA, Europe, Australia and New Zealand as a proxy for resource availability. We combined our published filter for qualitative research with a diabetes search filter developed by information scientists.22, 23 We searched within the existing results for publications with the following words in the title or abstract: food*, diet*, nutrit*, eat*, meal*, challeng*, modif*, lifestyle. Two authors read titles and abstracts. If consensus was not reached with a title and abstract review, the full text was reviewed for eligibility and discussed by three authors.

Inclusion & exclusion criteria:

We included studies that were published between January 1, 2002 and April 1, 2015. They consisted of primary, empirical qualitative research using any descriptive or interpretive methodology. Eligible publications studied an adult patient population (> 18 years of age) with type 2 Diabetes Mellitus or an unspecified type of diabetes. The studies took place in North America, Europe, Australia or New Zealand and addressed any aspect of the experience of diet modification, nutrition, food, or meals. The studies were published in English and available either through the McMaster University library system or from the corresponding author.

We excluded studies when the topic of diet (as previously defined) was not sufficiently prominent to merit mention in the title or abstract (e.g. general self-management studies with no specific mention of diet). We excluded studies that primarily addressed the experiences of people with type 1 diabetes, gestational diabetes, or those without a diagnosis of diabetes. We also excluded unpublished studies (e.g. theses) and those that did not use primary empirical data. Finally, we excluded quantitative research, which we defined as using statistical hypothesis testing, quantitative data and analyses or studies that expressed results in quantitative or statistical terms.

We did not exclude qualitative research on the basis of methodology or independently assessed quality. The decision to include findings from all relevant studies is based on a number of
factors: the relative similarity of qualitative data analysis, regardless of methodological orientation; the common occurrence of research reports with no cited methodological orientation; the ongoing debate among qualitative researchers about what constitutes methodological adherence and quality.24, 25 Consistent with our methodology, we excluded studies for only one reason: when we could not discern data to support the findings.24 This approach evaluates the rigor of qualitative research by looking for empirical evidence in support of the reported judgments or inclusions. One cannot easily evaluate "methodological conformity, congruence or sophistication" (p. 155).24 in a methodological field where researchers conventionally underreport procedural details, and the quality of findings tends to rest less on methodological processes than on the conceptual prowess of the researchers.26

Analytical method:

Using the technique of integrative qualitative meta-synthesis, we analyzed the findings from all eligible studies.24, 25 Qualitative meta-synthesis is an integrative technique that combines findings from multiple studies to produce a synthesis of evidence which both retains the original meaning of the authors and offers a new, integrative interpretation of the phenomenon.24, 25 Consistent with this methodology, we started with pre-defined research questions and a search strategy that guided data collection, relevance determination and data extraction. Our research questions are: What barriers do people with type 2 diabetes experience when trying to modify their diets? How does social marginalization affect the experience of diet modification?

At least two authors extracted the data, with discrepancies resolved by team consensus. The data for this synthesis were the researchers’ qualitative findings: the “data-driven and integrated discoveries, judgments, and/or pronouncements researchers offer about the phenomena, events, or cases under investigation” (p. 909). Through a staged coding process similar to that used in grounded theory,24, 54 we broke the studies’ findings into their component parts (key themes, categories, concepts, etc.), which we then thematically re-grouped across studies. These categories developed based on relevance to the research question, prevalence, coherence, and significance, provided the foundation for analysis. We then synthesized and further developed the categories using an inductive and constant comparative approach.

Data consists of previously published evidence, so research ethics approval was not required.

Results

The database search yielded 16,127 citations published between January 1, 2002 and April 1, 2015 (with duplicates removed). Figure 1 illustrates the bibliographic search process.
We synthesized 120 papers. These 120 papers describe the experiences of 3,721 participants (3,283 patients, 203 family members, and 235 clinicians). Ninety-two studies (76%) involved marginalized participants, and many included participants experiencing multiple types of marginalization. Tables 1-3 describe the included studies, including geographic location, methodology, and forms of social marginalization studied, respectively.

We discuss 5 key barriers to diet modification: (1) self-discipline, (2) emotions, (3) family and social support, (4) social significance of food, and (5) knowledge and information. These barriers are overlapping and inter-related, and have a cumulative effect when combined (Table 4). Social marginalization further magnifies the challenges experienced in relation to each barrier.

