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**Patient Experiences of Medication Adherence: A systematic
review and qualitative meta-synthesis**

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Abstract

Background

Adherence to prescribed medication regimens is an important part of self-management for patients with diabetes. This report synthesizes qualitative information on how patients respond differently to the challenges of medication adherence, suggesting avenues for future research and intervention to assist patients with this aspect of self-management. Qualitative and descriptive evidence can also illuminate challenges that may affect the success and equitable impact of medication adherence interventions.

Objectives

To examine the challenge of medication adherence from the perspective of patients with Type 2 diabetes and to describe the barriers and facilitators to medication regimens reported by this group.

Data Sources

This report synthesizes 86 primary qualitative studies to examine barriers and facilitators to medication adherence from the perspective of adult patients with Type 2 diabetes mellitus. Included papers were published between 2002 and 2013 and studied adult patients in North America, Europe, and Australia/New Zealand.

Review Methods

Qualitative meta-synthesis was used to integrate findings across primary research studies.

Results

Analysis identified that medication adherence should be considered within the context of an individual patient's life, with barriers identified in three categories: lived experiences, health beliefs and understandings, and practical considerations.

Limitations

While qualitative insights are robust and often enlightening for understanding experiences and planning services in other settings, they are not intended to be generalizable. The findings of the studies reviewed here—and of this synthesis—do not strictly generalize to the Ontario (or any specific) population. This evidence must be interpreted and applied carefully, in light of expertise and the experiences of the relevant community.

Conclusions

Medication adherence is an important part of improving clinical outcomes for patients with diabetes. Barriers to medication adherence are complex and individualized, reflecting the fact that each patient

manages his or her medications in the context of his or her own life. A patient-centered approach to medication regimen should consider the unique circumstances, resources, and situation of the patient. A regimen which is responsive to the individual requirements of each patient may result in increased concordance with clinical recommendations.

Plain Language Summary

Type 2 diabetes is a chronic condition that requires daily self-care for a person's entire life. People with Type 2 diabetes are often prescribed multiple medications that must be taken throughout the day, for the person's whole life. Following directions to take the recommended medication regularly, promptly,

and in the right amount can improve symptoms of diabetes and help to maintain stable blood sugar levels. For people with Type 2 diabetes, consistent medication management is important for long term survival and well-being. Many people find it a challenge to follow medication directions, especially over long periods of time. Medications may be expensive, difficult to tell apart, they may cause unpleasant side effects. It may be difficult to integrate a medication routine with the requirements of work, school, family and social life. Following medication routines presents challenges in three areas: practical issues, health beliefs and understandings, and lived experiences. Health care providers who understand the challenges that patients face when trying to follow medication routines may be able to work with patients to create routines that are easier to follow and more acceptable to patients.

Objective of Analysis

To examine the challenge of medication adherence from the perspective of patients with Type 2 diabetes and to describe the barriers and facilitators to medication regimens reported by this group.

Clinical Need and Target Population

Diabetes

Diabetes is a metabolic condition characterized by a deficiency in either insulin production or uptake. It is a chronic disease associated with multiple complications, including cardiovascular disease, stroke, blindness, kidney damage/failure, nerve damage, and amputations.¹ In 2012, it was estimated that approximately 371 million people in the world have diabetes; this number is increasing in every country.² More than 90% of people with diabetes have type 2 diabetes, a form that is associated with increased age, body weight, and family history.¹ The number of Canadians with diabetes has increased dramatically over the last decade: in 2008/2009, almost 2.4 million people were living with the disease.¹ The number of Canadians with diabetes is expected to increase to 3.7 million by the year 2019.¹ Some groups of Canadians are at higher risk for diabetes and related complications. First Nations populations have an age-adjusted prevalence of diabetes that is 3 to 5 times higher than the Canadian average.^{3,4} In a 2009 report commissioned by the Canadian Diabetes Association, the estimated economic burden of diabetes in Canada was \$12.2 billion in 2010, projected to increase to nearly \$17 billion by 2020, although caution should be used when interpreting these figures due to the difficulty in identifying direct and indirect costs of diabetes.⁵⁻⁷

Technique

Medication is a common component of the management of type 2 diabetes (T2DM), but because of the variability in T2DM, medication regimens vary from patient to patient.⁸ Some patients may be able to achieve glycemic targets through lifestyle management (e.g. diet, exercise) alone, and may not need additional medication, although glucose levels tend to worsen over time and so medication may be needed in the future.⁸ Pharmacologic therapy for T2DM includes an antihyperglycemic medication, of which there are a variety of classes, including insulin. The 2013 Canadian Diabetes Association Clinical Practice Guidelines recommend that multiple medications are tried in combination when a patient has more severe hyperglycemia, with adjustments made to the medication regimen in a timely manner.⁸ Antihyperglycemic medications may have side effects including gastrointestinal symptoms, hypoglycemic episodes if meals are missed, congestive heart failure, edema, fractures etc. They may be expensive, cause weight gain, and may take weeks or even several months before optimal effect is witnessed.⁸ There is no definitive "best" choice of medication, and both physician and patient must be prepared to try a combination of medications and weigh the advantages and disadvantages in order to determine what the optimal pharmacologic regimen is for that patient.

Evidence-Based Analysis

Research Questions

1. What barriers and facilitators do adult patients with T2DM face to adherence with prescribed medication regimens?

Research Methods

Literature Search

Search Strategy

A literature search was performed on August 10, 2013, using OVID MEDLINE, EBSCO Cumulative Index to Nursing, Allied Health Literature (CINAHL), and ISI Web of Science Social Sciences Citation Index (SSCI), for studies published from January 1, 2002, until August 10 2013. We developed a qualitative mega-filter by combining existing published qualitative filters.⁹⁻¹¹ The filters were compared and redundant search terms were deleted. We added exclusionary terms to the search filter that would be likely to identify quantitative research and reduce the number of false positives. We then applied the qualitative mega-filter to a diabetes-specific search filter. Search terms are available in this report as Appendix A. Titles and abstracts were reviewed by 2 reviewers to determine eligibility. Full-text articles were obtained when review of title and abstract failed to yield enough information to determine eligibility.

