

# Accepted Manuscript

## Review

Understanding ‘context’ in the self-management of type 2 diabetes with comorbidities: A systematic review and realist evaluation

Jacqueline Schmidt-Busby, Janine Wiles, Daniel Exeter, Timothy Kenealy

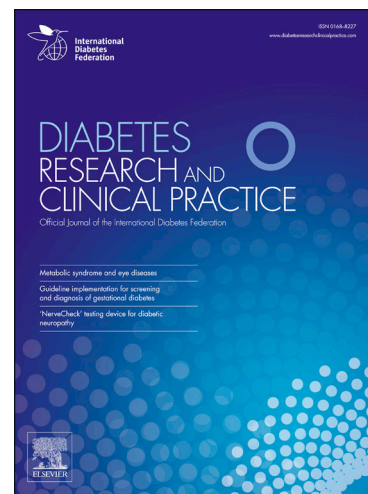
PII: S0168-8227(17)31808-9  
DOI: <https://doi.org/10.1016/j.diabres.2018.06.003>  
Reference: DIAB 7414

To appear in: *Diabetes Research and Clinical Practice*

Received Date: 20 November 2017  
Revised Date: 14 May 2018  
Accepted Date: 6 June 2018

Please cite this article as: J. Schmidt-Busby, J. Wiles, D. Exeter, T. Kenealy, Understanding ‘context’ in the self-management of type 2 diabetes with comorbidities: A systematic review and realist evaluation, *Diabetes Research and Clinical Practice* (2018), doi: <https://doi.org/10.1016/j.diabres.2018.06.003>

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.



# Understanding 'context' in the self-management of type 2 diabetes with comorbidities: A systematic review and realist evaluation

Jacqueline Schmidt-Busby <sup>a,b</sup>

j.schmidt-busby@auckland.co.nz

Janine Wiles <sup>b</sup>

j.wiles@auckland.ac.nz

Daniel Exeter <sup>b</sup>

d.exeter@auckland.ac.nz

Timothy Kenealy <sup>c</sup>

t.kenealy@auckland.ac.nz

- a. Counties Manukau Health, Middlemore Hospital, Auckland, New Zealand
- b. School of Population Health, Faculty of Medical and Health Sciences, University of Auckland, New Zealand
- c. School of Medicine, Faculty of Medical and Health Sciences, University of Auckland, New Zealand

## Corresponding author:

Jacqueline Schmidt-Busby

Counties Manukau Health, Middlemore Hospital, Auckland, New Zealand

Email: c/- j.schmidt-busby@auckland.co.nz

**Declarations of interest:** None

## Acknowledgements:

Funding: This work was supported by Counties Manukau District Health Board (2016 CMH Research Fellowship: Jacqueline Schmidt-Busby)

## ABSTRACT

**Objective.** To identify contextual factors that affect self-management of diabetes with comorbidities, and to evaluate in what way these factors affect self-management effectiveness.

**Methods:** A systematic review of literature considered English language articles published within Medline, PsycINFO, Pubmed, CINAHL Plus, and Scopus databases that focussed on individuals' experiences of type 2 diabetes from primary intervention or observational studies. A realist evaluation approach was used to analyse themes identified within the literature. Context-mechanism-outcome theories were constructed to identify underlying contextual factors and to construct a model illustrating diabetes self-management effectiveness.

**Results.** Of 1,519 articles identified, 30 met inclusion criteria. Adherence was found to be the common mechanism that (within given contexts) determined self-management effectiveness. Limited financial resources were identified as the key context. Our model makes explicit a structural weaknesses of diabetes self-management.

**Conclusions.** Coping with diabetes in the context of people's lives requires attention to issues that are often outside the remit of the person with diabetes, the health care team, and the health system within which self-management is located. Realist evaluations illuminate programme mechanisms and fine-tune context. They aid initial understandings of how an intervention or programme is thought to work, in order to influence and (re)design (new) programmes.

### Key words:

Diabetes self-management;  
Self-management effectiveness;  
Barriers to blood glucose management.

## 1. Introduction

Care for type 2 diabetes (diabetes) demands constant self-management by individuals and their family. This load is increased when comorbidities are present – which is often the case. If there are 8760 hours in a year, an individual who spends approximately six hours per year with a health care provider in scheduled routine appointments, needs to manage the other 8754 hours themselves. Self-management has become a widely-used term, underpinned by the premise that the individual (with the long-term condition) is an active participant in their treatment [1-4]. Self-management involves individuals taking necessary actions to meet their health, psychological, social, and emotional needs associated with living with one or more long-term condition. Self-management places the responsibility with the individual.

The need to better understand the factors that may influence an individual's participation and (poor) engagement in their own health care is an issue that many researchers and health practitioners have raised [5-7]. For example, misunderstanding of their condition and options (low health literacy) could result from confusion of symptoms between comorbidities [8] or limited access to information [9]. In both cases further exploration is needed to understand the fundamental reasons leading to poor engagement. Therefore, to appreciate why and to what extent individuals engage in the management of their well-being, we must examine the influences that shape both the personal characteristics of their often-complex lives, and the context within which health care decision making occurs.

Much research on self-management has attempted to draw a causal link between successful self-management and favourable health outcomes, or to describe barriers within self-management that prevent effective management for individuals experiencing long-term conditions. Notwithstanding this, the proliferation of literature on improving implementation of self-management suggests strategies are being implemented without a proper understanding of how they work, and for whom. This lack of understanding risks placing an undue burden on individuals seeking effective management of their long-term

condition(s). Much of the literature discusses health outcomes and system outcomes, improvements to implementation, and services redesign. However, there is a paucity of literature that articulates the philosophy behind self-management; specifically, the structural and contextual factors that influence self-management effectiveness.

Realism as a methodological orientation is concerned with the foundations, methods and consequences of science. In addition to being theory-driven, an assumption is that social programmes are social systems with structures and layers that interact to form mechanisms and contexts [10-12]. Within this framework causation stems from a process where a specific context triggers a particular mechanism, which in turn generates an outcome. Pawson and Tilley [11], who developed realist evaluation methodology, contend it is this process: context + mechanism = outcome that distinguishes a realist review (including evaluation) from all other types of review.

As theory-driven appraisals, realist evaluations give a comprehensive understanding of why multi-dimensional or complex interventions are successful or unsuccessful [11]. Unlike traditional evaluations where assessment focuses on outcomes, realist evaluations 'unpack' the relationship between intervention and outcome. A realist evaluation identifies what works, for whom, in what circumstances, and is "*not performed for the benefit of science as such, but pursued in order to inform the thinking of policy makers, practitioners, program participants, and public*" [11, p.xii-xiii].