**Self-Discipline**

Many authors describe self-discipline as a central intrapersonal challenge to diet modification\(^\text{29-35}\) both for people who identify as socially marginalized\(^\text{29-31, 33, 34, 36-55}\) and non-marginalized.\(^\text{32, 56-68}\) Some authors explore the nature and experience of exercising self-control, but most concentrate on the challenges and enablers of self-discipline for those trying to modify their diets.
The central challenge to self-discipline is losing the pleasure that particular foods bring, whether related to the taste, eating circumstances, or the freedom to consume whatever one wishes.\textsuperscript{67, 69} Other challenges to self-discipline included disliking the taste of healthy food, or the taste of food prepared with diabetes-friendly substitutes\textsuperscript{36, 37, 43, 50, 55, 56, 70}, and having a hard time giving up unhealthy favourites\textsuperscript{29, 31, 37, 39, 44-46, 48-51, 54, 55, 58-60, 71-73} whether because of taste or because of social or cultural significance\textsuperscript{36, 38, 39, 43, 45, 71, 74-87}. Self-discipline is further challenged when eating away from home, especially during celebrations and holiday gatherings.\textsuperscript{33, 35, 49, 55, 60, 68}

Portion control is a frequently discussed self-discipline strategy, acting as both a barrier and facilitator of diet modification. As a barrier, portion control is described as time consuming, associated with feelings of hunger, and resulting in a reduction of pleasure from food.\textsuperscript{31, 35, 38, 70, 74, 81, 88, 89} As a facilitator, portion control can encourage diet modification by allowing participants to continue to eat enjoyable foods, albeit in small quantities.\textsuperscript{29, 31, 32, 36, 41, 55, 60, 74} Regardless of whether portion control is described as a barrier or facilitator, it is still labeled as a challenging strategy that is not enjoyable or easy to do.

Participants conceptualize self-discipline as something that \textit{can} and \textit{should} be controlled by the individual,\textsuperscript{59, 61, 63, 64, 90} and something that exists in limited capacity, eroded by repeated temptations or difficult circumstances. Participants would activate self-discipline by avoiding tempting food and circumstances where unhealthy food is typically consumed.\textsuperscript{49, 54, 55, 67} Other enablers to self-discipline include awareness and education of how and why people with diabetes should change their diet.\textsuperscript{36, 48, 52, 91} Awareness of the consequences of not changing one’s diet can be a powerful motivator of dietary self-discipline. Awareness was typically explained to mean having a fear of the complications of uncontrolled diabetes\textsuperscript{49, 56, 67, 79, 92} whether from personal experience,\textsuperscript{32, 39, 45, 57, 61, 93, 94} or witnessing the experiences of others.\textsuperscript{37, 95}

There is a gendered divide in the reports of self-discipline and how it affects diet modification, with several authors reporting findings that “dietary struggles were a much more prominent part of women’s self-care behavior” (p. 6).\textsuperscript{38, 49, 53-55, 66, 68} This may be related to the common experience of using food consumption practices to regulate weight, as reported by the female participants in Balfe's study.\textsuperscript{57} Gendered roles may also shape spousal interaction around self-discipline; Beverly found that men who relied on their spouses to maintain a healthy diet exhibited lower levels of self-control, and that control over food-related decisions is often a source of conflict between spouses.\textsuperscript{58}

\textit{Emotions}

Numerous researchers describe negative emotions as one type of intrapersonal barrier detrimental to dietary change. Stress is the most frequently mentioned emotion.\textsuperscript{31, 36, 41, 43, 57, 61, 63, 64, 68, 71, 76, 77, 83, 92, 96-104} Stress is described by Jones and colleagues as particularly detrimental to dietary modification because “high levels of stress divert priority away from management”\textsuperscript{52} (p. 91-97).
Coping with stressful circumstances in one's everyday life may present barriers to healthy eating. The stress of everyday life may include busy routines as a result of work or family commitments, caregiving stress, or stress from living in poverty or experiencing discrimination and racism. Diabetes itself may be a cause of stress, as patients try to cope with the diagnosis of diabetes and the many self-management activities they are instructed to engage in. Participants also describe feelings of stress related to the fear of diabetic side effects and their consequences, including a fear of hypoglycemic events.