Inclusion Criteria

English language full-reports

- published online between January 1, 2002, and August 10, 2013
- primary qualitative empirical research (using any descriptive or interpretive qualitative methodology, including the qualitative component of mixed-methods studies) and secondary syntheses of primary qualitative empirical research
- adult patients (> 18 years of age) with Type 2 diabetes mellitus (articles which included participants with both Type 1 and Type 2 were included)
- Research conducted in Canada, United States, Europe, Australia, and New Zealand
- published research work (no theses)
- studies addressing medication adherence from the patient's perspective

Exclusion Criteria

- studies addressing topics other than adherence to prescribed medications
- studies that did not include patients with type 2 diabetes
- studies labelled “qualitative” but that did not use a qualitative descriptive or interpretive methodology (e.g., case studies, experiments, or observational analyses using qualitative categorical variables)
- quantitative research (i.e., using statistical hypothesis testing, using primarily quantitative data or analyses, or expressing results in quantitative or statistical terms)
- studies that did not pose an empirical research objective or question, or involve primary or secondary analysis of empirical data

Qualitative Analysis

We analyzed published qualitative research using techniques of integrative qualitative meta-synthesis.¹²⁻¹⁴ Qualitative meta-synthesis, also known as qualitative research integration, is an integrative technique that summarizes research over a number of studies with the intent of combining findings from multiple papers. The objective of qualitative meta-synthesis is 2-fold: first, the aggregate of a result should reflect the range of findings while retaining the original meaning; second, by comparing and contrasting findings across studies, a new integrative interpretation should be produced.¹⁵

Predefined topic and research questions guided research collection, data extraction, and analysis. Topics were defined in stages as relevant literature was identified and corresponding evidence-based analyses proceeded. First, all qualitative research relevant to the conditions under analysis was retrieved. In consultation with Health Quality Ontario, a theoretical sensitivity to patient centeredness and vulnerability was used to further refine the dataset. Finally, specific research questions were chosen and a final search performed to retrieve papers relevant to these questions. The current analysis included papers that addressed the issue of medication adherence behaviours in patients with T2DM.

Data extraction focused on—and was limited to—findings that were relevant to this research topic. Qualitative findings are the “data-driven and integrated discoveries, judgments, and/or pronouncements researchers offer about the phenomena, events, or cases under investigation.”¹³ In addition to the researchers’ findings, original data excerpts (participant quotes, stories, or incidents) were also extracted to illustrate specific findings and, when useful, to facilitate communication of findings.

Using a staged coding process similar to that of grounded theory,^{16,17} findings were broken into their component parts (key themes, categories, concepts) and then regrouped across studies and related to each other thematically. This allowed for organization and reflection on the full range of interpretative insights across the body of research.^{13,18} These categorical groupings provided the foundation from which interpretations of the social and personal phenomena relevant to medication adherence were

synthesized. A “constant comparative” and iterative approach was used, in which preliminary categories were repeatedly compared with the research findings, raw data excerpts, and coinvestigators’ interpretations of the studies, as well as with the original Ontario Health Technology Assessment Committee (OHTAC)–defined topic, and feedback from OHTAC deliberations and expert panels on issues related to the topic.

Quality of Evidence

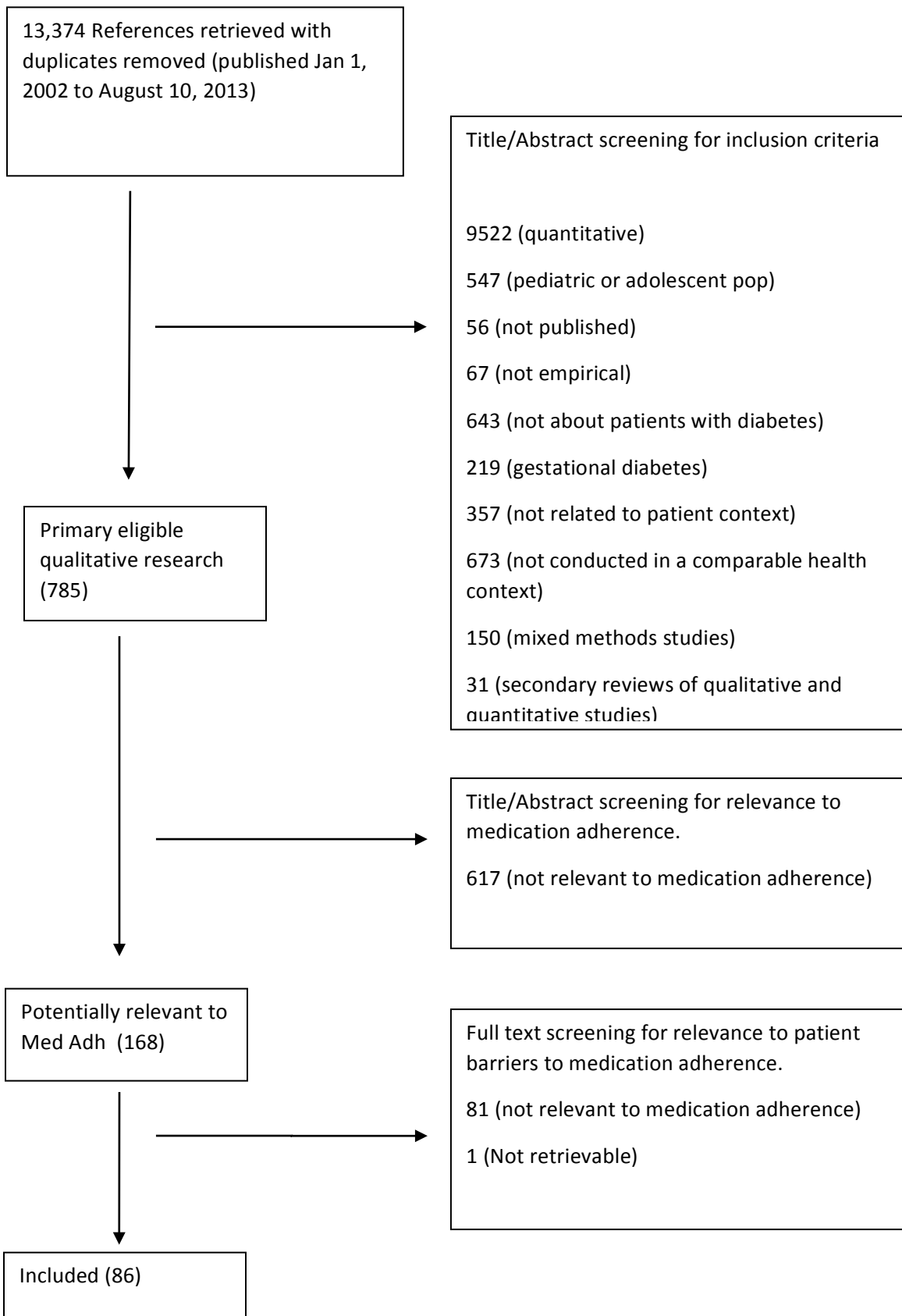
For valid epistemological reasons, the field of qualitative research lacks consensus on the importance of (and methods/standards for) critical appraisal.¹⁹ Qualitative health researchers conventionally underreport procedural details, and the quality of findings tends to rest more on the conceptual prowess of the researchers than on methodological processes.^{14,19} Theoretically sophisticated findings are promoted as a marker of study quality because they make valuable theoretical contributions to social science academic disciplines.²⁰ However, theoretical sophistication is not necessary to contribute potentially valuable information to a synthesis of multiple studies, or to inform questions posed by the interdisciplinary and interprofessional field of health technology assessment. Qualitative meta-synthesis researchers typically do not exclude qualitative research on the basis of independently appraised “quality.” This approach is common to multiple types of interpretive qualitative synthesis.^{12,13,15,20-24}