This article examines the concepts of diabetes self-management where, 'self-management' has been broadly conceptualised to be a programme "*a plan or system under which action may be taken toward a goal*" [13], and, where the term 'self-management' encompasses self-care and self-management support. As diabetes self-management is inclusive of many actions, the five most common (glucose monitoring, taking and managing medications, attending appointments, doing regular exercise, and eating appropriately) have been chosen from national

and international guidelines for diabetes self-management, education, and support [2, 14-16]. These five actions will be used to assess diabetes self-management.

Guided by a realist evaluation approach, the focus centres on the following questions:

1. What are the underlying contextual factors that activate the mechanism(s) of diabetes self-management?
2. In what way do these factors affect the effectiveness of self-management?

Addressing these questions may assist health providers, policy and decision-makers, and funders to better understand what prevents people with diabetes from gaining full benefit from self-management.

## **2. Methods**

Approaches to integrating qualitative and quantitative evidence include realist synthesis/evaluation, thematic, framework, narrative, and meta-narrative [10, 17-20]. Our choice of realist evaluation allows a review of complex interventions or programmes such as self-management, and is consistent with the nature of both the research questions and the purpose of synthesising the evidence; it [18, 20, 21]. The systematic review was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses reporting guidelines [22].

### **2.1 Literature search strategy**

Search terms were compiled by JS-B, JW and DE, and comprised a list relevant to experiences of individual engagement with diabetes self-management. Search terms included: ([diabetes mellitus type 2] or [type 2 diabetes] or [diabetes] or [T2DM] AND [self-care] or [self-management] or [self-management support]); with (patient or consumer or client or individual or person\*) AND (perspective\* or perception\* or belief\* or experience\* or realist\*) AND (barrier\* or obstacle\* or

hurdle\* or difficult\* or problem\* or challenge\* or enable\* or benefit\* or success\* or activat\* or engag\* or participat\*) AND (co-morbidit\* or multi-morbidit\*).

### **2.1.1 Literature selection**

Literature inclusion considered primary intervention studies or observational studies that used either qualitative or quantitative methodologies to focus on individuals' experiences of type 2 diabetes self-management, specifically within glucose monitoring, medication adherence, appointment attendance, regular exercise, and eating appropriately. Article inclusion was limited to English language, human, adults aged >19 years, published between 2000 and 2016, and within urban or metropolitan areas in Australia, Canada, New Zealand, United Kingdom, United States and Western Europe (countries which New Zealand traditionally compares itself with). Databases assessed were relevant to public health and health promotion: Medline, PsycINFO, Pubmed, CINAHL Plus, and Scopus (see Figure 1).

#### **Figure 1: Literature selection process**

*Insert Figure 1*

### **2.2 Quality assessment and data extraction**

To improve searching for relevant and sound quality articles [23], each article was classified for "format" (as a primary intervention study or an observational study), for "interest" (on individuals' self-management of diabetes, including comorbidities), and "purpose" (pertaining to all three categories: (a) individuals' activities: glucose monitoring, taking and managing medications, attending appointments, doing regular exercise, and eating appropriately, (b) individuals' experiences of self-management, and (c) facilitators and/or barriers to engagement in self-management).

Studies reporting qualitative findings were appraised for validity using the Critical Appraisal Skills Programme (CASP) tool for qualitative research [24]. This tool addresses the principles and assumptions underpinning qualitative research, and

allowed us to systematically assess the appropriateness of each study's research design, sample, data collection and analysis, findings, and the value or contribution of each study to existing knowledge, practice or policy. Studies reporting quantitative findings were appraised using the National Institute for Health and Care Excellence (NICE) quality appraisal checklist for correlations and associations [25]. The NICE checklist assessed study design and internal and external validity.

### 2.3 Analysis of data

A general inductive approach was employed to identify themes, and sort facilitators and barriers to self-management. A realist approach was then used to analyse and synthesise the data. This methodological approach commonly involves the formulation of hypotheses that are then tested using multiple methods of data collection. In our analysis, we validate our hypothesis (see below) by way of literature review; drawing on the results of primary intervention or observational studies that focus on diabetes self-management.

Realist evaluations assume programmes to be *theories* of what might cause change [10, 11, 26, 27]. Constructing an initial theory begins with having an understanding of the issue or concern, and then hypothesising how changes or interventions to the issue might be made. It is through implementing the *initial* theory that the assumptions are tested. Diabetes best practice guidelines, standards and toolkits [2, 10, 11, 26-28] were used to construct our initial theory, that '*self-management is an effective programme for managing diabetes*'. From here, we drew upon our knowledge from earlier self-management research [5, 6, 29] and personal experience to formulate a hypothesis that explored the minimisation of risk or progression of diabetes; that '*self-management (what might work) effectively helps all individuals with diabetes (for whom) regardless of socio-economic status (in what circumstances).*'

### 3. Results

Of the 1,517 articles retrieved, a total of 30 articles met inclusion criteria; 22 primarily related to self-management of diabetes with the remaining 8 relating to



self-management of comorbidities and other conditions (see Table 1). Microsoft Excel was used to support the research questions and thematic analysis used to identify themes. Context-Mechanism-Outcome theories were then constructed to identify the underlying contextual factors that influence the effectiveness of diabetes self-management.

**Table 1.** Overview of included articles

*Insert Table 1*

### **3.1 Analysis of the articles**

In this study, we assume adherence is on the final common pathway in the causal chain linking behaviours of providers and individuals to self-management outcomes. We found 'adherence' was the common mechanism that (within given contexts) brought about positive and negative changes to the effectiveness of a self-management programme. Adherence to glucose monitoring, taking and managing medications, attending appointments, doing regular exercise, and eating appropriately was triggered by contextual factors that facilitated or inhibited effective diabetes self-management.

#### **3.1.1 Facilitators of diabetes self-management**

A small number of contexts facilitated a positive impact on diabetes self-management health outcomes (see Table 2). Access to information and resources increased self-efficacy, and aided individuals to adhere to appointments, diet and exercise. Combined with a good knowledge about appropriate foods, blood glucose and symptom management, individuals reported improved sense of well-being and a positive outlook to living with diabetes [30-36]. For one individual, having had polio motivated him to exercise [9], while others experiencing additional conditions were motivated to understand their multiple medications [37]. Many articles reported family or social support provided assistance and motivation to adhere to all aspects of diabetes self-management; individuals indicated family support gave them feelings of comfort and a sense of inclusion within the family [9, 31-33, 35, 38-42].

**Table 2:** Facilitators to diabetes self-management*Insert Table 2*

### 3.1.2 Key barriers of diabetes self-management

The biggest barriers to (effective) self-management were time, financial difficulties, and low self-efficacy (see Table 3). Time constraints included work commitments that prevented individuals attending appointments [43, 44]. Working irregular hours such as night or shift work also made it difficult to take scheduled medications [43, 45]. Food shopping and preparation were seen as inconvenient and costly; often ready-to-eat meals or fast food options were purchased even though the food was not appropriate for diabetes [36, 38, 45, 46].