No matter what the cause, stress may challenge self-discipline, leading people to feel less motivated to manage their diets. Others may seek comfort from stress in food. When experiencing challenges with their self-management regimens, patients may experience guilt or anger, which may in turn cause stress and further challenge their self-management efforts, creating a cycle of defeat.

Other negative emotions related to diet modification include depression, loneliness and isolation, especially when people with diabetes are not able to freely partake in the social occasions and rituals which centre around food.

**Family and Social Support**

The influence of family is an important part of dietary self-management and the interpersonal relationships surrounding a person with diabetes can act as both a barrier or facilitator of dietary change. As the household is the main site of food planning, preparation, and consumption, other household members often have a strong influence over diet modification efforts. Many authors suggest that efforts towards dietary change must accommodate the routines, resources, and activities of the household. Sometimes this influence can be very helpful: family members can provide instrumental and social/emotional support, especially when they have been educated on the needs and requirements of a diabetic diet.

Family members can also present significant barriers to dietary change. It is difficult to integrate new eating patterns into established family preferences and habits, which may have intergenerational and cultural significance. Family eating habits reflect the preferences of the members, which the diabetic individual may feel reluctant or powerless to change, or guilty about requesting such a ‘sacrifice.’ When acting as the main cook for the family, a person with diabetes may feel beholden to the wishes of others in terms of what type of food is served, and when. Those who are not the main cook for the family may have little control over menu planning or portion allocation. These issues of control and cooperation are described as a gendered
problem; families may be more likely to accommodate the needs of men with diabetes, while women with diabetes are more likely to sacrifice meal plans to accommodate family requirements or desires.37, 42, 45, 47, 62, 73, 123, 125, 129

Social Significance of Food

The social significance of food and the role of food in social and celebratory occasions are powerful interpersonal barriers to achieving dietary change.29, 31, 35, 36, 38, 41, 42, 45, 47, 48, 52-57, 59, 61, 63-68, 74, 77-82, 85, 92, 95, 98, 101, 102, 113, 116, 119, 123, 124, 129-132 Food is an important part of social life, and dietary adherence during social occasions is difficult for many reasons.29, 42, 48, 55, 61, 64, 66, 80, 87, 92, 98, 113, 123, 124, 132 Participants in many studies expressed a reluctance to decline food, to be a burden to the host by asking for accommodation, or stand out from the crowd by eating smaller quantities or different items.48, 52, 55, 57, 65, 66, 68, 78, 80, 101, 110, 131 Many participants were reluctant to disclose or draw attention to their status as a person with diabetes.48, 55, 66, 77, 78, 131 This finding was especially strong in studies of marginalized groups.45, 48, 52, 55, 66, 77, 78, 80, 101, 131 The unwillingness to draw attention to oneself by eating or drinking differently from the group made eating in a diabetes-friendly way more difficult during social occasions, especially when those occasions take place away from home. Even when acting as hosts, which would presumably afford more control over the food available, participants perceived a social obligation to cook and serve traditional foods, regardless compatibility with the diabetic diet.74, 81, 98

People with diabetes may feel a sense of social isolation when they are not able to fully participate in social occasions because of their dietary needs.31, 52, 66, 78, 101 Participants in many papers also emphasized the enjoyment that food brought to them during these social occasions and the importance of participating in community and family life in this way.31, 41, 42, 45, 54, 56, 78, 81, 98, 116, 119 “Socialising and enjoying oneself may be valued more highly than health, so people sometimes opt for ‘doing the wrong thing’” (p. 2378), 59 which can also be understood as prioritizing social well-being, community and family memberships over diabetes care.