For this review, the academic peer review and publication process was used to eliminate scientifically unsound studies according to current standards. Beyond this, all topically relevant, accessible research using any qualitative interpretive or descriptive methodology was included. The value of the research findings was appraised solely in terms of their relevance to the research questions and the presence of data that supported the authors’ findings.

Results of Evidence-Based Analysis

The database search yielded 13,374 citations published between January 1, 2002, and August 2013 (with duplicates removed). Articles were excluded based on information in the title and abstract; 2 reviewers reviewed all titles and abstracts to confine the database to qualitative research relevant to any of the chronic diseases. Figure 1 shows the breakdown of when and for what reason citations were excluded from the analysis.

Eighty-six studies met the inclusion criteria. Most studies were conducted in the United States (44) or the United Kingdom (18), with six studies conducted in Ontario. The vast majority of studies did not specify a particular qualitative methodology (58). The 86 included studies incorporated data from 2803 patients, 40 caregivers, and 363 clinicians.



For each included study (n = 86), the study design, location, and the type and number of participants were identified and are summarized in Tables 1, 2 and 3, respectively.

Table 1: Body of Evidence Examined According to Study Design

| Study Design | Number of Eligible Studies |
|---|----------------------------|
| Content analysis | 5 |
| Ethnographic analysis | 4 |
| Framework analysis | 1 |
| Grounded theory/constant comparative analysis | 9 |
| Other (case study, comparative, discourse analysis, narrative, participatory) | 6 |
| Phenomenological | 3 |
| Qualitative (otherwise unspecified) | 58 |
| Total | 86 |

Table 2: Body of Evidence Examined According to Study Location

| Study Location | Number of Eligible Studies |
|-----------------------|----------------------------|
| Australia/New Zealand | 1 |
| Canada (not Ontario) | 0 |
| Europe | 35 |
| Ontario | 6 |
| United States | 44 |
| Total | 86 |

Table 3: Body of Evidence Examined According to Type and Number of Participants

| Type of Participant | Number of Participants |
|---------------------|------------------------|
| Patient | 2803 |
| Caregiver | 40 |
| Clinicians | 363 |
| Total | 3206 |

Results

Themes

The barriers to medication adherence identified by patients and providers can be grouped into three inter-related categories: health beliefs and understandings, practical considerations, and lived experiences. Patients and providers also offered a number of ideas about what facilitated medication adherence, with some recommendations for improving medication adherence.

Lived Experiences

Many papers mentioned the influence of the experience of living with diabetes as the setting in which medication adherence takes place. Lived experiences of diabetes colour the way that patients experience diabetes and adapt self-management activities to fit their lives over the long term.²⁵⁻³⁰ Patients' lived experiences place medication adherence within the context of their social lives, influencing the ways in which they prioritize or de-prioritize self-management activities in the context of their daily lives.^{31, 32} A patient's social context is influenced by co-morbidities, economic, material, and socio-cultural conditions, and the support or lack of support experienced from family, friends, and colleagues.^{33, 34}

Lived experiences were often related to health beliefs and understandings as well as to practical considerations about living with diabetes. For example, many studies discussed the influence of medication side effects on medication adherence. Sometimes, this was a fear of side effects that *might* be experienced,³⁵⁻⁴⁷ while other papers described the actions that patients took to alleviate or avoid side effects they experienced, such as deciding to take a smaller amount of medication.^{25, 27, 36, 42, 48-54} Sometimes, patients mistook diabetes symptoms for medication side effects, for instance sexual dysfunction, or hypoglycemic symptoms such as headache, dizziness, and anxiety.^{39, 49, 50} Experiences of side effects resulted in patients refusing medication, self-adjusting the dose, timing, or frequency of medication in an attempt to avoid or alleviate side effects.^{53, 55} Conversely, some patients continued to adhere to their medications, even when the side effects interfered with their ability to engage in social activities or work. For example, Hunt reports a patient who described not being able to leave her home due to medication side effects of diarrhea and hypoglycemia. These side effects meant that the patient must eat and go to the bathroom very frequently, and these requirements resulted in the patient deciding she would rather not leave her home.⁵⁰ This patient reported that her physician was very happy with her blood pressure, A1C and cholesterol levels and did not want to change the medication, despite the adverse effect it had on her life.⁵⁰