Financial difficulties were mainly expressed in terms of affordability. A number of households had limited, and at times insufficient money to cover daily living expenses [5, 9, 39, 46]. Others focussed on being unable to afford equipment and medication, transport, and food. To cope, individuals described undertaking glucose monitoring only when necessary [36, 44, 47, 48], and missing or lengthening times between medication doses [39, 49, 50]. Those unable to afford transport and parking costs chose to attend only the most important appointments - often missing out on receiving medication prescriptions [39, 47]. Unaffordability severely impacted food availability where individuals described eating insufficient food, skipping meals, and buying cheaper foods to offset costs [9, 36, 39, 43, 45-47, 49-51].

Self-efficacy or confidence is an outcome that can be viewed as an individual result of the context-mechanism theory. However, we found that in most cases, individuals had low self-efficacy or lacked confidence that spiralled downwards, highlighting an underlying context that destabilises the effectiveness of a self-management programme. Low self-confidence in the ability to self-manage lead to infrequent or no glucose monitoring [34, 36, 39, 48], as well as increasing worry and concerns about adverse effects from (multiple) medications or wrong dosages,

[25, 38, 40]; decreasing motivation [36, 45, 51]; and a fear of being responsible for so many things – diet, exercise, medication, comorbid conditions [35, 43, 45].

**Table 3:** Contributing barriers of diabetes self-management

*Insert Table 3*

### **3.1.3 Contributing barriers of diabetes self-management**

Individuals stated a lack in continuity of care and effective communication impeded them from keeping of scheduled appointments. Asymmetry of information provided by health care team members was also described as a frustration, along with the insufficient or overload of information provided [30, 35, 49, 50, 52-54]. Individuals perceived a central issue to be the absence of an engaged relationship between themselves and the health care team. Many felt they were treated as ‘just another number’ with diabetes rather than being seen as an individual person needing support to manage living with diabetes [5, 6, 30, 34, 35, 52, 53]. Some individuals believed the health care provider was not-effective, and had no recollection of being taught self-management strategies [6].

For some, family support proved to be a hindrance. Family tensions were evident and individuals had difficulties in maintaining an appropriate diet and keeping to medication and exercise regimes [39, 41, 45]. Often family members did not want to eat the same meals as the individual with diabetes, or other people were prioritised above the individual with diabetes [35, 36, 41]. Instances were reported of family sabotaging individual’s efforts to manage their diet, encouraging them to eat the wrong foods. Separate meals needed to be prepared, and in one case, an individual ate alone [45].

Comorbidities and other conditions added extra burden [37, 49, 55] especially when individuals found themselves juggling between their conditions, managing multiple medications, and needing to prioritise the most severe symptoms or conditions they were experiencing at any one time. Physical limitations such as injuries, breathing difficulties, and poor eyesight created additional barriers [37,

55] where tasks such as exercising or reading glucose levels became almost impossible.

Individuals said they were embarrassed administering insulin outside of the home. Many stated they were reluctant to give themselves insulin at work or when in social situations [36, 43, 48, 54] because they felt uncomfortable and feared being judged. A stigma surrounded having diabetes and the need to eat diabetes-appropriate foods within a social setting made diabetes visible. Some described a loss of enjoyment in eating out and said affordability and social pressure often exacerbated the problem of feeling stigmatised [38, 56]. Other barriers included pain from lancing the finger for glucose monitoring [36, 46, 48] and feeling constantly preoccupied with having to be mindful of managing diabetes [40].

#### **Figure 2: Diabetes self-management effectiveness model**

*Insert Figure 2*

#### **4. DISCUSSION**

In this realist evaluation of the diabetes self-management programme, we show how underlying contextual factors have a dominant ability to positively or negatively influence diabetes self-management effectiveness. Contextual facilitators and barriers of self-management are much wider than the health system. Analyses of the studies included in this evaluation suggest that while diabetes self-management does help individuals to self-manage their diabetes, for reasons of context, it does not help all individuals equally.

To support the integration of evidence and to capture the complexity of self-management, we constructed a conceptual model (Figure 2) to represent the underlying contexts that influence diabetes self-management effectiveness [18]. The results indicate factors that can impede people with diabetes from gaining full benefit from self-management, and which warrants the attention of health service providers, policy makers, and health system funders. It is likely that our findings apply equally to the self-management of other long term conditions. An increasing number of individuals are experiencing comorbidities and other conditions. A

deeper inquiry into the way we provide services and resources within the health system is needed to better understand the burden on peoples' already constrained lives.

Self-management can become a central focus within people's lives as it involves regular, daily tasks. However, the opportunity to engage in self-management requires access to resources, information and services, and access to relationships with health care workers; in order to develop, increase and maintain the health literacy which is needed to make informed decisions about medication and treatment plans; and, to determine which health-related goals need pursuing. When these conditions are right, opportunities for engagement can even include influencers commonly associated with obstructing engagement. For example, experiencing comorbidities can build motivation to understand the interaction between medications for each condition, and therefore improve self-efficacy in diabetes self-management. Through developing coping skills to manage the day-to-day experience of multiple conditions, individuals may acquire improved emotional well-being and more confidence in decision-making.

Ineffective self-management is often attributed to an individual's behaviour. This is not surprising considering explanations of 'self-management' frequently focus on changing behaviour [57-60]. Within our model (Figure 2), behaviour is an action that is influenced by contexts that shape how individuals act and cope with diabetes. Looking further upstream, self-management and engagement have a bi-directional relationship that is dependent upon access to be effective. This relationship regulates the flow of information between the individual and their health provider - determining the degree of action taken by the individual in the management of their health care [61]. In turn, these actions support individuals to develop and strengthen self-efficacy [62-65], therefore, reducing dependency on the health system.

Hibbard and Cunningham [61], among others, suggest individuals need to have belief in themselves, and the ability to engage with their health care [7, 44, 66]. Again, we found that ability is strongly determined by context - the characteristics

that shape peoples' lives, such as, socio-economic status, gender, age, culture, beliefs, experience of illness, work and family obligations, position within the family, and what is most important to them. Moreover, we found that whilst these contexts fell within a number of categories - external supports, experiences of comorbidities and other conditions - financial ability was an underlying central factor.

Financial inability to access resources, information and services has been a long-standing concern of most health systems [67]. Effectively (self) managing diabetes with insufficient personal financial resources is described as impossible and requires a balancing between health and personal issues where individuals' management strategies often have a short-term effect that can place them at greater risk [46, 50, 68].

