

Review

Connectivity, contest and the ties of self-management support for type 2 diabetes: a meta-synthesis of qualitative literature

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What is known about this topic

- Previous research into self-management support tends to focus on individual attitudes and motivations.
- The difficulties people have in incorporating self-management into pre-existing life contexts have been conceptualised in terms of concepts such as non-compliance, non-adherence and lack of concordance or difficulties in the regulation of the self.
- Existing literature does not problematise the conditions under which diabetes-related experiences unfold.

What this paper adds

- Peoples' accounts are of themselves located with reference to daily life within a social network and how this network affects their self-management.
- Connectivity is an important element of self-management.
- Self-management support needs to be targeted to take account of the appropriate context operating at micro-, meso- and macro-levels.

Abstract

This paper presents a meta-synthesis of the literature on community-based self-management to support experiences of people diagnosed with type 2 diabetes. The aim was to synthesise findings on both formal and informal self-management support with particular reference to the relevance and influence of the social context operating at different levels. The review forms part of EU-WISE, a project financed through EU's 7th Framework Programme. The review was performed by systematically searching MEDLINE, PubMed, EMBASE, CINAHL, PsycINFO and Web of Science for English language publications between 2005 and 2014 presenting research conducted in Europe on the experiences and perspectives of self-management concerns of patients diagnosed with type 2 diabetes. The search yielded 587 abstracts, which were reduced through search strategy refinement and eligibility and quality criteria to 29 papers that were included in the review. This review highlights the relevance of contextual factors operating at micro- and macro-levels. The synthesis yielded six second-order thematic constructs relating to self-management: sense of agency and identity, the significance and meaning of social networks, minimal disruption of everyday life, economic hardship, the problem of assigning patients' responsibility and structural influences of primary care. Using a line of argument synthesis, these themes were revisited, and a third-order construct, connectivity emerged which refers to how links in daily life are interwoven with peoples' social networks, local communities, economic and ideological conditions in society in a way which support self-management activities. This meta-synthesis indicates a need to heed the notion of connectivity as a means of mobilising and supporting the self-management strategies of people with type 2 diabetes in everyday life.

Keywords: chronic illness, meta-synthesis, qualitative research, self-management, type 2 diabetes

Introduction

Projections from the International Diabetes Federation estimate that the global prevalence of diabetes will increase to 7.1% of the total population (380 million) by 2025, and 90% of this increase will be attributed to type 2 diabetes (Economist Intelligence Unity 2007). The escalation of the prevalence of long-term conditions is motivating substantial changes in healthcare services. New organisational developments centred on the management of long-term conditions have been a common characteristic of contemporary healthcare politics in Europe (Genet *et al.* 2012). Over the past decade, healthcare systems have been subjected to reforms consistent with the prevailing neoliberal trend, resulting in individualism, privatisation and/or deregulation and decentralisation (Ajo 2012). A central part of this policy is to strengthen primary care, including increased community involvement in healthcare and an amplified integration of healthcare activities in and between public and private agencies (Sheaff & Pilgrim 2006, WHO 2008, Ham 2010). This approach fits with the overall manner in which self-management policy and practice has been cast across Europe (Scheller-Kreisen *et al.* 2009).

The increasing growth in the prevalence of chronic conditions combined with an enhanced focus on individuals' responsibilities for their own healthcare has led to a focus on self-management, support and a panacea for a healthcare system under pressure (Wilson *et al.* 2006, Kendall *et al.* 2011). Self-management support has also been promoted in a primary care context (Kousoulis *et al.* 2014).

The basis of this study was existing literature on self-management support, as presented in existing reviews. Self-management support refers to the help from both professional and non-professional sources in the community that help patients monitor and address their condition, establish a favourable lifestyle, adjust medication and access community services (Blakeman *et al.* 2010). This definition focuses on self-management as a broad, encompassing and contextual practice in which various sources in the individuals' context are heeded. Various assumptions underpinning the understanding of self-management and practise of self-management support among policy makers, professionals and users have been identified (Kendall *et al.* 2011). In a review aimed to identify the contemporary usage of the term self-management, Kendall *et al.* (2011) identified various definitions based on the discourses of self-management, which are respectively seen as a cost-cutting mechanism based on ideals of individualist-behavioural assumptions; a domain of

health professional experts leading to the notion of 'knowers' versus 'non-knowers'; and an emancipation related to the ideology of 'free choice' assuming that lifestyle is a question of choice. The implications of these conceptions are that self-management policy is practised as a standardised package based on the conception of educating (passive) consumers on how to manage and by being a 'good' citizen in choosing to take responsibility of their own health (Kendall *et al.* 2011). Furthermore, it is argued that the conceptualisation of self-management support has placed individual behaviour change at the centre (Ong *et al.* 2014). Accordingly, recent reviews of qualitative literature on patients' perspectives of self-management of diabetes tend to focus on concepts of compliance (Campbell *et al.* 2003), adherence (Vermeire *et al.* 2007) and self-control (Gask *et al.* 2011), conceptualising 'the self' within a discourse of personal accountability and blame and presenting self-management as a question of control and of 'bossing one's own mind'. It has been argued that this perspective obscures the context under which diabetes-related experiences unfold (Gomersall *et al.* 2011) that patients have to address and that are far from being 'freely chosen'. The authors suggest that 'a satisfactory account of diabetes care requires paying attention to the inner world while acknowledging the social and political conditions in which diabetes-related experiences unfold' (Gomersall *et al.* 2011, p. 855). This standpoint is supported by a recent study based on the experiences of patients' recovery, in which the authors raise doubts on current policy based on patients' accounts by relating to choice and control. Instead, the authors support a greater focus on health policy on quality of life and engagement with meaningful activity and foster positive social relationships (Brooks *et al.* 2014).