Lived experiences of diabetes include the emotions that co-exist with chronic disease. Commonly described emotions include anxiety, nervousness, loss of control, depression, failure, fear, guilt, and stress. These emotions are sometimes described as being caused by the diabetes, and sometimes described as originating from other sources, such as others' experiences. In both instances, negative emotions can disrupt medication regimens. Feelings of anxiety, nervousness, or loss of control over health may create stress and fear about diabetes medication regimens.^{25, 29, 31, 35, 56, 57} Emotions of stress and fear may have an effect on blood sugar levels and also are de-motivating, potentially causing patients to avoid self-management activities in an effort to ignore their medical situation.^{28, 29, 33, 58-61} Sources of fear included injections, pain, the restrictive nature of medication and self-management routines, side effects of medication, and morbidity associated with diabetes.^{28, 29, 35-47, 49, 52, 57, 58, 60-68} Several papers mentioned depression as disruptive to medication adherence. Patients may feel depressed at the thought of being "sick" and requiring medication and other self-management activities for the rest of their lives. This depression may be exacerbated by the restrictions that medication regimens require and the corresponding loss of freedom.^{25, 29, 35, 49, 53, 69} When a patient is depressed, no matter what the etiology, apathy and low energy may interfere with maintaining a self-management routine.⁶⁹

Negative emotions may result in a patient "opting out" of self-management activities; emotions are not often recognized as an influential factor on self management, by patients or providers.²⁹ Patients "could not relate their struggles to an aspect of their self-management and so did not believe they should call the clinic or rely on their health providers for help. In other words, they knew exactly how to perform the task, for example, give a shot, but not what to do with their anger that they had to give themselves a shot. Simply being angry, or hurt, or depressed, in their eyes, was not a legitimate management issue".²⁹

A patient's lived experience influences her relationship with her clinician. Some patients may find living with diabetes such an overwhelming life change that they do not feel as if their clinician understands what they are experiencing, and therefore discount the advice or opinion of the clinician.^{35, 70} Support from clinicians was described as important to facilitate positive medication behaviour.^{34, 36, 47} Negative relationships, such as perceived disinterest from the clinician about medication management, or clinicians who spent little time with the patient were described as unhelpful and promoted distrust of the clinician's advice.⁷¹ Several studies reported negative patient-clinician relationships ascribed to passively racist clinician behaviour or action, typically described as an ignorance of the patient's needs and social context.^{35, 39, 58, 72}

Health Beliefs

Health beliefs and understandings influenced medication adherence in a number of ways. By far the most prevalent theme in this category was a lack of understanding about medication. Most studies identified this as a barrier to medication adherence, and many particular gaps in knowledge were identified, including how to use the medication to regulate fluctuating blood sugar levels,^{25, 71, 73, 74} how diabetes works and how medication works to counteract the effects of diabetes,^{25, 36, 43, 53, 58, 69, 70, 75-82} how food, activity, and medication are related and how medication can be adjusted to incorporate demands of daily life and changes in routine,^{29, 33, 48, 61, 66, 70, 72, 74, 79, 81, 83-85} the consequences of non-adherence,^{36, 58, 62, 65, 86} how to cope with side effects,^{25, 77, 79} and what to do in the event of a problem such as a missed dose.^{33, 71, 73, 74, 80, 87}

Understandings of what the purpose and role of medication is can impact a patient's commitment and attitude to that medication. For some people with T2DM, the switch to insulin may represent a failure to control diabetes with diet and exercise alone, or may be seen as a punishment from the clinician for failing to achieve stable blood sugar levels.^{40, 42, 49, 56, 60, 63, 88} A number of studies reported that patients understood that being prescribed insulin meant that their diabetes was getting worse, and was becoming a more serious concern.^{34, 61, 62, 65, 68} While the realization that their diabetes was getting worse was sometimes described as stressful, scary, or demoralizing, it was also described as motivating. Some patients who started to experience the consequences of diabetes or saw friends or relatives experience these consequences were motivated to take their medication in the hopes of avoiding similar morbidity.^{27, 36, 46, 63}

Patients often had different understandings of self-management than providers did, and would adjust their medications accordingly, in a form of strategic non-compliance that was consistent with their own beliefs about their body and illness.^{46, 52, 53, 84, 87}Lynch, 2012 #59, 89 It is important to note that patients may not understand these adjustments to be non-compliant, but simply a manner of adapting routines to suit their own lives and understandings of their illness.⁸⁷ For instance, some studies reported that patients did not perceive that actions such as altering the timing or dose of their medications was a problem.^{84, 89} Others adjusted their own medication regimen, questioning the value of the medication and reasoning that they understood the needs of their bodies better than their clinicians did.^{44, 46, 52, 53}

Health beliefs and understandings of illness, the body, and treatment are mediated by social and cultural factors. There is significant evidence that medication adherence is mediated by cultural health beliefs for diabetic patients from other cultures.^{28, 40, 51, 61, 65, 66, 79, 90} The ways in which cultural beliefs interact with medication practices varies by culture, but may include an aversion to insulin therapy, injections, or disclosing their diabetic status to others.^{40, 65, 66} Cultural beliefs may also result in a strong preference for alternative, complementary, and traditional treatments which may or may not coincide with a wariness of Western pharmaceutical interventions.^{27, 35, 39, 40, 42, 44, 46, 47, 51, 54, 55, 58, 60, 61, 69, 72, 76, 79, 91} On the other hand, some patients with a strong desire to use alternative or traditional treatments may see no conflict with pharmaceutical intervention and be strongly supportive of taking medication in conjunction or instead of other treatments.^{30, 44, 51}

