

Dynamics and nature of support in the personal networks of people with type 2 diabetes living in Europe: qualitative analysis of network properties

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Abstract

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Background Living with and self-managing a long-term condition implicates a diversity of networked relationships. This qualitative study examines the personal communities of support of people with type 2 diabetes.

Methods We conducted 170 biographical interviews in six European countries (Bulgaria, Greece, the Netherlands, Norway, Spain and UK) to explore social support and networks. Analysis was framed with reference to three predetermined social support mechanisms: the *negotiation* of support enabling engagement with healthy practices, *navigation* to sources of support and *collective efficacy*. Each interview was summarized to describe navigation and negotiation of participants' networks and the degree of collective efficacy.

Results Analysis highlighted the similarities and differences between countries and provided insights into capacities of networks to support self-management. The network support mechanisms were identified in all interviews, and losses and gains in networks impacted on diabetes management. There were contextual differences between countries, most notably the impact of financial austerity on network dynamics. Four types of network are suggested: generative, diverse and beneficial to individuals; proxy, network members undertook diabetes management work; avoidant, support not engaged with; and struggling, diabetes management a struggle or not prioritized.

Conclusions It is possible to differentiate types of network input to living with and managing diabetes. Recognizing the nature of active, generative aspects of networks support is likely to have

relevance for self-management support interventions either through encouraging continuing development and maintenance of these contacts or intervening to address struggling networks through introducing the means to connect people to additional sources of support.

Background and framing for the analysis

Within a contemporary culture and context of chronic disease management, how a person deals with a long-term condition is predominantly viewed as one emanating from the personal responsibility and activities of the individual.^{1,2} This ideal type notion may not correspond with the way in which people actually go about the business of coping and seeking out resources to manage their condition. The former view, evident in health policy, has led to the operationalization of a model of self-management support (SMS) which has been limited in its uptake, reach and effectiveness.^{3–6} The provision of SMS as part of mainstream chronic illness management is predominantly viewed in terms of a course, an internet programme or an information leaflet which is in line with patients as activated and responsible self-managers.^{7–12} Separating out the individual from their need for other people and ability to mobilize resources in order to manage effectively has meant that the notion of a personal community of support – the array of personal ties with which people are located and embedded – has not tended to be included in understanding or deploying SMS. The importance of bringing more of a focus onto illuminating networks of support is supported by recent evidence that social involvement with a wider variety of people and groups feeds into and enables the capacity for personal self-management and physical and mental well-being.¹³ The latter suggests that there is a complex process of suffusion (or blurring of roles) between the individual and those in people's personal communities.¹⁴

Here, we examine the contribution, relevance and expression of personal community network members through exploring the types of relationship and activities in differing contexts.

Diabetes type 2 is a prevalent long-term condition, which disproportionately affects older people and causes physiological changes which may impact on daily life.¹⁵ Living with and managing diabetes involves operating within a range and diversity of network relationships, and our view is that the quality and nature of the relationships matter.¹⁶ Our attempt was to unpack personal communities of support for type 2 diabetes (T2DM) self-management and show how the support was negotiated and enacted within actual relationships. This marks out a different approach to previous studies of networks, which have described network relationships in very broad terms for example as family, friend or physician centred or as diverse or restricted.^{17–20} Recent work has explored the role of agency in social network dynamics, describing changes to relationships and social interaction over time. Perry²¹ for example in the context of mental health refers to the notion of a social network strategy as a purposive action by which individuals can up- or downgrade existing ties of support over time. In this study, we are interested in the *content* rather than the form, the nature and qualities of relationships associated with T2DM management, and in examining the role of different kinds of personal ties directly. The biographical data suggest underlying moral and normative expectations about the different relationships in networks – for example what motivates people to interact with some and avoid others. Of interest is whether the extent and nature of a process of suffusion* is important in relation to chronic illness management.²²

*Patterns of suffusion are where people play overlapping roles with the individual – in acting as a source of support (or not) for example overlapping and/or separation out of roles – having similar or differentiated roles such as friends becoming more like a family member.

The concepts derived from a metasynthesis outlining the mechanisms linking social networks with chronic illness management which acted as a sensitizing framework for analysis.²³ Network mechanisms are considered as located within a social context that shapes practices, behaviours and the multiplicity of functions and roles that network members fulfil. For the purposes of this study, the three social support mechanisms of networks defined in the review are as follows: *Network navigation* involves identifying from pre-existing relationships who should be contacted to make decisions, identifying from whom to access previously unused resources and prioritizing access to some ties whilst abandoning others. *Negotiation within networks* involves reshaping relationships, roles, expectations and terms of engagement and communication between and by network members. *Collective efficacy* refers to developing a shared perception and capacity aimed at successful management through shared efforts and objectives.

This analysis is set in the context of a cross-European study (EU-WISE[†]) examining the role of social support and networks in self-management for people with T2DM. The aim of EU-WISE is to undertake research to inform and develop future initiatives relevant to peoples' everyday life across selective settings in Europe. The six European countries (Bulgaria, Greece, the Netherlands, Norway, Spain and UK) represent a range of cultures and structures and provide the capacity to compare across contexts the enactment of principles of SMS with reference to differences in health service provision, structure and culture. More detail can be found in related project publications.²⁴

Research objectives

Aim 1: To test whether the social network support mechanisms of navigation, negotiation and collective efficacy outlined in a metasynthesis²³ were apparent in this large multinational data set.

Aim 2: To explore and generate themes around the dynamics and nature of support for self-management within social networks.