A further premise is that self-management support has the potential to improve the efficiency of health services by reducing other forms of utilisation. However, reviews have concluded that self-management support is associated with small and uncertain improvements in health outcomes (Elzen *et al.* 2007, Desroches *et al.* 2013, Kennedy *et al.* 2013, Panagioti *et al.* 2014). This relationship suggests the need to increase the understanding of what it means to face the comprehensive demands of self-managing a chronic condition such as type 2 diabetes. Investigating existing knowledge based on data capturing patients' own experiences through various theoretical understandings of self-management may be a method to meet this need.

This review is conducted as part of the EU-WISE research project funded by EU's 7th Framework Programme and was undertaken to investigate current

knowledge of patients' perspectives relevant to self-management support in Europe. Many of the studies included in previous reviews (Campbell *et al.* 2003, Gask *et al.* 2011, Gomersall *et al.* 2011) were conducted in the United States, Canada and Australia. Although the healthcare context and the manifestations of primary care organisation in European countries are different (Saltman *et al.* 2006), there are also similarities, as most European countries aim to strengthen primary care to combat chronic conditions in their agendas (Busse *et al.* 2010b). Self-management support for people with long-term conditions is described as relatively underdeveloped in Europe (Elissen *et al.* 2013, Kousoulis *et al.* 2014). As this review is part of an EU-funded study that also aims at providing an overview on European progress in the field, we have chosen to focus on studies reporting European patients' perspectives of self-management. Due to limited resources, we only included studies published in the English language.

The aim was to synthesise findings from qualitative research articles with a specific focus on patients' perceptions of both formal and informal self-management support of type 2 diabetes in the community. The specific perspective adopted in the review is based on the understanding of self-management as a broad, encompassing and contextual practice consistent with the chosen definition of self-management (Blakeman *et al.* 2010). The experiences of patients, which are referred to the micro-level of individuals' experiences in qualitative literature, can feed into and promote understanding of the social processes at a meso- and macro-level of groups and organisations. The overall objective of this review was thus to provide insights based on a bottom-up approach that have the potential to develop innovations in policy/practice that are patient-led.

Method

The chosen method for this review is meta-ethnography. Meta-ethnography was described by Noblit and Hare (1988) and later developed by Campbell *et al.* as one of the several possible methods for synthesising qualitative research (Britten *et al.* 2002, Campbell *et al.* 2011). Campbell *et al.* (2003) argued that synthesis should go beyond the description and summarising associated with a narrative literature review towards advancing the field by reinterpretation based on published findings through a process of induction (Campbell *et al.* 2003, p. 672). As we were aiming to develop new understandings based on existing publications, this form of interpretive review synthesis was suitable as a possible way to advance the

description and gain new insights into patients' perspectives on self-management support.

The basic principles described by Campbell *et al.* (2011) were used to identify interpretations offered by the original researchers (second-order construct), followed by the development of new interpretations (third-order constructs) that go beyond those offered in the individual primary studies. Studies are described to relate to each other in three ways: directly comparable as reciprocal translations; stand in opposition to one another as refutational translations; or taken together to represent a line of argument (Britten *et al.* 2002). The line of argument synthesis essentially involves a process of interpretation and conceptual advancement into a third-order construct. This process is conducted by reordering, relinking and reanalysing, finally leading to a representation of the synthesised material.

Search strategy

Because qualitative research lacks indexing terms and standardised keywords, we followed the advice of Campbell *et al.* (2011, p.27), to use a "wide net – approach". Familiarity with the topic and experiences from a realist review already conducted within the EU-Wise project (Kousoulis *et al.* 2014) helped identify the search terms. We included subject headings and keyword searches, and various search terms were used to include both MeSH terms and other glossary databases. The main search terms used were patient perception, patient perspective, qualitative, interview, group interview, chronic disease, type 2 diabetes, self-care support, self-care management, chronic illness management, self-management, health behaviour and local communities. Additionally, we also searched the reference lists of relevant studies and reviews. The following databases were searched for literature references: MEDLINE, PubMed, CINAHL, EMBASE, PsycINFO and Web of Science. Inclusion of the most recent literature (January 2004–January 2014) ensured that the most recent changes in policy development will be reflected in the meta-synthesis.

Inclusion/exclusion criteria

To be included in this review, the literature had to meet the following criteria:

- Published articles providing patient perspectives of the self-management of type 2 diabetes (as the only respondent group or as one of the several clearly described groups)
- Published in English
- Presenting studies conducted in Europe

Papers were excluded if:

- Papers were not published in English
- Papers were published before 2005
- Papers that did not explicitly state inclusion of participants with type 2 diabetes (only described as having 'chronic illness')

We included studies that used individual interviews, group interviews, or observations and provided qualitative data. Papers that reported mixed-method studies were included if the qualitative data were presented separately.

Quality appraisal process

We based our criteria for excluding studies on those implied in the work of Campbell *et al.* (2011). First, Campbell *et al.* (2011) stated that the purpose of a qualitative synthesis is to achieve a greater level of insight into particular phenomena and to generate theory. They also suggested that the inclusion of poorer quality studies is unlikely to have a distorting impact on a qualitative synthesis and considered that the worth of studies is determined in the process of achieving a synthesis. Following Campbell *et al.* (2011), we used the following few key questions in the appraisal process.