Over the past 20 years of published research, individuals have voiced their frustrations and anger at the stresses of trying to cope with diabetes self-management [6, 9, 36, 39, 43, 45-51]. It seems that effective and sustainable strategies to help (low income) individuals with diabetes are no farther ahead. Affordability must be understood as a context that is subject to change. Much literature has associated low income with food insecurity and unhealthy foods. For those with diabetes, a lack of financial ability to access diabetes appropriate foods will impede optimal blood glucose management. However, for these individuals, a lack of financial ability might also be associated with, for example, sickness "presenteeism" (continuing to work while unwell) [69, 70]. Time off work when there is insufficient annual or sick leave often means unpaid leave, and for those already financially constrained, can be a strong motivator for sickness presenteeism.

Structural weaknesses of diabetes self-management are made explicit by our model (Figure 2). It illustrates how one context may influence other contexts, as well as the mechanism of adherence, and where some outcomes can also become contexts. Further, our model highlights the broader issue that, an effective (diabetes) self-management programme requires supports from agencies external

to health. While health care workers may be aware of the financial burden experienced by individuals in their care, a deeper insight into individual's ability to undertake self-management is required. Many commentators have suggested self-management strategies for low-income individuals might require health care providers to (re)negotiate their ideal treatment strategy and co-partner in the development of potential strategies with individuals (which may include family members and carers).

While the mechanism of adherence primarily remains within the medical and health care domain, the contexts are socially derived and outside the remit of the person with diabetes, the health care team, and the health system. Therefore, when (re)negotiating ideal self-management strategies are undertaken within the health care environment, often social issues are addressed with limited resolve and ability to influence. The social, economic, political, environmental and commercial influences upon health have long been acknowledged and intersectoral collaboration has been promoted as an approach to improve population health and health equity. However, establishing such collaborations is challenging, complex and often constrained by limited time and resources. Failures in collaboration and coordination between agencies, often mean individuals fall between the gaps.

#### **4.1 Limitations**

This study has several limitations. The analysis is necessarily limited to the available literature. Further, we explicitly limited our review to individuals' experiences. We recognise that our findings require corroboration from other analyses followed by a model that integrates individuals' perspectives with other perspectives. There were other strategies available to synthesise the literature, and it is possible these might lead to difference conclusions and emphases. We chose a realist evaluation approach to synthesising literature because it allows knowledge to be accessed from a wide range of studies allowing for programme outcomes, impacts, and contexts to be described in studies that have been peer-reviewed and shown to have high reliability and validity.

## 5. CONCLUSION

These findings do not invalidate the current or continued practise of using self-management by health care workers promoting and supporting diabetes self-management. However, there is a need to recognise and incorporate realist evaluation (what works for whom, and in what circumstances) as part of the initial design and/or implementation strategy for diabetes self-management. Findings from realist evaluation illuminate programme mechanisms and fine-tune context rather than generalise overall programme outcomes. Service providers, policy decision makers, health system funders, and social welfare government agencies can use such finding's (new or revisions of the initial understanding of how an intervention or programme was thought to work) to influence and (re)design (new) programmes. In conjunction with this methodological requirement, such evaluations (and programme designs) need to incorporate key stakeholders from all sectors, not just health. To further evaluate the diabetes self-management programme issues raised in this study for example, context-mechanism-outcome theories could be continued across social sectors and used to identify suitable solutions.

This article demonstrates where an evaluation tool such as realist evaluation, can illustrate the (in)effectiveness of a self-management programme across multiple sectors. Our findings suggest that the diabetes self-management programme will bring about change (positive health gain) for individuals if the change is triggered by the mechanism (adherence) acting in the right conditions or circumstances (context). The findings support affordability as a key weakness of the self-management programme; a context that impedes effective self-management preventing those with insufficient financial resources from gaining (full) benefit from self-management.



## REFERENCES

1. Martinez, J.M.V., et al., *Patient engagement: Technical series on safer primary care*. 2016, World Health Organisation.
2. American Association of Diabetes Educators, *Self-care behaviors position statement*. 2014.
3. Wagner, E.H., B.T. Austin, and M.V. Korff, *Organizing Care for Patients with Chronic Illness*. The Milbank quarterly, 1996. **74**(4): p. 511-544.
4. Clark, N.M., et al., *Self-management of chronic disease by older adults: a review and questions for research*. Journal of aging and health, 1991. **3**(1): p. 3-27.
5. Sheridan, N.F., et al., *Helplessness, self blame and faith may impact on self management in COPD: A qualitative study*. Primary care respiratory journal : journal of the General Practice Airways Group, 2011. **20**(3): p. 14, 1 p following 314.
6. Sheridan, N.F., et al., *Patients' engagement in primary care: powerlessness and compounding jeopardy. A qualitative study*. Health Expectations, 2015. **18**(1): p. 32-43.
7. Barello, S., G. Graffigna, and E. Vegni, *Patient engagement as an emerging challenge for healthcare services: mapping the literature*. Nursing research and practice, 2012. **2012**: p. 7.
8. Patel, M.R., et al., *An examination of adverse asthma outcomes in US Adults with multiple morbidities*. Annals of the American Thoracic Society, 2013. **10**(5): p. 426-431.
9. Coventry, P.A., et al., *Capacity, responsibility, and motivation: a critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity*. BMC health services research, 2014. **14**(1): p. 536.
10. Wong, G., et al., *Realist synthesis: RAMESES training materials*. 2013, London: The RAMESES Project.
11. Pawson, R. and N. Tilley, *Realistic evaluation*. 1997: Sage Publications Inc. 235.

12. Chen, H.-T. and P.H. Rossi, *The multi-goal, theory-driven approach to evaluation: A model linking basic and applied social science*. Social forces, 1980. **59**(1): p. 106-122.
13. Merriam, W., *Definition of program*. 2017.
14. Ministry of Health, *Self-management support for people with long-term conditions*. 2016.
15. New Zealand Guidelines Group, *New Zealand Primary Care Handbook 2012*. 3rd ed. 2012, Wellington: New Zealand Guidelines Group.
16. Haas, L., et al., *National Standards for Diabetes Self-Management Education and Support*. Diabetes Educ, 2012. **38**(5): p. 619-629.
17. Snilstveit, B., S. Oliver, and M. Vojtkova, *Narrative approaches to systematic review and synthesis of evidence for international development policy and practice*. Journal of development effectiveness, 2012. **4**(3): p. 409-429.
18. Harden, A., et al., *Cochrane Qualitative and Implementation Methods Group guidance series—paper 5: methods for integrating qualitative and implementation evidence within intervention effectiveness reviews*. JOURNAL OF CLINICAL EPIDEMIOLOGY, 2018. **97**(1): p. 70-78.
19. Rycroft-Malone, J., et al., *Realist synthesis: illustrating the method for implementation research*. Implementation Science, 2012. **7**(1): p. 33.
20. Noyes, J., et al., *Qualitative research and Cochrane reviews*, in *Cochrane handbook for systematic reviews of interventions*, J.P. Higgins and S. Green, Editors. 2011, John Wiley & Sons: West Sussex: England.
21. Pawson, R., et al., *Realist review--a new method of systematic review designed for complex policy interventions*. Journal of health services research & policy, 2005. **10 Suppl 1**: p. 21-34.
22. Moher, D., et al., *Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement*. Systematic reviews, 2015. **4**(1): p. 1.
23. Wong, S.S.-L., N.L. Wilczynski, and R.B. Haynes, *Developing optimal search strategies for detecting clinically relevant qualitative*. Medinfo, 2004. **107**: p. 311.
24. Critical Appraisal Skills Programme, *CASP Qualitative Research Checklist*. 2017.