Health beliefs and understandings were often closely related to the lived experiences of diabetes. For example, decisions to take medication were often linked to the understanding and experience of symptoms of diabetes. Many authors found that acute physical symptoms of diabetes were understood by patients as a reason to take medication. When these symptoms were alleviated, the patients no longer thought it necessary to take medication.^{35, 46, 47, 51, 61, 63, 70, 72, 79, 86, 88, 90, 92, 93} For some patients, symptoms were seen as more important than blood sugar levels when determining whether or not to take medication; when symptoms and blood sugar readings conflicted, patients tended to go with how they felt rather than the glucose monitor reading.⁵⁸ The "invisibility" of diabetes was a common theme, and one which was mentioned as concerning by some patients, that diabetes was only noticeable when blood sugar started to reach dangerous levels.⁴⁸ Conversely, patients who did not experience symptoms may not consider diabetes to be a serious condition and therefore not worth the time and effort required by self-management activities.⁸⁵ The use of symptoms as a way of understanding the severity of diabetes was common. In another study, patients who experienced symptoms of diabetes were more likely to accept the adoption of insulin therapy.⁶⁸

Patient understandings and beliefs are closely linked to their relationship with their own clinicians, and their understandings of the nature of the general patient-clinician relationship. For instance, the patient's assessment of the clinician skill and their judgment of whether or not the clinician has made correct decisions greatly influences the likelihood of whether or not they will choose to follow the medication regimen set by that clinician.^{44, 46, 53, 63} Trusting the clinician was mentioned as essential by numerous studies; a lack of trust in the clinician's judgment, skill, or motivation to do well for the patient was detrimental to medication adherence.^{27, 35, 36, 39, 44, 51, 52, 58, 77, 79, 87, 94} One way in which clinicians may increase patient trust is by including the patient as an active partner in decision-making about medication regimens, in order to develop

a regimen that is understood by and acceptable to the patient and consistent with the patient's goals and health beliefs.^{31, 47, 60, 63, 80, 95-97}

Practical Considerations

Practical considerations is a theme which describes logistical, instrumental, and pragmatic barriers to medication adherence. Many of these barriers centre around the complexity of the medication regimen, especially activities associated with administering medication. Financial and resource issues were a significant theme, as was managing diabetes at the same time as managing other chronic diseases with competing requirements that acted as an additional drain on time, energy, and resources. There were also practical barriers to a good, effective relationship with a clinician.

The complexity of the medication regimen was a common and significant barrier to medication adherence, especially for patients who took multiple medications and struggled to remember what needed to be administered when, and to differentiate between the medications.^{27, 36, 42, 52, 53, 55, 65, 69, 71, 75, 93, 96} Keeping track of medications and complex medication regimens was especially difficult for patients who had cognitive challenges, even when they had caregivers to assist.^{33, 42, 53, 59, 62, 98} Complex medication regimens were challenging because they were hard to remember, hard to schedule, hard to manage prescription refills so as not to run out of medication.^{36, 37, 42, 53, 81, 96, 99} Following a medication regimen consistently, through changes of routine and the normal challenges of life required a sophisticated understanding of the regimen and the ways in which it could or should be adjusted.^{53, 94, 100} For instance, adjusting medication to accommodate changes in diet was mentioned as a particular concern, especially when eating out, as restaurants seldom gave enough information about the food to allow a patient to adjust his or her insulin dose.^{29, 33, 73} When patients were not able to adjust their medication regimens to respond to the needs of their lives, adherence meant they needed to adjust their lives to accommodate their medication regimens, resulting in many descriptions of diabetes medication regimens as inconvenient or restrictive.^{25, 27, 29, 31, 33, 40, 49, 52, 58, 60, 63, 76, 79, 87, 93, 101} Inconvenient, restrictive, insufficient or incomprehensible medication regimens sometimes caused a patient to devise his or her own medication regimen, without the help or input of a clinician.^{34, 53, 60, 87, 102} Patients tended to self-adjust their medication regimens by reducing the amount of medication, taking insulin at sub-optimal times so they could inject in private, or reducing the amount of medication when they had to skip a meal.⁴⁷ {Jenkins, 2011 #49, 51, 52, 57, 84, 89

Administering medication was also associated with a number of practical challenges. Sometimes doses were forgotten and patients were unsure how to adjust their next dose in

response.^{42, 52, 68, 76, 96} Physical problems, such as waning eyesight or lack of manual dexterity also posed challenges for medication administration.^{33, 36, 53, 62, 103} The discomfort associated with injection was cited by some patients, but for others was not a significant barrier and less painful than blood glucose monitoring.^{27, 40, 57} Fear of needles was more frequently reported as a more significant barrier than the pain associated with those needles.^{28, 35, 40, 49, 52, 57, 58, 60-68} Many studies also mentioned the stigma of using an injectable medication, which led many patients to try and avoid injecting in public places, or in the presence of other people.^{29, 33, 40, 49, 52, 60, 63, 66, 68, 89, 101}

Financial and resource restrictions were a significant barrier for many patients, who had trouble affording medication, syringes, and blood testing supplies.^{27, 28, 31, 33, 34, 38, 44, 50, 52-54, 59, 70, 82, 86, 90, 93, 96, 101, 104} Socioeconomic considerations also affected the way that diabetes self-management activities were prioritized in a patient's life, when household resources were scarce and had to be allocated to fit the needs of the entire family.^{31, 33, 104} The jobs held by some patients made diabetes self-management a particular challenge, especially when financial need meant that the patient had to conceal their condition for fear of losing their job, could not afford to take breaks from work when needed, or adjust work schedules to accommodate medication administration and meal times.^{34, 86} However, some authors explicitly reported that cost of medication and supplies was not mentioned as a barrier.^{25, 79}