We first chose to screen the abstracts using two questions: does the paper report findings from qualitative research, and is the research relevant to the synthesis topic? The studies were discarded if they did not fit these criteria. Studies that fit the inclusion criteria were retrieved. We then applied the criteria of a clear identification of: the aim and objectives of the research, description of the method and research process and whether the data analysis was sufficiently rigorous to support the interpretations. Accordingly, we used criteria of credibility, transparency and reflexivity as described by Campbell *et al.* (2011). Two papers were excluded because they did not provide an adequate description of the methods of sample selection or of the strategies employed for data analysis (Figure 1). Any uncertainty about eligibility after assessing the full text was assessed by the second author.

Data synthesis

We based our synthesis on the steps described by Noblit and Hare and elaborated by Campbell *et al.* (2011). Two researchers independently read the selected papers and focused on the findings and the discussion sections. Both researchers drew a visual map identifying main themes central to the overall aim of the review and also suggested the relationship

of themes. This process was done separately, and then, the researchers compared 'maps'. The maps were then discussed between the researchers and adjusted into one agreed map. As the focus of the analysis was based on an understanding of self-management as a contextual practice, we sought to identify accounts of self-management as part of the interactions within a family, in the community and where self-management support was related to the broader society. In this process, the studies were synthesised 'into each other' by looking for similarities and nuances in the various cases, which were inductively coded in a raw textual synthesis. This initial coding was repeatedly compared and discussed among the first two authors. Existing codes were refined and then developed into descriptive 'second-order' themes (Campbell *et al.* 2011). Second-order constructs were shared with other team members. They were shared first with the project leader (last author), who also participated in the development of the third-order construct, in which the core of the second-order construct was developed into the third-order construct as exemplified (Table 1). In this process, the third-order theme was further refined. In the final stage, the second- and third-order themes were shared between all members of the research team, which was a strategy to advance alternative perspectives and the development. This collaboration resulted in minor adjustments.

Findings

The 29 studies spanned 8 European countries, with an overrepresentation of studies from the UK (Table 2). There was a pattern of responses related to self-management support that reflects many common experiences across various countries and healthcare systems. The studies vary in the use of qualitative methods, diverse perspectives and populations (Table 2).

First-order accounts from people diagnosed with type 2 diabetes indicate that self-management extends compliance and control, and requires a mix of cognitive, practical and social skills. Contextual factors that are implicated are described as a set of processes deeply embedded in unique life situations and as complex, non-linear, cyclical and continuous processes of struggling to cope with the ever-changing conditions of life (Moser *et al.* 2008b, Hinder & Greenhalgh 2012, Booth *et al.* 2013).

We present the findings in six separate headings that reflect the identified second-order constructs. Although the constructs represent various areas and levels of self-management and self-management support, they are interrelated.

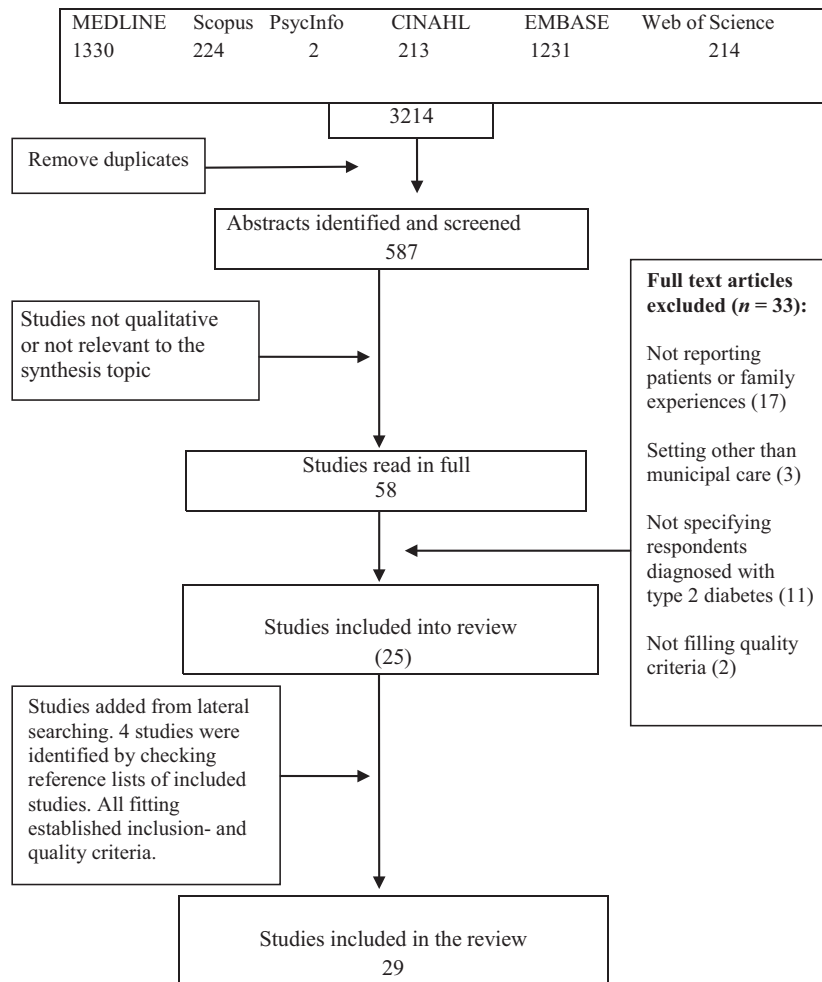


Figure 1 Flow chart for the international qualitative literature review. Articles retrieved between 2005 and 2014.