25. National Institute for Health and Care Excellence. *Methods for the Development of NICE Public Health Guidance (Third Edition)*. 2012 [cited 2017 October]; Available from: <https://www.nice.org.uk/process/pmg4/chapter/appendix-g-quality-appraisal-checklist-quantitative-studies-reporting-correlations-and>.
26. Donaldson, S.I., *Program theory-driven evaluation science: Strategies and applications*. 2012, New York: Routledge.
27. Funnell, S. and P. Rogers, *Purposeful program theory: effective use of theories of change and logic models*. Vol. 31. 2011, San Francisco, CA: John Wiley & Sons.
28. Chen, H.T., *Theory-driven evaluations*. 1990, Thousand Oaks, California: Sage Publications Inc.
29. Kenealy, T., et al., *Alleviating the Burden of Chronic Conditions in New Zealand (The ABCC NZ Study)*. 2008, The University of Auckland.
30. Chlebowy, D.O., S. Hood, and A.S. Lajoie, *Gender differences in diabetes self-management among African American adults*. *Western journal of nursing research*, 2013. **35**(6): p. 703-721.
31. Moser, A., et al., *Self-management of type 2 diabetes mellitus: a qualitative investigation from the perspective of participants in a nurse-led, shared-care programme in the Netherlands*. *BMC Public Health*, 2008. **8**(1): p. 91.
32. Beverly, E.A. and L.A. Wray, *The role of collective efficacy in exercise adherence: a qualitative study of spousal support and type 2 diabetes management*. *Health education research*, 2010. **25**(2): p. 211-223.
33. Ferrand, C., C. Perrin, and S. Nasarre, *Motives for regular physical activity in women and men: a qualitative study in French adults with type 2 diabetes, belonging to a patients' association*. *Health & social care in the community*, 2008. **16**(5): p. 511-520.
34. Onwudiwe, N.C., et al., *Barriers to self-management of diabetes: a qualitative study among low-income minority diabetics*. *South African Journal of Diabetes and Vascular Disease*, 2014. **11**(2): p. 61-65.
35. Burke, J.A., et al., *Patients with diabetes speak: Exploring the implications of patients' perspectives for their diabetes appointments*. *Health communication*, 2006. **19**(2): p. 103-114.

36. Von Goeler, D.S., et al., *Self-management of Type 2 diabetes: a survey of low-income urban Puerto Ricans*. The Diabetes educator, 2003. **29**(4): p. 663-672.
37. Hershey, D.S., et al., *Perceived impact of cancer treatment on diabetes self-management*. The Diabetes educator, 2012. **38**(6): p. 779-790.
38. Carolan, M., J. Holman, and M. Ferrari, *Experiences of diabetes self-management: a focus group study among Australians with type 2 diabetes*. Journal of Clinical Nursing, 2015. **24**(7-8): p. 1011-1023.
39. McElfish, P.A., et al., *Family model of diabetes education with a Pacific Islander community*. The Diabetes educator, 2015. **41**(6): p. 706-715.
40. Rise, M.B., et al., *Making and maintaining lifestyle changes after participating in group based type 2 diabetes self-management educations: a qualitative study*. PLoS one, 2013. **8**(5): p. e64009.
41. Mayberry, L.S. and C.Y. Osborn, *Family support, medication adherence, and glycemic control among adults with type 2 diabetes*. Diabetes care, 2012. **35**(6): p. 1239-1245.
42. Ward, N.J., et al., *With good intentions: complexity in unsolicited informal support for Aboriginal and Torres Strait Islander peoples. A qualitative study*. BMC public health, 2011. **11**(1): p. 686.
43. Chlebowy, D.O., S. Hood, and A.S. Lajoie, *Facilitators and barriers to self-management of type 2 diabetes among urban African American adults: focus group findings*. The Diabetes educator, 2010. **36**(6): p. 897-905.
44. Gucciardi, E., et al., *Factors contributing to attrition behavior in diabetes self-management programs: a mixed method approach*. BMC health services research, 2008. **8**(1): p. 33.
45. Hu, J., et al., *Perceptions of barriers in managing diabetes: perspectives of Hispanic immigrant patients and family members*. The Diabetes educator, 2013. **39**(4): p. 494-503.
46. Rendle, K.A., et al., *Persistent barriers and strategic practices: why (asking about) the everyday matters in diabetes care*. The Diabetes educator, 2013. **39**(4): p. 560-567.
47. Hallgren, E.A., P.A. McElfish, and J. Rubon-Chutaro, *Barriers and opportunities: a community-based participatory research study of health*

- beliefs related to diabetes in a US Marshallese community*. The Diabetes educator, 2015. **41**(1): p. 86-94.
48. Polonsky, W.H., et al., *What is so tough about self-monitoring of blood glucose? Perceived obstacles among patients with Type 2 diabetes*. Diabetic Medicine, 2014. **31**(1): p. 40-46.
49. Bayliss, E.A., et al., *Descriptions of barriers to self-care by persons with comorbid chronic diseases*. Annals of family medicine, 2003. **1**(1): p. 15-21.
50. Senteio, C. and T. Veinot, *Trying to make things right: adherence work in high-poverty, African American neighborhoods*. Qualitative health research, 2014. **24**(12): p. 1745-1756.
51. Lynch, E.B., et al., *Concepts of diabetes self-management in Mexican American and African American low-income patients with diabetes*. Health education research, 2012. **27**(5): p. 814-824.
52. Langst, G., et al., *Factors associated with medication information in diabetes care: differences in perceptions between patients and health care professionals*. Patient preference and adherence, 2015. **9**(1): p. 1431-1441.
53. Pooley, C.G., et al., *'Oh it's a wonderful practice...you can talk to them': a qualitative study of patients' and health professionals' views on the management of type 2 diabetes*. Health & social care in the community, 2001. **9**(5): p. 318-326.
54. Ritholz, M.D., et al., *Barriers and facilitators to self-care communication during medical appointments in the United States for adults with type 2 diabetes*. Chronic illness, 2014. **10**(4): p. 303-313.
55. Janevic, M.R., et al., *Self-management of multiple chronic conditions among African American women with asthma: a qualitative study*. Journal of Asthma, 2014. **51**(3): p. 243-252.
56. Shultz, J.A., et al., *A comparison of views of individuals with type 2 diabetes mellitus and diabetes educators about barriers to diet and exercise*. Journal of health communication, 2001. **6**(2): p. 99-115.
57. Rijken, M.J.M.H.M.D.A., *Supporting self-management*, M.M. E. Nolte, Editor. 2008, Open University Press: Berkshire. p. 116-142.