The concept of food as a form of social participation was especially pronounced in studies of people who are members of culturally marginalized communities.38, 41, 42, 45, 47, 54, 56, 59, 63, 74, 78-80, 82, 116, 129-131, 133 For these people, food is an important way of participating in traditions and staying in touch with cultural communities, with many specific foods mentioned as integral to cultural identity and membership.36, 38, 41, 45, 47, 54, 74, 78, 79, 81, 130 For example, “rice is viewed as a symbol of strength, sustenance, sacrifice, wealth and togetherness and may be eaten at every meal. Reducing or eliminating rice from one’s diet may be perceived as rejecting Filipino culture and is thus considered a difficult loss for many Filipino Americans” (p. 847).79 The cultural significance of food also extended to traditional methods of preparation, making diabetes-friendly substitutes or cooking methods less appealing.36, 45, 81 Declining, abstaining or asking for accommodation might be considered offensive in some situations.36, 42, 45, 54, 79, 82, 130
Knowledge and Information

Many studies described the importance of knowledge about nutrition when making dietary changes. Knowledge is treated in very different ways across this body of literature, with some studies focused on describing specific gaps in knowledge. Common knowledge gaps include the consequences of uncontrolled diabetes, portion control, the concept of calories, how to count carbohydrates for diabetes management, the relationship between food and blood glucose level, the difference between sugar and fat, which vegetables should be counted as carbohydrates, and how to plan meals with fruit.

Other authors deeply interrogate the relationship between knowledge, motivation, and behaviour change, e.g. Greenhalgh and colleagues. One synthesis of findings on knowledge identified that there are two types of important knowledge for dietary modification. First, a person with diabetes must have knowledge of the basic information about dietary modification. Second, that person must also have the knowledge that allows them to adapt their diet to the changing circumstances of their lives, accommodating schedules, special events, cravings, slip-ups, etc. “Participants emphasized the importance of having general knowledge about T2DM as well as knowing how to manage the disease” (p. 902). Greenhalgh names this distinction ‘knowing that’ (abstract knowledge) and ‘knowing how’ (practical understanding), hypothesizing that when patients are ‘non-compliant’ it may be that they lack practical understanding of knowing what to do. This idea is present (explicitly or implicitly) in many papers that emphasize the need for information about specific strategies that can be adapted to the needs and preferences of people with diabetes. Researchers give many different examples of what these particular strategies might include, such as meal-planning with specific circumstances in mind, which diabetes-friendly foods are affordable, how to read food labels, how to incorporate traditional foods and cooking practices, how to adapt and plan when you have a lack of time for cooking or limited cooking skills, how to accommodate celebrations, cravings, and slip-ups.

There is a wide recognition that knowledge may be a necessary condition for dietary modification, but it is not a sufficient condition to make and sustain dietary change. Knowledge may be difficult to apply because of the affordability of food, incompatibility between dietary recommendations and personal or traditional eating habits, a lack of time for planning, shopping, and preparation, a lack of cooking skills, comorbid conditions with conflicting requirements, insufficient numeracy and literacy skills to interpret food labels, and challenges incorporating recommendations for unfamiliar foods and ingredients. Sometimes there are interpersonal barriers, such as when the person with the
knowledge about diabetes is not in control of the meal planning, food shopping, and preparation.42, 63, 131

There are only subtle distinctions between the topic of knowledge across studies of marginalized and non-marginalized people, with studies of socially marginalized people placing more emphasis on the specific circumstances of an individual’s life that require adapted information. For example, diet recommendations may incorporate foods that some people are not familiar with, or do not typically use.37, 50 Other groups may need information on how to adapt traditional ingredients and cooking methods to a diabetes-friendly diet.76, 81, 83 Literacy and numeracy challenges to gaining knowledge and finding information may be higher in some groups, and in those who do not fluently speak or read the dominant language.121

Magnifying Effect of Social Marginalization

A simple explanation of the challenges faced by people with diabetes as they modify their diets is that food is an important part of life, and diet modification requires changes that ripple through most other aspects of life. Food requires resources, planning, and knowledge; food brings people together, solidifying community, maintaining identity, and conveying love. Changing the way you eat means changing the way you live. Because of the profound change required for diet modification, even the most motivated, highly resourced individuals face challenges. People who face one or more types of social marginalization are trying to make the same changes with fewer socio-material resources and in the face of greater challenges.