Sense of agency and identity

Social position in life belonging to various gender and cultural groups shapes self-management and vice versa. The literature adopts a specific gendered perspective and suggests that self-management has a gendered dimension. Peel *et al.* (2005) found that women draw upon discourses of responsibility and guilt in their accounts more than men, which is consistent with gendered notions of women's relationships with diet and their bodies. Gender differences also relate to other experiences of support. Female patients with type 2 diabetes describe a lack of support from children and partners who are unwilling to adopt a diabetic-friendly diet (Peel *et al.* 2005). Women also describe more active use of socially interactive resources and networks in their management (such as group-based patient education/support groups or friends), whereas men prefer more self-directed learning (books, Internet sites) and

tend to rely on more narrower networks (e.g. spouse or close family) for support (Hjelm & Berterö 2009).

The effect of a collectivistic versus an individualistic culture (Satterwhite *et al.* 2000) is evidenced in ethnically diverse perceptions of type 2 diabetes. Lawton *et al.* (2007) described 'white patients' as tending to blame themselves for developing diabetes, whereas patients from Pakistani and Indian backgrounds reportedly had more varied accounts to explain their diabetes, with a stronger focus on external stress factors in life. Based on identified differences, the authors suggest a lack of resonance between the individualistic paradigms contained within western diabetic education models aimed at promoting self-efficacy and the socio-centric concept of selfhood conveyed by South Asian respondents. Furthermore, the authors suggest that advice on lifestyle could be culturally adapted. Studies focusing on barriers in multi-ethnic communities conclude that there is a need for a more culturally sensitive approach that capitalises on

Table 1 Example of the process of identifying second- and third-order constructs

Concepts	Second-order interpretations	Third-order interpretations
<p>Patients often talked about different aspects of their <i>daily life</i> in a way that focused them not as individuals but as <i>part of a family and/or a community</i>. Exemplified; 'She' (the participant's wife) 'is my assistant. She cooks, she thinks with me, she takes care of the medication. I also do all these things, but she keeps me company in managing the whole diabetes thing, which is essential to me.' (Moser <i>et al.</i> 2008b)</p>	<p>The importance of networks as affecting self-management was agreed as a second-order construct</p>	<p><i>Being part of something</i> as constituting life (with the illness) established the foundation for connectivity as a third-order construct</p>

conditions of everyday life that are deemed important by patients (Lawton *et al.* 2005a, 2006a,b, 2008a, Berterö & Hjelm 2010). However, based on the accounts found in multiple papers, it appears that the need to adapt advice and strategies applies to sub-cultures of groups based on class and other dimensions. Self-management actions and choices are described by the respondents in the literature as strongly influenced by peoples' desire to act appropriately and maintain contact with their social group and local community (Lawton *et al.* 2008a,b, Jenkins *et al.* 2010, Hinder & Greenhalgh 2012). Furthermore, the focus on particular features of self-management in minorities has also been subjected to criticism, as it may promote cultural stereotypes (Lawton *et al.* 2009a).

Minimal disruption of everyday life

Family support is described as essential by patients precisely because it forms part of everyday life. A range of tangible as well as complex and subtle aspects of family life are described as influencing self-management in both positive and negative ways (Lawton *et al.* 2006b, Gunn *et al.* 2012). Patients describe their immediate and extended family as sources of emotional and practical support (Moser *et al.* 2008a,b, Gunn *et al.* 2012). Family support is designated as specifically valued with respect to practical support related to everyday challenges, which are described as being frequently ignored by health-care practitioners (Ofstedal *et al.* 2010b). Gunn *et al.* (2012) found that people describe their role within the family as important in more indirect and subtle health-promoting ways, indicating that it is not only the family support but also the connectedness to a network that influences self-management.

Variations in available social networks (social anchoring, contact frequency and social participation)

have been associated with demographic variables. Elderly people diagnosed with diabetes and living alone described feeling vulnerable due to a poorer family network (Gunn *et al.* 2012). Hjelm and Berterö (2009) indicated the lack of qualitative literature explicitly focusing on the experiences of persons belonging to deprived socioeconomic groups. Thus, little is known about whether lay definitions of social support are transferable to the nuances of social support that this group might prioritise, as also reflected in our search (Table 2). The few studies explicitly focusing on deprived persons or persons diagnosed with poor glycaemic control stress the need to explicitly focus on the individual's specific local context and environmental conditions (Zoffmann & Kirkevold 2005, Gomersall *et al.* 2012, Hinder & Greenhalgh 2012).

In a grounded theory study of persons with poor glycaemic control, some patients described the health-care providers as having a 'disease-oriented view' that conflicts with patient approaches based on a 'life-over-disease' priority (Zoffmann & Kirkevold 2005). The conflicting views result in patients feeling that their experiences are devalued, a feeling also described by respondents in other studies as resulting in discouraging of self-management efforts (Hinder & Greenhalgh 2012). Although Zoffmann and Kirkevold (2005) interpreted the conflict as a lack of connectivity between life and disease in health professionals, others have described a tension between 'official, authoritative voices' associated with optimal glycaemic control and 'unofficial voices' that 'speak at a more lived, embodied level' (Gomersall *et al.* 2011). Based on interviews with women with poorly controlled type 2 diabetes, Gomersall *et al.* (2012) found that patient accounts are split into (i) accounts of the speaker's personal relationship to her social circles and lived experiences and (ii) the rational 'correct' and disconnected self-management to avoid diabetic complications.