58. Kaiser Permanente, *Behavior Change Counseling Using the Brief Negotiation Method*. 2005, Oakland, CA: Regional Health Education, Northern California Region.
59. Shrivastava, S.R., P.S. Shrivastava, and J. Ramasamy, *Role of self-care in management of diabetes mellitus*. *Journal of Diabetes & Metabolic Disorders*, 2013. **12**(1): p. 14.
60. Pearson, M.L., et al., *Patient self-management support programs: an evaluation*. 2007, Agency for Healthcare Research and Quality. p. 48.
61. Hibbard, J. and P. Cunningham, *How engaged are consumers in their health and health care, and why does it matter*. *Res Brief*, 2008. **8**: p. 1-9.
62. Hibbard, J. and H. Gilburt, *Supporting people to manage their health: an introduction to patient activation*. 2014, London: The King's Fund. 54.
63. de Silva, D., *Evidence: helping people help themselves*. 2011, The Health Foundation.
64. Glasgow, R.E., et al., *Self-management aspects of the improving chronic illness care breakthrough series: implementation with diabetes and heart failure teams*. *Annals of Behavioral Medicine*, 2002. **24**(2): p. 80-87.
65. Lorig, K.R. and H.R. Holman, *Self-management education: history, definition, outcomes, and mechanisms*. *Annals of behavioral medicine*, 2003. **26**(1): p. 1-7.
66. Bean, D., T. Cundy, and K.J. Petrie, *Ethnic differences in illness perceptions, self-efficacy and diabetes self-care*. *Psychology and Health*, 2007. **22**(7): p. 787-811.
67. Starfield, B., *The hidden inequity in health care*. *International journal for equity in health*, 2011. **10**(1): p. 15.
68. Cheer, T., R. Kearns, and L. Murphy, *Housing policy, poverty, and culture: "discounting" decisions among Pacific peoples in Auckland, New Zealand*. *Environment and Planning C: Government and Policy*, 2002. **20**(4): p. 497-516.
69. Aronsson, G., K. Gustafsson, and M. Dallner, *Sick but yet at work. An empirical study of sickness presenteeism*. *Journal of Epidemiology & Community Health*, 2000. **54**(7): p. 502-509.

70. Johns, G., *Presenteeism in the workplace: A review and research agenda*.  
Journal of Organizational Behavior, 2010. **31**(4): p. 519-542.

ACCEPTED MANUSCRIPT

**Table 1 Overview of included articles**

	<b>Author(s), Year, Country</b>	<b>n</b>	<b>age</b>	<b>Ethnicity</b>	<b>Income</b>	<b>Conditions: Diabetes +</b>	<b>Investigation</b>	<b>Findings / Themes</b>
49^	Bayliss et al., (2003), United States	16	31-70+	White/European (16)	↑Low	Heart disease, HTN, Asthma, OA, Depression, Vision, Other	Barriers of care	Access to resources, information and services Compound effects of (multiple) conditions Lack of knowledge Financial and physical constraints Side effects from medications
32	Beverly et al., (2010), United States	23	51+	ND	ND	ND	Spousal support in exercise adherence	Collective support, responsibility, motivation
35	Burke et al., (2006), United States	8	42-82	African American (3) White European (5)	ND	Heart disease, Renal, HTN, Depression, Vision, Other	Perspectives of appointments	Need for better communication Time consumption Useful for information
38	Carolan et al., (2015), Australia	22	40-70	Other (11) White/European (11)	Low	ND	Experiences of self- management	Access to resources, information and services Burden of managing diabetes care Challenges with the invisibility of diabetes
43	Chlebowy et al., (2010), United States	38	44-87	African American (38)	ND	ND	Facilitators and barriers to self- management	Access to knowledge Burden of managing diabetes care Collective support from family Financial constraints
30	Chlebowy et al., (2013), United States	38	37-89	African American (38)	↑Low	ND	Gender differences in self-management	Access to resources, information and services Burden of managing diabetes care Side effects from medications Time constraints
9^	Coventry et al., (2014), United Kingdom	20	52-88	ND	Low	COPD, Heart disease, Asthma, OA, Depression, Other	Self-managing with comorbidities	Access to resources, information and services Burden of managing diabetes care Financial constraints Motivations and responsibility



Table 1 (continued)

	<b>Author(s), Year, Country</b>	<b>n</b>	<b>age</b>	<b>Ethnicity</b>	<b>Income</b>	<b>Conditions: Diabetes +</b>	<b>Investigation</b>	<b>Findings / Themes</b>
33	Ferrand et al., (2008), France	23	35-78	ND	ND	ND	Motives for regular physical activity	Social and psychological motives
44	Gucciardiet al., (2008), Canada	100	42-65+	ND	Mixed	ND	Barriers of SME programmes	Access to resources, information and services Compound effects of (multiple) conditions. Lack of family/social support
47	Hallgren et al., (2015), United States	13	18+	Pacific (13)	Low	ND	Perceptions of self- management	Access to resources, information and services Burden of managing diabetes care Change in cultural diet Financial and time constraints
37 <sup>^</sup>	Hershey et al., (2012), United States	43	50+	African American (5) Hispanic (1) White/European (37)	Mixed	Cancer, Other	Impact of cancer and treatment on diabetes self- management	Challenges with juggling conditions, treatments Challenges with medication management Prioritisation of self-care tasks
45	Hu, et al., (2013), United States	36	18+	Hispanic (36)	ND	ND	Perceived barriers to self-management	Access to resources, information and services Burden of managing diabetes care Financial constraints Physical and emotional impact of disease
55 <sup>^</sup>	Janevic et al., (2014), United States	25	20-63	African American (25)	↑Low	ND	Impact of asthma and treatment on diabetes self- management	Challenges with juggling conditions, treatments Challenges with medication management Prioritisation of self-care tasks

Table 1 (continued)

	<b>Author(s), Year, Country</b>	<b>n</b>	<b>age</b>	<b>Ethnicity</b>	<b>Income</b>	<b>Conditions: Diabetes +</b>	<b>Investigation</b>	<b>Findings / Themes</b>
52	Langst et al., (2015), Germany	25	18+	White/European (25)	ND	ND	Facilitators and barriers to self- management	Access to resources, information and services Burden of managing diabetes care Collective support from family Patient-physician communication/information sharing
51	Lynch et al., (2012), United States	84	45-67	African American (35) Hispanic (49)	Low	ND	Perspectives of self- management	Access to resources, information and services Burden of managing diabetes care Financial constraints
39	McElfish et al., (2015), United States	6	18-44	Pacific (6)	Low	ND	Pilot test SME programme	Access to resources, information and services Burden of managing diabetes care Financial constraints
41	Mayberry & Osborn, (2012), United States	96	40-78	African American (28) White/European (67)	Mixed	ND	Perspectives of family support	Instrumental support with daily care Sabotaging behaviour - diet, transport
31	Moser et al., (2008), The Netherlands	15	55-77	White/European (15)	ND	ND	Autonomy of self- management in nurse-led setting	Improves daily adherence of self- management
34	Onwudiwe et al., (2014), United States	31	43-81	African American (29) Hispanic (1) White/European (1)	ND	ND	Barriers to self- management	Access to resources, information and services Continuity of care