As an example of the way social marginalization magnifies the challenges of diet modification, consider the effect of poverty. All people make dietary changes within their household group or family, and are challenged to balance the needs and preferences of family members with and without diabetes. For people with diabetes living in poverty, this challenge may be especially acute, as diabetes-friendly food is often more expensive, drawing resources away from other family members.42, 50, 88, 102, 109, 148 The diversion of resources included not just the cost of the food, but also the time and resources required to buy the food, which may not be readily accessible in all neighborhoods.46, 50, 69, 70, 88, 102, 149 Meal planning and preparation was a common challenge across most studies, but people living in poverty may face additional planning and procurement challenges including “having to choose between lower prices and long commutes by public transportation, taking up several hours at a time and carrying multiple bags, or higher prices at closer-by stores, where often they are also forced to shop due to time constraints (e.g. holding multiple low-paying jobs)”( p. 152). 102

Discussion

Diet modification is an important part of the control and management of T2DM, but continues to challenge many patients. A strong body of literature has demonstrated that self-management interventions, including diet modification, can be at least as effective as medication in preventing
diabetes and in controlling diabetic side effects and comorbidities.\textsuperscript{150-152} Despite a proliferation of programs and interventions to encourage and support dietary change, sustained change remains elusive. While studies have shown a wide variety of interventions to have positive effects on diet modification, a meta-analysis by Norris and colleagues revealed that the benefits of many interventions decline after the end of the intervention.\textsuperscript{153} The difficulty in sustaining dietary change resonates with our findings, which emphasize the central role food plays in social life, and the influence of a myriad of social factors on food planning and preparation. This is recognized by international guidelines that recommend that self-management interventions and counseling should consider the health beliefs, decision-making skills, cultural preferences, and the financial and social resources of the person with diabetes.\textsuperscript{8, 9, 14}

The discursive and theoretical emphasis on self-management in the diabetes literature emphasizes the control, motivation, and behaviour of the individual. Our findings are congruent with a social-ecological model of behaviour change, highlighting that “self-management is dependent on the environmental contexts that surround the individual” (pg. 1523).\textsuperscript{154} The barriers identified by people with diabetes as they engage in diet modification correspond to the different levels of influence identified by social-ecologists.\textsuperscript{154-157} For example, at the intrapersonal individual (biological and psychological) level, people with diabetes may struggle with taste preferences or emotional comfort eating. At the interpersonal (family, friends, small group) level, people with diabetes may struggle to accommodate the tastes and preferences of their family members into meal changes, they may feel sabotaged by friends or family members, and they worry about not wanting to spoil a celebration by declining to eat in the same way as everyone else. At the system, group, or cultural level, people with diabetes may encounter dietary recommendations that conflict with their cultural food preferences or they may feel stigma in disclosing their diabetes. At the community or policy level of influence, they may not be able to afford diabetes-friendly foods, and they may not have access to information that supports adaptive problem solving.

For people with diabetes who experience social marginalization, environmental factors may present larger barriers in the area of culturally inappropriate or incongruent education and information, language difficulties, financial or physical obstacles to procuring and preparing healthy food, etc. The particular social location of each person with diabetes will influence the social-ecological environment in which that person is making dietary change, and present a correspondingly individual set of barriers and facilitators.\textsuperscript{155, 157} For instance, a form of social marginalization such as poverty can influence diet modification on many different levels: a lifetime of eating available food may shape an individual’s tastes and food preferences for cheap, high-fat, carbohydrate-heavy food.\textsuperscript{50} Interpersonal relationships may lead people living in poverty to have to choose how to allocate scarce familial resources. For example, with limited money for food, a person with diabetes living in poverty might have to choose between feeding the whole family with less expensive food, or buying a smaller amount of more expensive

diabetes-friendly food for themselves. At the system, group, or cultural level, people living in poverty might experience stress at higher levels than others, which people with diabetes have identified as a causal factor for poor eating habits. At the community or policy level, the lack of fresh produce and healthy foods in poor neighborhoods might make it inaccessible to many people living in poverty. The use of a social-ecological theoretical lens clarifies the multiple, magnifying impacts that social marginalization has on diet modification.

Our findings and socio-ecological perspectives to health behaviour change both suggest that multi-level interventions most effectively change behaviour, rather than person-focused approaches which target the individual in isolation from his or her environment. Interventions that target the individual’s knowledge, motivation, and behaviour often neglect the influence of the social and environmental factors that shape and reinforce health behaviours.