Table 2 Papers included in the review

Source papers (<i>N</i> = 29)	Country and setting	Methodology	Respondents	Focus
Lawton <i>et al.</i> (2005a)	UK, Scotland	Repeated in-depth interviews	40 persons (19 women 21 men) newly diagnosed with T2D	Patients' accounts of disease causation and management
Lawton <i>et al.</i> (2005b)				Patients' perception of disease and health services
Peel <i>et al.</i> (2005)				Patients' perspective on adopting and maintaining a healthy diet
Zoffmann and Kirkevold (2005)	Denmark	2 conversations 8 interviews	8 persons with poor glycaemic control diagnosed with T2D	Patients' perception of interaction between patient and healthcare provider
Lawton <i>et al.</i> (2005a)	UK, Scotland	In-depth interviews	23 Pakistani and 9 Indian patients with T2D	Patients' experiences of taking oral hypoglycaemic agents
Lawton <i>et al.</i> (2006b)				Patients' accounts of what prohibit/ facilitate physical activity
Lawton <i>et al.</i> (2006a)				Patients' experiences of health services
Lawton <i>et al.</i> (2007)				Patients' perception of disease causation
Lawton <i>et al.</i> (2008a)				Patients' perception of food and eating practices
Moser <i>et al.</i> (2008a)				Patients' experiences of identification with the disease
Moser <i>et al.</i> (2008b)	The Netherlands	In-depth interviews	15 older adults diagnosed with T2D	Patients' experience of self- management in a nurse-led programme
Lawton <i>et al.</i> (2008b)	UK, Scotland	Repeated in- depth interviews	20 persons diagnosed with T2D	Patients' accounts of disease causation and management
Lawton <i>et al.</i> (2009b)				Patients' experiences of the devolvement of diabetes care from secondary to primary healthcare setting
Ockleford <i>et al.</i> (2008)	UK	Semi-structured interviews	36 adults diagnosed with T2D	Patients' views of patient education
McDowell <i>et al.</i> (2009)	UK	Focus group interviews	8 groups with 35 people with T2D	Patients' experiences of the service redesign in diabetes care
Hjelm and Berterö (2009)	Sweden	Semi-structured interviews (as part of a mixed-method study)	49 Swedish adults (24 men and 16 women) diagnosed with T2D	Patients' experiences of the meaning and impact of self- management support
Berterö and Hjelm (2010)	Sweden	Semi-structured interviews (as part of a mixed-method study)	34 foreign-born persons (24 men and 10 women) diagnosed with T2D	Patients' experiences of the meaning and impact of self- management support
Edwall <i>et al.</i> (2010)	Sweden	In-depth interviews	20 patients diagnosed with T2D	Patients' experience of consultation with diabetes nurse specialist
Oftedal <i>et al.</i> (2010a)	Norway	Focus group interviews	3 focus groups with a total of 19 adults diagnosed with T2D	Patients' experience of self- management support to increase motivation
Oftedal <i>et al.</i> (2010b)	UK	In-depth interviews (part of trial)	41 persons diagnosed with T2D	Patients' perceived support from healthcare practitioners
Jenkins <i>et al.</i> (2010)				Patients' experiences of insulin therapy
Peytremann- Bridevaux <i>et al.</i> (2012)	Switzerland	Focus group interviews	4 groups with a total of 39 patients With diabetes type 1 and 2	Patients' experiences of diabetes care
Gomersall <i>et al.</i> (2012)	UK	Interviews	8 women with poorly controlled T2D	Patients' experiences of self- management

Table 2 (continued)

Source papers (<i>N</i> = 29)	Country and setting	Methodology	Respondents	Focus
Lucius-Hoene <i>et al.</i> (2012)	Germany	Interviews	26 patients with T2D and 30 patients with chronic pain	Patients' experience with the encounter with the GP
Gunn <i>et al.</i> (2012)	UK	Semi-structured interviews	45 patients diagnosed with type 1 or 2 diabetes	Patients' experience of the role of family members in self- management
Hinder and Greenhalgh (2012)	UK	Observation and interviews	30 patients with type 1 and type 2 diabetes	Self-management – why is it challenging?
Adolfsson <i>et al.</i> (2008)	Sweden	Interview	28 patients from seven primary care centres	Patients' experience of participating in group-based education
Booth <i>et al.</i> (2013)	UK	Focus group interviews	16 patients newly diagnosed with T2D	Patients' experience of self- management
Meyfroidt <i>et al.</i> (2013)	Belgium	Focus group interviews	21 patients with uncontrolled T2D	Patients' experience of seeking information

T2D, type 2 diabetes; GP, general practitioner.

Network affecting self-management

The experiences of support, based on patient accounts, produced a definition centred on the notion of a resource:

a feeling of confidence in the situation, through having opportunities to be in contact with persons with whom it is possible to discuss the situation and problems in self-care. (Hjelm & Berterö 2009, p. 29)

This resource stretches beyond the family (Peel *et al.* 2005) to include themes about diet, which do not reflect individual behaviour but are rather shaped by local (and broader) contexts.

Patients' perceptions of the quality of support vary contextually and from patient to patient within the same study (Ofstedal *et al.* 2010b, Peytremann-Bridevaux *et al.* 2012). Self-management support through patient education (predominantly provided by lay people) has been implemented in several European countries. Although some find group-based initiatives a site for 'participatory and shared learning' (Adolfsson *et al.* 2008), these measures have also been described by participants as having an individualistic approach, leaving the patients with the burden of full responsibility and a feeling that 'everything was up to me' (Ofstedal *et al.* 2010b). Peel *et al.* (2005) found that the challenge for people with diabetes is to envision various ways of positioning diet within the lived context of attempting to manage and control their disease. In their conclusion, Peel *et al.* (2005) stress the need to move past prescriptive advice to the individual towards focusing on the internal and external barriers of health-promoting self-management that patients face in their daily lives, in addition to assisting people to adequately address these barriers.