Relationships with health care providers also presented practical concerns for medication adherence. Some patients found it challenging to get to reach their clinician when needed, because that person was busy and appointments required advance booking, because of the physical travel required, or because communication with providers was difficult.^{44, 53, 79, 101, 105, 106} These concerns were greater for people who were not fluent in the dominant language of their country, and those who had low health literacy.^{32, 33, 40, 44, 47, 51, 59, 61, 79, 101}

These practical concerns were all exacerbated by the presence of co-morbid conditions with competing self-management requirements, medication regimens, costs, and side effects.^{33, 45, 53, 59, 86, 95, 98}

Practical considerations also overlap with lived experiences and health beliefs and understandings. For example, many authors reported that worry about hypoglycemic episodes resulted in patients self-adjusting their medication, skipping doses, or not complying with diet instructions.^{27, 31, 47, 48, 53, 54, 62, 65-68, 102} Hypoglycemia was described by patients as worrying because it was uncomfortable, unpleasant, and might result in serious health consequences. Some patients described maintaining higher than recommended blood glucose levels in an

effort to prevent hypoglycemia.³¹ Patients who lived alone or spent periods of time where help was not available in the event of a hypoglycemic event tended to be more engaged in this type of behaviour, worried about what might happen if they needed help and help was not available.⁶⁶

Recommendations

The qualitative literature on medication adherence provided many recommendations, most of which are applicable to individual clinicians, reflecting the participants and issues identified in the research.

Providing information was one of the most prevalent recommendations, with most authors emphasizing that the most crucial information was practical information about managing medication regimens; patients require more information not on *what to do* but *how to do it*.^{62, 75, 36, 38, 76, 25, 33, 39, 83, 107, 27, 29, 41, 46, 47, 66, 68, 70, 73, 85, 89, 102, 108} For instance, information on the relationship between medication, food, exercise, and blood glucose levels was often mentioned as important, especially provided in a way that will help patients "troubleshoot" or figure out how to adjust their self-management practices to fit their lives and activities.^{28, 29, 34, 42, 60, 61, 66, 73, 74, 85, 87, 93, 94} Of course, the content of educational information on *how* to adhere to medication guidelines will greatly depend on an individual patient's own health and social circumstances. Information should be tailored to the individual, taking into account his or her health beliefs, preferences, social and material resources.^{27, 33, 39, 40, 42, 51, 54, 55, 58, 61, 63, 67, 69, 91, 101, 107} Suggestions for sharing information about medication adherence include: asking patients specifically about their medication activities and not relying on blood glucose levels to provide information on the success or challenges of medication adherence;^{37, 51, 59, 87, 103} initiating conversations about accessible, comprehensive, and comprehensible information sources the patient may access, and providing critical appraisal on the information sources they have found independently;^{25, 43, 53, 61, 64, 77, 96, 100, 101, 103} initiating open and non-judgmental discussion of complementary, alternative, and traditional medicine and treatment the patient may be using or considering;^{40, 54, 91} repeating information and continuing to educate throughout the course of the patient's illness, not just immediately following diagnosis;^{25, 42, 68, 83, 100, 103} providing patients with the opportunity to ask questions about information after they have had a chance to reflect on new information;^{25, 37, 53, 83, 87, 96, 101, 103}; spending time to familiarize patients with new medication administration methods (e.g. needles), allaying fears and building confidence.^{38, 40, 62, 68} These recommendations for education place a significant burden on clinicians. An inter-professional team approach may be helpful to ensure each patient receives the information he or she needs in a comprehensible and comprehensive format, with the opportunity to ask questions.^{38, 52, 53, 65, 78, 102, 105, 109} Education and training for clinicians on how to effectively inform, motivate, and educate adult patients may also be helpful.^{33, 62, 86, 100}

Much of the literature reviewed emphasized a patient-centred approach to medication adherence, which entails including the patient as an active partner in his or her care.^{27, 33, 41, 47, 52, 54, 107} Self-management plans should be tailored to the priorities, abilities, and resources of the individual.^{28, 30, 33, 35, 41, 57, 68, 75, 80, 87, 92, 95, 103, 107} Setting treatment goals in partnership with patients may help ensure their relevance to the patient and encourage motivation in self-management activities.^{26, 29, 30, 33, 54, 95, 103} Open discussion with patients about individual circumstances and understandings may be especially important for particular groups of patients. There is literature suggesting particular strengths and challenges that may be present around medication adherence for patients who are members of minority cultural, ethnic, or racial groups,^{35, 39-42, 45, 47, 51, 54, 58, 61, 67, 72, 75, 79, 80, 90-92, 101, 110} aged patients,^{87, 95, 106} patients with co-morbid conditions,^{46, 52, 53, 69, 96, 98}, and patients of low socio-economic status.^{33, 44, 52, 80, 101, 104} The incorporation of peer support or peer mentors was mentioned as universally helpful, but it may be particularly important for socially marginalized patients.^{25, 34, 45, 53, 66, 67, 72, 75, 81, 83, 100, 110} This peer support can provide invaluable social support in self-management activities, but also be a source of practical information about navigating medication challenges specific to patients' lives.