**Table 1** (continued)

	<b>Author(s), Year, Country</b>	<b>n</b>	<b>age</b>	<b>Ethnicity</b>	<b>Income</b>	<b>Conditions: Diabetes +</b>	<b>Investigation</b>	<b>Findings / Themes</b>
48	Polonsky et al., (2014), United States	886 <sup>#</sup>	50+	African American (113) Hispanic (57) Native American (40) Other (136) White/European (532)	ND	ND	Barriers to self- management of blood glucose	Burden of managing diabetes Health literacy Financial and time constraints
53	Pooley et al., (2001), United Kingdom	47	50-76	ND	ND	ND	Perspectives of care from GPs	Time constraints Continuity of care Patient-physician communication
46	Rendle et al., (2013), United States	20	43-69	African American (5) Hispanic (8) Other (3) White/European (4)	↑Low	ND	Barriers to self- management	Access to resources, information and services Burden of managing diabetes care Financial and time constraints
40	Rise et al., (2013), Norway	23	35-72	ND	ND	ND	Facilitators and barriers to self- management	Access to knowledge Support from family, friends Motivations
54	Ritholz et al., (2014), United States	34	43-70	Hispanic (6) White/European (28)	↑High	ND	Perspectives of appointments	Need for better communication Trust and acceptance by physicians
50 <sup>^</sup>	Senteio & Veinot, (2014), United States	37	21-90	African American (37)	↑Low	Renal, HTN	Facilitators and barriers to self- management	Access to resources, information and services Burden of managing diabetes and other conditions Continuity of care, relationships Financial constraints Intergenerational learning

**Table 1** (continued)

	<b>Author(s), Year, Country</b>	<b>n</b>	<b>age</b>	<b>Ethnicity</b>	<b>Income</b>	<b>Conditions: Diabetes +</b>	<b>Investigation</b>	<b>Findings / Themes</b>
5 <sup>^</sup>	Sheridan et al., (2011), New Zealand	42	55-74	Māori (8) Other (3) Pacific (19) White/European (20)	Low	COPD, Heart disease, OA, Depression, Other	Perspectives of care from GPs	Access to information and resources Continuity of care, relationships Financial constraints Need for better communication and support
6 <sup>^</sup>	Sheridan et al., (2015), New Zealand	29	65-89	Māori (2) Pacific (18) White/European (9)	↑Low	COPD, Heart disease, Asthma, Depression, Other	Experiences of self- management	Access to resources, information and services Burden of managing multiple conditions Feelings of helplessness Financial constraints
56	Shultz et al., (2001), United States	97	48-73	ND	ND	Heart disease, Renal, Vision, Other	Barriers to diet and exercise	Burden of managing diet and activity tasks Complications of comorbidities Financial, physical, time and social constraints
36	Von Goeler et al., (2003), United States	30	34-80	Hispanic (30)	Low	Heart disease, Renal, Vision	Barriers to self- management	Access to resources, information and services Burden of managing tasks Complications of comorbidities Financial, physical, time and social constraints
42 <sup>^</sup>	Ward et al., (2011), Australia	31	34-70	Aboriginal/Torres Strait Islander (31)	Low	COPD, Heart disease	Experiences of family/social support	Instrumental support with daily care and psychological support

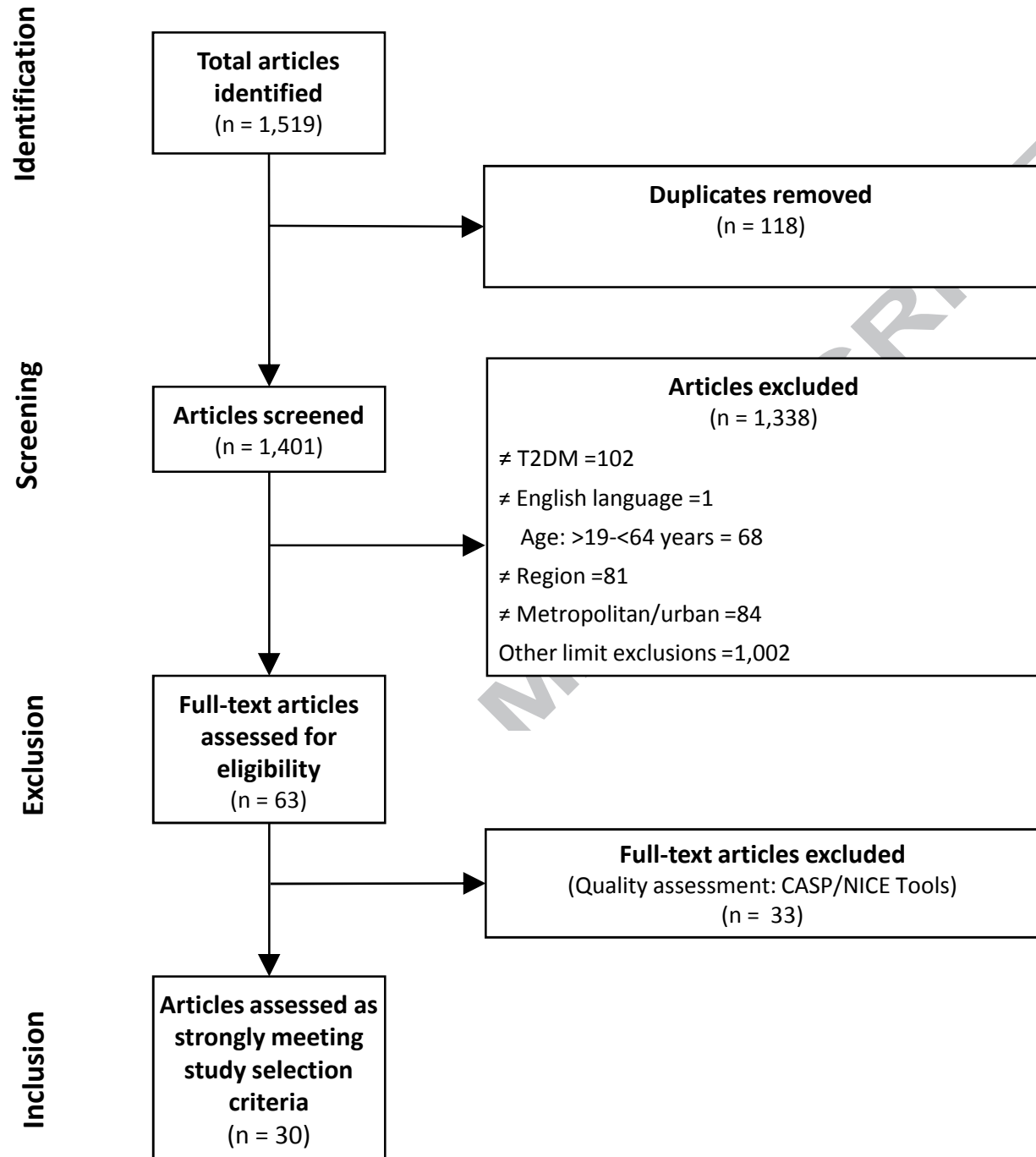
<sup>^</sup>Articles primarily relating to comorbidities and other conditions; ND: Not defined; #discrepancy; Low: All low; Mixed: High and low; ↑Low: mostly low; ↑High: mostly high; COPD: Chronic Obstructive Pulmonary Disease; HTN: Hypertension; OA: Osteoarthritis.