Economic hardship as part of negotiating life with diabetes

Economic and material resources at a micro-level within the family and economic conditions at a macro-level within the community are found to create a constraining (or enabling) context for self-management (Hinder & Greenhalgh 2012). Patients express concerns about the costs of multiple medical (pharmaceutical) prescriptions (Lawton *et al.* 2005a) and healthy food (Berterö & Hjelm 2010). In some studies, respondents describe the lack of reimbursement for foot care, glucose test stripes and medication expenses (Lawton *et al.* 2006b). Others discuss how the time of austerity has resulted in the cancellation of state financial support (e.g. for diet) (Peytremann-Bridevaux *et al.* 2012). Accounts of economic strain indicate that some patients live with continuous trade-offs between paying essential bills, buying high-quality food and paying for medicines. Based on the literature, it is possible to identify groups that are especially vulnerable. People who are immigrants or with low education or elderly people (Lawton *et al.* 2005b, Berterö & Hjelm 2010, Gomersall *et al.* 2012) often live in economically strained situations due to unemployment and dependency on social benefit allowances. The latter are infrequently raised in encounters with health professionals.

The ideology of responsibility

Discourses of individual responsibility impact the encounters between patients and healthcare professionals because the contemporary ideology of 'being responsible' creates a need to present 'a credible self' that does not disrupt the patients' sense of compe-

tence (Ofstedal *et al.* 2010a, Lucius-Hoene *et al.* 2012). Respondents strive to construct themselves as responsible and 'morally good', and this impetus is not exclusively the product of encounters with health professionals. At a macro-level, there is a general focus on individual choice and individual responsibility for health and healthy living that is reflected in the media, literature and health policy. Because patients make efforts to maintain a credible identity by 'keeping up appearances and emphasising a healthy status', self-management can be a difficult and contentious topic to address. Patient accounts further indicate that a lack of time in patient-professional encounters is a factor hindering good communication about self-management (Lawton *et al.* 2005b, c). Patients experience a lack of time during consultations and expressed feelings of uncertainty about whether social and emotional matters are appropriate to address with healthcare professionals.

Structural influences on self-management

The structure and organisations for the delivery of diabetes care and its impact on the experience of self-management support for persons with type 2 diabetes are considered important in the context of a comprehensive re-structuring of chronic care, particularly at the interface between primary and secondary care (Busse *et al.* 2010a). Regardless of whether the researcher explicitly focuses on patient experiences with direct reference to new structures in diabetes care (McDowell *et al.* 2009), or to specific programmes (Adolfsson *et al.* 2008, Peytremann-Bridevaux *et al.* 2012), the settings and locations in which people receive their diabetes care are considered important by the patients in several ways. Moving care for patients with type 2 diabetes from hospitals to primary care has been found to influence the actual perception of the illness. For example, the location away from an acute setting implies that patients may not believe that diabetes is a serious disease (Ockleford *et al.* 2008, Lawton *et al.* 2009b), with consequences for how seriously people take advice on lifestyle changes. Research focusing on patient experiences with primary healthcare after the re-structuring (particularly if diagnoses are established in primary healthcare) found that although people are found to express appreciation of their care management within the primary care setting (McDowell *et al.* 2009), others found that patients report a low frequency of contact with staff specialised in diabetes care (Lawton *et al.* 2005c, Hjelm & Berterö 2009). The lack of contact with specialists is seen as a problem by some who express a lack of

informative support and a lack of adequate competence and knowledge about diabetes among primary healthcare workers. Additionally, patients articulate that receiving good local care would reduce the financial and time burdens of going to the hospital and thus would be easier (Lawton *et al.* 2005b). Furthermore, although the revision of existing professional roles and the re-configuration into multidisciplinary clinical teamwork in primary care are advocated by European governments (Scheller-Kreisen *et al.* 2009), patient accounts of their encounters with primary healthcare professionals are characterised by a lack of communication and collaboration (Lawton *et al.* 2005c, Zoffmann & Kirkevold 2005, Peytremann-Bridevaux *et al.* 2012).

The enhanced focus on chronic disease management in primary healthcare involves a redistribution of tasks. More chronic disease management is performed by nurses working alongside general practitioners (GPs). Research has indicated that patients report that nurses have more time for them than the GP and possess the necessary competence and expertise to function as consultants in addition to the GP (Lawton *et al.* 2005b, Peytremann-Bridevaux *et al.* 2012). Some patients express less confidence in their GP's in-depth knowledge of diabetes care compared with hospital specialists; others express the same concern with respect to nurses (Lawton *et al.* 2006b).

In a Belgian study, patients described the GP as an important source of information (Meyfroidt *et al.* 2013), and others found that nurse specialists in diabetic care play an important role in supporting patients' self-management (Moser *et al.* 2008b, Edwall *et al.* 2010). Still, the literature describes issues in the co-operation between GPs and specialist nurses and also a lack of diabetic nurse specialists in primary care. Collaboration between private sector organisations is described as being easier than that between the private and public sectors with professionals expressing a desire for a better alignment of health initiatives between organisations (South *et al.* 2010). Furthermore, co-operation between sectors might be hampered by structural factors, including variations in funding mechanisms, shifting priorities and accountabilities (McDonald *et al.* 2011). In addition to a focus on self-management, professionals and patients consider a biopsychosocial approach essential, but several studies have found that patients describe this approach as lacking in practice (Ockleford *et al.* 2008). Although patients ask for new ways to ensure better communication, more information, better co-ordinated care and lower financial strains, professionals tend to ask for the reinforcement of existing structures and more time (Peytremann-Bridevaux *et al.* 2012).