Strengths and Limitations

This study provides a comprehensive synthesis of the perspectives of people with T2DM on barriers to diet modification. There is a significant amount of qualitative research on this topic, and it has not yet been gathered together in this way. Existing systematic reviews of qualitative research focus on diabetes management more broadly, and in this broader view are not able to address some of the nuances of diet modification. The large number of studies included in this meta-synthesis provides a breadth and depth of information from a wide range of participants and health care contexts, increasing the transferability of our findings across settings.

Limitations of this work include a focus on English-language reports, and a focus on resource-rich nations. Caution should be used when considering the relevance of these results to low and middle income jurisdictions.

Conclusion

Analysis of 120 primary, qualitative studies on challenges to diet modification revealed several inter-linked and overlapping barriers to diet modification, including self-discipline, emotions, family and social support, the social significance of food, and knowledge. The analysis also highlighted the magnifying effect of social marginalization on the identified barriers, with different forms of social marginalization compounding the barriers experienced by patients. The particular social location and circumstances of a person with diabetes will significantly affect the challenges that individual faces.
Table 1: Included studies, by location.

<table>
<thead>
<tr>
<th>Study Location</th>
<th>Number of Eligible Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia/New Zealand</td>
<td>13 (11%)</td>
</tr>
<tr>
<td>Canada</td>
<td>10 (8%)</td>
</tr>
<tr>
<td>UK</td>
<td>17 (14%)</td>
</tr>
<tr>
<td>Europe</td>
<td>10 (9%)</td>
</tr>
<tr>
<td>United States</td>
<td>68 (56%)</td>
</tr>
<tr>
<td>Multiple Countries</td>
<td>2 (2%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>120 (100%)</strong></td>
</tr>
</tbody>
</table>

Table 2: Included studies, by study design

<table>
<thead>
<tr>
<th>Study Design</th>
<th>Number of Eligible Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content analysis</td>
<td>5 (4%)</td>
</tr>
<tr>
<td>Ethnographic analysis</td>
<td>8 (7%)</td>
</tr>
<tr>
<td>Grounded theory/constant comparative analysis</td>
<td>10 (8%)</td>
</tr>
<tr>
<td>Other (case study, comparative, discourse analysis, narrative, cross-case analysis, exploratory, interpretive, descriptive)</td>
<td>16 (13%)</td>
</tr>
<tr>
<td>Phenomenological</td>
<td>10 (8%)</td>
</tr>
<tr>
<td>Qualitative (otherwise unspecified)</td>
<td>62 (52%)</td>
</tr>
<tr>
<td>Framework analysis</td>
<td>4 (3%)</td>
</tr>
<tr>
<td>Thematic analysis</td>
<td>2 (2%)</td>
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<tr>
<td>Community-based participatory research</td>
<td>3 (3%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>120 (100%)</strong></td>
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Table 3: Included studies, by type of social marginalization.

<table>
<thead>
<tr>
<th>Type of Marginalization Identified</th>
<th>Number of Eligible Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minority ethnicity or culture</td>
<td>58 (48%)</td>
</tr>
<tr>
<td>Immigrant</td>
<td>19 (16%)</td>
</tr>
<tr>
<td>Non-immigrant</td>
<td>34 (28%)</td>
</tr>
<tr>
<td>Both</td>
<td>5 (4%)</td>
</tr>
<tr>
<td>Low socioeconomic status</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>31 (26%)</td>
</tr>
<tr>
<td>Rural dweller</td>
<td>12 (10%)</td>
</tr>
<tr>
<td>Old age</td>
<td>21 (18%)</td>
</tr>
<tr>
<td>Physical disability</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Any type of social marginalization</td>
<td>92 (76%)</td>
</tr>
</tbody>
</table>

*Many studies mentioned multiple types of marginalization, so the total equals more than 92.