**Table 2: Facilitators to diabetes self-management**

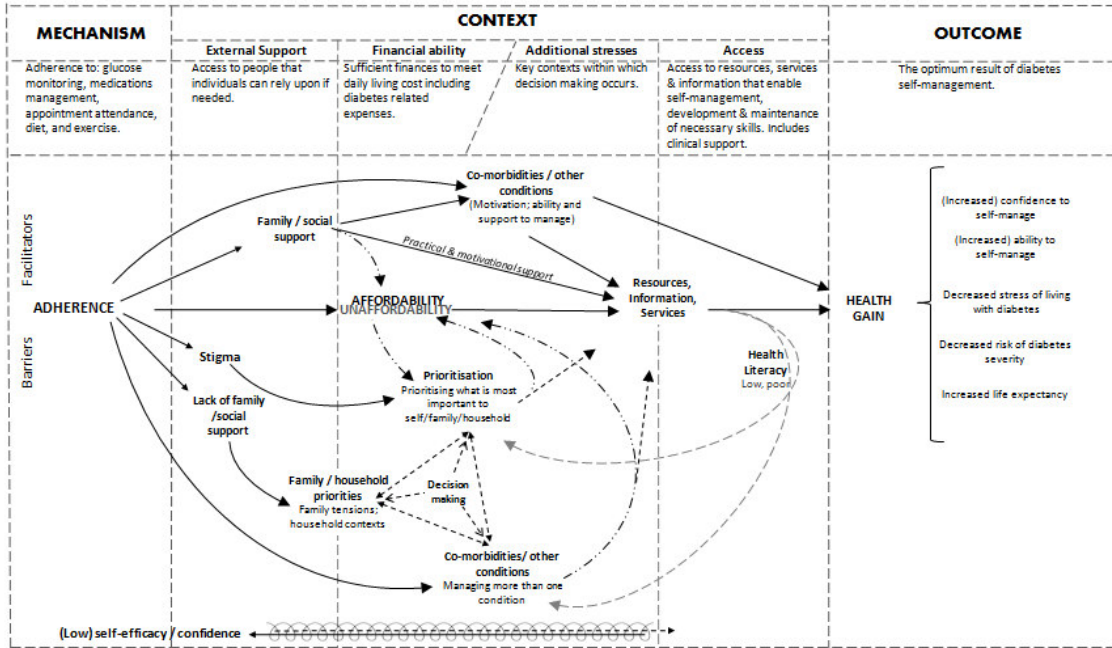
<b>Mechanism</b>	<b>Context</b>	<b>Outcome</b>
Adherence to: <ul style="list-style-type: none"> <li>• glucose monitoring,</li> </ul>	Access to (tailored) information, teaching and reinforcing of information.	Improved sense of well-being; a positive outlook to living with diabetes; patient engagement, improved self-efficacy.
<ul style="list-style-type: none"> <li>• taking/managing medications,</li> <li>• attending appointments,</li> </ul>	Ideal communication using common (non-clinical) language by health care workers.	Improved sense of well-being; a positive outlook to living with diabetes; patient engagement, improved self-efficacy.
<ul style="list-style-type: none"> <li>• doing regular exercise, and</li> </ul>	The experience of comorbidities and/or additional conditions.	Motivation to understand multiple medical conditions; improved self-efficacy.
<ul style="list-style-type: none"> <li>• eating appropriately</li> </ul>	Support from family or social networks.	Practical assistance and motivation to adhere to all aspects of diabetes self-management; increased feelings of comfort and a sense of inclusiveness in the family.

**Table 3: Barriers to diabetes self-management****Key barriers**

<b>Mechanism</b>	<b>Context</b>	<b>Outcome</b>
Adherence to: <ul style="list-style-type: none"> <li>• glucose monitoring,</li> <li>• taking/managing medications,</li> <li>• attending appointments,</li> <li>• doing regular exercise, and</li> <li>• eating appropriately</li> </ul>	Work commitments, working irregular hours/shifts.	Hindrance to taking medications, glucose monitoring, shopping and preparation of foods.
	Time constraints	Hindrance to taking medications, glucose monitoring, shopping and preparation of foods.
	Financial constraints	Insufficient money to cover daily living expenses. Unable to afford equipment, medication, transport, and/or food. Reduced monitoring of blood glucose and food intake. Missing doses or stretching medications across a longer timeframe. Non-attendance at appointments. Non-collection/dispensing of prescriptions.
<b>Contributing barriers</b>		
Adherence to: <ul style="list-style-type: none"> <li>• glucose monitoring,</li> <li>• taking/managing medications,</li> <li>• attending appointments,</li> <li>• doing regular exercise, and</li> <li>• eating appropriately</li> </ul>	Lack in continuity of care and communication; absence of fostered relationships.	Hindered the keeping of scheduled appointments
	Asymmetry, insufficient, or overload of information	Hindered the keeping of scheduled appointments
	Family tensions, lack of support, prioritisation of diabetes within family structure.	Hindrance to maintaining an appropriate diet, and keeping to medication and exercise regimes. Isolation within the family; sabotaging meals and exercise plans
	The experience of comorbidities and/or additional conditions	Extra burden; juggling between conditions. Unable to manage multiple conditions; physical limitations (eg. injuries, breathing difficulties, poor eyesight). Barrier to tasks such as exercise or reading glucose levels.
	Social stigma, embarrassment.	Barrier to glucose monitoring, maintaining appropriate diet. Low self-esteem.
	Lancing the finger (glucose monitoring).	Pain. Annoyance at constant reminder of having diabetes.



**Figure 1: Literature selection process**



ACCEPTED MANUSCRIPT