Line of argument synthesis

The 'line of arguments' emerging from the descriptions of first- and second-order constructs indicate the importance of seeing people as strongly connected to their family and friends, their local community and to the wider society. Patients exhibit efforts to maintain a 'normal everyday life' with minimal disruption, and perceptions of self-management from accounts were 'filtered' through societal- or community-level or sub-cultural norms and values related to type 2 diabetes. Although the social and economic preconditions were more complex, forceful norms provided discourses of a 'good' lifestyle, an 'acceptable' self-management and the characteristics of a 'good' spouse, mother, etc. The synthesis revealed that self-management practices are a product of many interrelated factors operating on various levels that exist not as a part of the lives of patients but as actually founding or constituting their lives, and these are presented as second-order constructs;

- The *sense of agency and identity* in self-management is constructed through and with affiliations to culture and gender, indicating that environmental factors are connected to everyday lives and individual behaviours.
- Peoples' reflections on self-management are connected to everyday life through accounts of habits, traditions and preferences. Respondents describe their self-management as being guided by the drive to obtain *minimal disruption to their everyday life*.
- In all the included studies, even those adapting a distinct individualistic perspective, in seeking individual accounts of what hinders or promotes adherence, peoples' accounts are accounts of themselves within a network, and they describe how this *network not only affects but also constitutes their self-management*.
- *Economic hardship* is connected to self-management by constituting a central part of the conditions of life and is the basis of constant negotiations of priorities relevant in self-management.
- A feature of patient accounts is how contemporary societal reactions to lifestyle-related conditions are integrated into peoples' stories. Accounts of respondents' encounters with health professionals refer to the *problem of assigning patients responsibility* for their own health, resulting in feelings of guilt and shame.
- *Structural influences of primary care* are vital and are described as relevant and connected to factors such as quality, focus and the accessibility of care.

Common features in these second-order constructs are how micro, meso and macro factors are interwoven

and form the conditions in the daily lives, as described by the respondents. The interconnectivity forms life itself and thus the conditions for self-management. Through the reading and analysis, the concept of *connectivity* thus emerged as an overall and inclusive concept related to everyday life (Figure 2). Third-order concepts described the interconnectedness between the patients and their network through micro- to macro-levels of systems of self-management and self-management support of type 2 diabetes.

Discussion

In our meta-synthesis, patient experiences and perspectives on self-management and self-management support were considered. The reviewed literature paints a picture of individuals struggling with social, emotional and economic challenges. People feel supported by healthcare at times, but sometimes the encounter with healthcare is experienced as yet another demand in their lives, with increased economic strains due to costly medicines and food and a feeling of falling short in 'doing the right thing'.

Our findings are quite distinct from the conclusions drawn from research based on more individualistic approaches (Campbell *et al.* 2003, Vermeire *et al.* 2007, Gask *et al.* 2011). The synthesised literature has provided novel insights. Although self-management has largely been conceptualised as an individual ability, patients' accounts indicate that self-management is dependent on support from personal networks and on support in the local community. It may be argued that the self-management focus within contemporary discourses of individuality misses the degree to which patients' narratives actually are accounts of 'living-in-tension and intervening-for-the-best' (Mol & Law 2004). By employing a line of argument approach in this review, connectivity emerged as a key concept. Possibilities to change lifestyle are found in everyday life circumstances, which are interwoven with circumstances at the micro-, meso- and macro-levels: close and remote networks, the local community and economic and ideological conditions in society. In short, people are connected through a web of various mutual relationships. Our findings support recent attention to social networks as 'systems of support' (Rogers *et al.* 2011), focusing on remote social network members as a source of important contributions to people's self-management (Vassilev *et al.* 2013).

Limitations of the study

Qualitative synthesis is described as a contentious enterprise. The synthesis of qualitative findings is

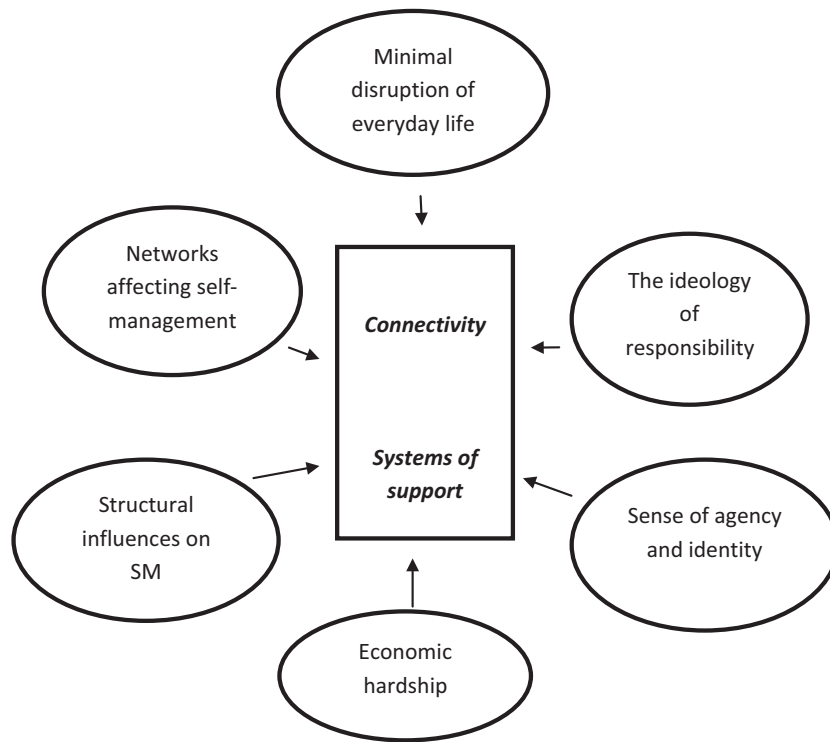


Figure 2 Line of argument synthesis: the connectivity of self-management.