Table 4: Five inter-connected barriers to diet modification that are magnified by social marginalization

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Key Points</th>
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<tbody>
<tr>
<td>Self-Discipline</td>
<td>- Self-discipline understood as something that can and should be controlled by people with T2DM, something which exists in a limited capacity.</td>
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<tr>
<td></td>
<td>- Self-discipline challenged by the loss of pleasure or enjoyment when traditional or favourite food is replaced with a diabetes-friendly substitute</td>
</tr>
<tr>
<td></td>
<td>- Self-discipline can be facilitated by portion control, allowing favourite or socially significant foods to be consumed in small quantities.</td>
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<tr>
<td></td>
<td>- Self-discipline can be facilitated by understanding the importance of changing the diet (e.g. side effects of uncontrolled blood sugars)</td>
</tr>
<tr>
<td></td>
<td>- Self-discipline more prominent in women’s accounts of challenges to diet modification</td>
</tr>
<tr>
<td>Emotions</td>
<td>- Negative emotions (e.g. stress, depression, loneliness) can be detrimental to dietary change.</td>
</tr>
<tr>
<td></td>
<td>- Stress is particularly prevalent in descriptions of barriers. Can divert attention and energy away from diet management.</td>
</tr>
<tr>
<td></td>
<td>- Stress may be caused by everyday life, caregiving, living in poverty or experiencing discrimination. Stress may also be</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Related to diagnosis of diabetes, management routines, fear of diabetic side effects. - When comfort from stress is sought from food, a vicious cycle of guilt or anger leading to more stress may ensue.</th>
<th><strong>Family and Social Support</strong> - Family can both facilitate and challenge diet modification. - Dietary change is facilitated when family and household members are educated about and supportive of the change. Family may provide emotional and instrumental support. - Family members can impede dietary change when they prioritize food preferences, wishes, and habits that are not congruent with a diabetes-friendly diet. - Some people with diabetes may have limited control over meal planning, shopping, and the timing of meals.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Social Significance of Food</strong> - Food is an important part of social life and dietary change during social occasions and celebrations is particularly difficult. - People with diabetes may not want to draw attention to their health needs or impose on others, and so may be reluctant to request accommodation or eat differently when in a group. - For members of minority communities, food is an important way to maintain cultural identity and membership. - Certain culturally significant foods may be especially hard to forego or substitute.</td>
<td><strong>Knowledge and Information</strong> - Knowledge is a necessary but not sufficient requirement for dietary change. Barriers such as affordability of food, lack of time, insufficient food literacy etc. can impede use of knowledge. - Knowledge about diabetes can be divided into “knowing how” and “knowing that” - “Knowing how” is practical knowledge necessary for disease management, including knowing how to adapt meal plans to life circumstances, read food labels, find affordable diabetes-friendly foods, incorporate traditional foods and cooking practices etc. - “Knowing that” includes abstract knowledge such as how to count carbohydrates, the relationship between food and blood glucose level, differences between sugar and fat etc.</td>
</tr>
</tbody>
</table>
Figure 1: Citation Flow Chart:

16,127 References retrieved with duplicates removed (published Jan 1, 2002 to April 1, 2015)

Primary eligible qualitative research (956)

Title/abstract screening for inclusion criteria:
- 11358 (quantitative)
- 667 (pediatric or adolescent pop)
- 59 (not published)
- 70 (not empirical)
- 675 (not patient perspective)
- 283 (gestational diabetes or T1DM only)
- 376 (not related to patient context)
- 717 (not conducted in a comparable health context)
- 165 (mixed methods studies)
- 33 (secondary reviews of qualitative and quantitative studies)
- 31 (secondary reviews of qualitative studies)

Total excluded: 15,170

Potentially relevant to diet modification (182)

Title/abstract screening for relevance to diet modification using terms: food*, diet*, nutrit*, eat*, meal*, challeng*, modif*, lifestyle
- 774 (not relevant to diet modification)

Full text screening for relevance to patient experiences of diet modification:
- 62 (not considered relevant)
- 0 (not retrievable)

Included (120)

References


98. Guell C. Diabetes management as a Turkish family affair: Chronic illness as a social experience. *Ann Hum Biol.* 2011; 38: 438-44.
99. Raphael D, Daiski I, Pilkington B, Bryant T, Dinca-Panaitescu M and Dinca-Panaitescu S. A toxic combination of poor social policies and programmes, unfair economic arrangements and bad

129. Redwood S, Gale NK and Greenfield S. 'You give us rangoli, we give you talk': using an art-based activity to elicit data from a seldom heard group. BMC Medical Research Methodology. 2012; 12: 7.


Author’s self-archived post-print version.