Social support is an important part of adherence to medication regimens and other self-management plans. Social support may come from friends and family, in the form of reminders, filling prescriptions and sorting pills, or simply showing emotional support and empathy.^{28, 36, 42, 45, 52, 53, 57, 62, 66, 67, 72, 81, 87, 95, 96, 101, 102, 106, 111} A trusting relationship between patient and clinician can also be a form of social support, especially when patients know that their clinicians care about their wellbeing and have their best interests at heart.^{30, 38, 52, 53, 83, 87, 92, 101-103, 105} Social relationships can help patients as they encounter obstacles to medication adherence such as stress, logistical issues, frustration, or lack of motivation.^{28, 29, 35, 52, 63, 92, 102, 103}

Motivating patients to adhere to medication regimens, seek help when needed, and persevere as medication is adjusted is a challenge for both patients and clinicians. Clinicians may motivate patients to see medication adherence as a chance to mitigate the symptoms of diabetes and prevent long term consequences, but clinicians discussing these issues should be sensitive to the fact that some patients may find these consequences frightening.^{25, 35, 43, 53, 63} Helping patients notice when symptoms have started to improve and celebrating these successes may also motivate continued adherence.^{27, 29, 33, 42, 43, 45, 53, 60, 62, 63, 66, 73, 101, 108} When treatment benefits are experienced, a patient's self-confidence in the ability to make and sustain change grows, encouraging future adherence.^{25-27, 35, 36, 38, 41, 43, 57, 58, 60, 62-64, 66} However, when a patient struggles with the medication regimen or treatment benefits are not experienced, the clinician should step back and with the patient try to identify adherence factors which are outside of the patient's control, such as the expense of medication or supplies.^{33, 35, 39, 52, 53, 56, 70-72, 101}

Many influential factors of medication adherence are outside of the patient's control. For some of these factors, clinicians may be able to help. For instance, the expense of medication and supplies was identified as an issue by many authors.^{27, 28, 31, 33, 34, 38, 44, 50, 52-54, 59, 70, 82, 86, 90, 93, 96, 101, 104} Clinicians may be able to help alleviate costs by distributing free samples when available, helping patients access any discounts or financial programs that are available (e.g. pharmaceutical industry

programs to waive drug costs), prescribing generic drugs, combination therapies, or more potent medications.^{25, 38, 50, 53, 80, 90, 93, 99, 101} Other forms of practical support might include helping a patient develop a medication routine, which may include a system for organizing multiple medications that must be taken each day along with a structure for what must be taken when. This medication routine might also include co-ordinated times to refill medicines, with prescriptions written for similar amounts of medication (e.g. one month) to reduce repeat trips to the pharmacy.^{26, 33, 36, 42, 53, 58, 73, 75, 76, 79, 82, 89, 96, 102} Some authors emphasized the need for change at a health systems or societal level, including sufficient funding and organization of programs to facilitate health promotion and to improve the home, work/school and community environments. These suggestions emphasized that medication adherence is not completely within the control of any individual patient or clinician and socio-economic and structural factors play an important role.^{33, 70, 86, 90, 104}

Summary

To improve patient adherence to prescribed medication regimens, health care providers should work with patients to address how medication regimens fit with the rest of the individual's life, lived experiences, and social context. This patient-centered approach to care includes the patient as an active decision-maker in the construction of a medication regimen that is understandable, acceptable, and feasible for that patient. This approach may help to alleviate common barriers to medication adherence, such as not understanding that medication needs to be taken regularly, even when no symptoms are experienced. While a patient-centered approach is important, it will not be sufficient to relieve structural barriers to medication adherence. Issues of medication cost, stigmatisation of diabetes and injectable medication, and cultural and communication barriers may all impede concordance with medication regimens. Open conversation between patient and provider may reveal ways that these challenges might be partially alleviated.

Limitations

Qualitative research provides theoretical and contextual insights into the experiences of limited numbers of people in specific settings. Qualitative research findings are not intended to generalize directly to populations, although meta-synthesis across a number of qualitative studies builds an increasingly robust understanding that is more likely to be transferable. While qualitative insights are robust and often enlightening for understanding experiences and planning services in other settings, the findings of the studies reviewed here—and of this synthesis—do not strictly generalize to the Ontario (or any specific) population. Findings are limited to the conditions included in the body of literature synthesized (i.e., diabetes). This evidence must be interpreted and applied carefully, in light of expertise and the experiences of the relevant community.

This work was completed in late 2013. Additional literature on this topic has likely been published and not included in this review.

Conclusions

Medication adherence takes place within the context of a patient's life and is affected by social circumstances, resources, understandings, and past experiences with medication. While educational interventions may help alleviate some adherence issues, targeting medication adherence through education interventions only will not alleviate many common barriers to practical issues, experiences, and health beliefs. Medication adherence presents an opportunity to practice patient-centered care, engaging the patient in the creation of a medication regimen that is clinically effective as well as understandable, acceptable, and feasible for that patient.

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Appendices

Appendix 1: Literature Search Strategies

Mega Filter: OVID MEDLINE

1. Interviews+
2. (theme\$ or thematic).mp.
3. qualitative.af.
4. Nursing Methodology Research/
5. questionnaire\$.mp.
6. ethnological research.mp.
7. ethnograph\$.mp.
8. ethnonursing.af.
9. phenomenol\$.af.
10. (grounded adj (theor\$ or study or studies or research or analys?s)).af.
11. (life stor\$ or women* stor\$).mp.
12. (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or (data adj1 saturat\$).tw. or participant observ\$.tw.
13. (social construct\$ or (postmodern\$ or post- structural\$) or (post structural\$ or poststructural\$) or post modern\$ or post-modern\$ or feminis\$ or interpret\$).mp.
14. (action research or cooperative inquir\$ or co operative inquir\$ or co- operative inquir\$).mp.
15. (humanistic or existential or experiential or paradigm\$).mp.
16. (field adj (study or studies or research)).tw.
17. human science.tw.
18. biographical method.tw.
19. theoretical sampl\$.af.
20. ((purpos\$ adj4 sampl\$) or (focus adj group\$)).af.
21. (account or accounts or unstructured or open-ended or open ended or text\$ or narrative\$).mp.
22. (life world or life-world or conversation analys?s or personal experience\$ or theoretical saturation).mp
23. (lived or life adj experience\$.mp
24. cluster sampl\$.mp.
25. observational method\$.af.
26. content analysis.af.
27. (constant adj (comparative or comparison)).af.
28. ((discourse\$ or discours\$) adj3 analys?s).tw.
29. narrative analys?s.af.
30. heidegger\$.tw.
31. colaizzi\$.tw.
32. spiegelberg\$.tw.