constructed not only through the perceptions of the adapted position within each study but also through that of the reviewers' readings of the included studies. In the debate on validity in a meta-synthesis, some link credibility to faithfulness by handling data in a way that it remains true to its source (Thorne *et al.* 2004), whereas others emphasise the criterion of trustworthiness achieved through having other researchers independently verify the steps of the process (Walsh & Downe 2005). Although we strived to follow these recommendations, we acknowledge that the process of interpreting qualitative data is inherently subjective, and the process of interpreting interpretations of qualitative data is perhaps even more so. Although the first author used the input of colleagues to temper personal biases, personal values still colour the lens through which the findings are viewed. Accordingly, this meta-synthesis is one among several possible constructions of patient perceptions of self-management and self-management support. The implication of this realisation is that this study is one of the several contributions to inform the development of practices in the field. The inclusion criteria did not include the perceptions of health professionals or families, and their experiences might have added valuable perspectives. Furthermore, we only included European research and papers

published in English, which might have missed findings of importance. Although the choice of databases was recommended by librarians, there may be papers that were not included in the chosen databases.

Implications for research

The synthesis strongly indicates that peoples' lives and responses to the challenges of self-management are shaped by their resources and their social position, although we identified few studies explicitly seeking data to illuminate the experiences of patients belonging to deprived groups. Both patients and health professionals describe social, personal and economic resources as tightly interconnected and influencing patient self-management. Recent evidence suggests that low social class position and presumptions of being able to participate are also implicated in chronic conditions overall, although this has not been addressed with respect to type 2 diabetes (Protheroe *et al.* 2013). Even in studies that describe patient characteristics, economic factors/income and education are often not described. Most included studies focused on single individual entities in the patients (i.e. gender, ethnicity) but do not consider how these factors interrelate and affect the encounter with healthcare practitioners. There is a lack of research adopting a

biopsychosocial approach (van Dijk-de Vries *et al.* 2012), contextual approach (Furler *et al.* 2008) or partnership approach (Gately *et al.* 2007) to explore the way people cope with conflicting demands and economic hardship in their attempts to balance a chronic illness and living a normal life. The line of argument based on the literature indicates a need for further research targeted at investigating self-management support through a context-sensitive focus heeding the connectivity between self-management and enabling or constraining factors at various levels. The reviewed literature indicates that self-management support needs to be targeted at all levels and that the developments of such an approach need further research. At the macro-level, economic conditions, social norms and structures in society and in health-care systems will provide important frameworks that influence local communities and infrastructures at a meso-level, which in turn strongly affects the families' and individuals' preconditions for self-management.

Implications for clinical practice

The reviewed literature indicates that there is a need to heed the connectivity that permeates patient accounts and to move the focus from supporting patients in managing or controlling their own illness towards supporting self-management strategies by including links to activities in local communities. Research specifically on patient information measures has found that information often fails to provide legitimacy to the person's own self-management strategies and possible alternatives (Grime & Ong 2007, Protheroe *et al.* 2008), representing tension between the focus of patients and health professionals. The principle of drawing on everyday challenges of living with long-term conditions and tailoring self-management support to everyday life and local resources was found to be beneficial in a recent experimental study (Blickem *et al.* 2013).

Patients' description of struggling with the costs of food and medicines is an indication that healthcare to patients diagnosed with type 2 diabetes needs to consider these issues that might have been neglected. The literature illuminates the magnitude of economic strain experienced by patients living with chronic illnesses, which impacts not only the ability to afford essential treatment and medication but also the ability to maintain a healthy lifestyle and quality of life. This burden does not seem to be fully acknowledged by health professionals. People with type 2 diabetes (or other chronic conditions) live in particular social, economic and (sub) cultural environments. Management of diabetes occurs within various settings, and

the literature indicates that self-management support needs to consider an individual's connectedness to his or her context of daily living in the community.

Our synthesis of literature pursuing patient experiences found that health professionals are a source of support in self-management. The literature also identifies areas in need of further development, including the need to move towards a stronger emphasis on the role of social networks and everyday context in self-management support. Consistent with other research (Bower *et al.* 2009, Vassilev *et al.* 2014), this synthesis finds that social and material resources and locality context influence the capacity to support self-management. The role of primary care in the management of chronic conditions has been the focus of policy makers in the European Union, who advocate positioning primary care at the centre of healthcare systems in Europe (Maier *et al.* 2008). However, the progress of changing approaches in the field of promoting 'healthy lifestyles' is described as slow (Michie 2008). Although there are important differences with regard to the primary care orientation among European countries (van Lieshout *et al.* 2011), the primary healthcare sector in Europe is 'on the move' (Busse *et al.* 2010a). Health providers in primary healthcare have the potential to better interact with patients' everyday lives, in contrast to hospitals, which may provide a 'suspension of realities' (Balcou-Debussche & Debussche 2009). Patient experiences thus far do not indicate that this potential has yet been fully realised.

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