33. (van adj manen\$).tw.
34. (van adj kaam\$).tw.
35. (merleau adj ponty\$).tw
36. .husserl\$.tw
37. foucault\$.tw.
38. (corbin\$ adj2 strauss\$).tw
39. glaser\$.tw.

NOT

40. p=.ti,ab.
41. p<.ti,ab.
42. p>.ti,ab.
43. p=.ti,ab.
44. p<.ti,ab.
45. p>.ti,ab.
46. p-value.ti,ab.
47. retrospective.ti,ab.
48. regression.ti,ab.
49. statistical.ti,ab.

Mega Filter: EBSCO Cumulative Index to Nursing & Allied Health Literature (CINAHL)

1. Interviews+
2. MH audiorecording
3. MH Grounded theory
4. MH Qualitative Studies
5. MH Research, Nursing
6. MH Questionnaires+
7. MH Focus Groups (12639)
8. MH Discourse Analysis (1176)
9. MH Content Analysis (11245)
10. MH Ethnographic Research (2958)
11. MH Ethnological Research (1901)
12. MH Ethnonursing Research (123)
13. MH Constant Comparative Method (3633)
14. MH Qualitative Validity+ (850)
15. MH Purposive Sample (10730)
16. MH Observational Methods+ (10164)
17. MH Field Studies (1151)
18. MH theoretical sample (861)
19. MH Phenomenology (1561)
20. MH Phenomenological Research (5751)
21. MH Life Experiences+ (8637)
22. MH Cluster Sample+ (1418)
23. Ethnonursing (179)
24. ethnograph* (4630)
25. phenomenol* (8164)
26. grounded N1 theor* (6532)
27. grounded N1 study (601)

28. grounded N1 studies (22)
29. grounded N1 research (117)
30. grounded N1 analys?s (131)
31. life stor* (349)
32. women's stor* (90)
33. emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$ (2305)
34. data N1 saturat* (96)
35. participant observ* (3417)
36. social construct* or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or interpret* (25187)
37. action research or cooperative inquir* or co operative inquir* or co-operative inquir* (2381)
38. humanistic or existential or experiential or paradigm* (11017)
39. field N1 stud* (1269)
40. field N1 research (306)
41. human science (132)
42. biographical method (4)
43. theoretical sampl* (983)
44. purpos* N4 sampl* (11299)
45. focus N1 group* (13775)
46. account or accounts or unstructured or open-ended or open ended or text* or narrative* (37137)
47. life world or life-world or conversation analys?s or personal experience* or theoretical saturation (2042)
48. lived experience* (2170)
49. life experience* (6236)
50. cluster sampl* (1411)
51. theme* or thematic (25504)
52. observational method* (6607)
53. questionnaire* (126686)
54. content analysis (12252)
55. discourse* N3 analys?s (1341)
56. discours* N3 analys?s (35)
57. constant N1 comparative (3904)
58. constant N1 comparison (366)
59. narrative analys?s (312)
60. Heidegger* (387)
61. Colaizzi* (387)
62. Spiegelberg* (0)
63. van N1 manen* (261)
64. van N1 kaam* (34)
65. merleau N1 ponty* (78)
66. husserl* (106)
67. Foucault* (253)
68. Corbin* N2 strauss* (50)
69. strauss* N2 corbin* (88)
70. glaser* (302)

NOT

71. TI statistical OR AB statistical
72. TI regression OR AB regression
73. TI retrospective OR AB retrospective
74. TI p-value OR AB p-value
75. TI p< OR AB p<
76. TI p< OR AB p<
77. TI p= OR AB p=

Mega Filter: ISI Web of Science, Social Science Citation Index

1. TS=interview*
2. TS=(theme*)
3. TS=(thematic analysis)
4. TS=qualitative
5. TS=nursing research methodology
6. TS=questionnaire
7. TS=(ethnograph*)
8. TS= (ethnonursing)
9. TS=(ethnological research)
10. TS=(phenomenol*)
11. TS=(grounded theor*) OR TS=(grounded stud*) OR TS=(grounded research) OR TS=(grounded analys?s)
12. TS=(life stor*) OR TS=(women's stor*)
13. TS=(emic) OR TS=(etic) OR TS=(hermeneutic) OR TS=(heuristic) OR TS=(semiotic) OR TS=(data saturat*) OR TS=(participant observ*)
14. TS=(social construct*) OR TS=(postmodern*) OR TS=(post structural*) OR TS=(feminis*) OR TS=(interpret*)
15. TS=(action research) OR TS=(co-operative inquir*)
16. TS=(humanistic) OR TS=(existential) OR TS=(experiential) OR TS=(paradigm*)
17. TS=(field stud*) OR TS=(field research)
18. TS=(human science)
19. TS=(biographical method*)
20. TS=(theoretical sampl*)
21. TS=(purposive sampl*)
22. TS=(open-ended account*) OR TS=(unstructured account) OR TS=(narrative*) OR TS=(text*)
23. TS=(life world) OR TS=(conversation analys?s) OR TS=(theoretical saturation)
24. TS=(lived experience*) OR TS=(life experience*)
25. TS=(cluster sampl*)
26. TS=observational method*
27. TS=(content analysis)
28. TS=(constant comparative)
29. TS=(discourse analys?s) or TS =(discurs* analys?s)
30. TS=(narrative analys?s)
31. TS=(heidegger*)
32. TS=(colaizzi*)
33. TS=(spiegelberg*)
34. TS=(van manen*)

35. TS=(van kaam*)
36. TS=(merleau ponty*)
37. TS=(husserl*)
38. TS=(foucault*)
39. TS=(corbin*)
40. TS=(strauss*)
41. TS=(glaser*)

NOT

42. TS=(p-value)
43. TS=(retrospective)
44. TS=(regression)
45. TS=(statistical)

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