Methods and analysis

Setting and recruitment

Biographical interviews²⁵ – a chronological narrative approach to eliciting personal explanatory accounts of events, people, places and situations – were undertaken by each partner research team to explore personal experiences of living with T2DM, the structure of personal networks and ability to access and mobilize resources (see Table 1 and Supporting information). Recruitment focussed on people living in deprived or marginalized circumstances. Each partner country managed recruitment in a variety of ways including via health-care professionals (for example specialists, GPs or diabetes nurses) and voluntary organizations or via snowballing sampling. Informed consent was obtained in accordance with each country's ethical guidelines. The interviews (undertaken and transcribed in the national language) took place in 2013 and were audio-recorded.

Analysis

The six partner countries were asked to provide case summaries in English for each of the 25–30 biographical interviews (see Table 2) which described how the participant navigated and negotiated their networks and to what degree there was collective efficacy (see Table 3 for examples). Quotes were then translated into English from up to five of the case studies in the data set which best exemplified these properties. Participants with no narrative related to navigation, negotiation or collective efficacy were noted. Each participant was given a unique ID indicating the country, gender and age; details of domestic arrangements and employment circumstances were included in the summary. Illustrative examples of two UK interviews provided an initial template for the work.

[†]EU-WISE is a research project funded by the EU's Seventh Framework Programme.

Table 1 Sampling and recruitment

| | |
|--|--|
| Purposeful sampling strategy | To reflect differences in networks, support, ways of managing and variations in peoples' backgrounds and contexts |
| Distinctions for sampling | 1. Deprived/affluent 2. Living alone/living with partner/other arrangements |
| Main criteria for definition of 'deprived' | People who have below average (median) income |
| Additional more country-specific criteria for definition of 'deprived' | 1. Low level of education 2. Renting rather than owning their homes 3. Not having health insurance 4. Other |
| Further diversifying criteria | Gender, presence or absence of one person living in physical proximity who provides support (up to a short bus ride), differences in residential areas (rural, urban and suburban districts in accordance with national characteristics), multimorbidity, well/poorly controlled diabetes, a range in stage of trajectory (newly diagnosed and those with long histories of diabetes), those with diabetes in their immediate networks and those without |
| Inclusion criteria | Reasonably fluent in the national language of the country. Where appropriate recruit a few representatives of ethnic minority groups |
| Recruitment | Recruitment to be managed in a variety of ways including using existing contacts with patients and/or via community health-care professionals (e.g. diabetes nurses or general practitioners), or by snowballing (using the contacts of study participants) |
| Interview structure: three sections | 1. Experience of diabetes and diabetes management 2. Responsibility, style of coping, orientation, resources, how politics of health impinge on management 3. Types of work and involvement of different network members (the personal network diagram) |

In the analysis, we forefronted the network role and relationships. From the start, there was a tension in the data between individuals and understanding the contribution of the network because the data came from biographical interviews which did forefront the individual. However, the latter have been treated as ego respondents of a broader network where the individual is the focal node.

The broad coding regarding network mechanisms was then subjected to further analysis. Firstly, the data from all partner countries were scrutinized to elucidate whether network support mechanisms were similar across the whole data set and to explore the differences. This was achieved at a data workshop which involved three of the partner countries (UK, Norway and Bulgaria). At this workshop, the data relating to navigating, negotiating and collective efficacy were then discussed in more depth to explore and generate themes around the dynamics and nature of support for self-management within social networks.

The quotes are identified in the results with country initials and identification number, gender and age.

Results

Network support mechanisms

Analysis found the network support mechanisms as outlined in the metasynthesis²³ were apparent to an extent in the biographical interviews across the partner countries; differences were contextual and related primarily to the country's economic situation.

Attrition – losses and gains?

In all data sets, gaps in a person's network caused by death, divorce, retirement, loss of work, partner's sickness or moving led to effort and struggle to renavigate and renegotiate the support or work performed by the missing element. Death or divorce often meant other family members stepped in and imposed more

Table 2 Characteristics of the sample ($n = 170$)

| | Bulgaria | Greece | The Netherlands | Norway | Spain | UK | Total |
|---|----------|--------|-----------------|--------|-------|----|-------|
| Age | | | | | | | |
| 0–59 | 3 | 7 | 5 | 15 | 10 | 4 | 44 |
| 60–74 | 22 | 17 | 13 | 9 | 14 | 16 | 91 |
| Over 75 | 5 | 6 | 7 | 1 | 6 | 10 | 35 |
| Multimorbidity | | | | | | | |
| Yes | 18 | 13 | 11 | 19 | 19 | 20 | 100 |
| No | 12 | 17 | 14 | 6 | 11 | 10 | 70 |
| Ethnicity | | | | | | | |
| Majority | 30 | 30 | 20 | 19 | 28 | 28 | 155 |
| Minority | 0 | 0 | 5 | 6 | 2 | 2 | 15 |
| Gender | | | | | | | |
| Male | 13 | 11 | 11 | 13 | 18 | 16 | 82 |
| Female | 17 | 19 | 14 | 12 | 12 | 14 | 88 |
| Civil status | | | | | | | |
| Married | 16 | 26 | 12 | 16 | 20 | 21 | 111 |
| Widowed | 9 | 3 | 7 | 0 | 5 | 5 | 29 |
| Divorced | 4 | 1 | 1 | 4 | 2 | 1 | 13 |
| Never married | 1 | | 2 | 5 | 3 | 3 | 14 |
| Socio-economic status country relative | | | | | | | |
| Low | 28 | 25 | 11 | 11 | 17 | 9 | 101 |
| Medium or high | 2 | 5 | 14 | 10 | 8 | 21 | 60 |
| Self-reported general health | | | | | | | |
| Very good | 3 | 0 | 2 | 4 | 12 | 0 | 21 |
| Good | 18 | 18 | 10 | 13 | 8 | 8 | 75 |
| Poor | 9 | 12 | 13 | 4 | 5 | 22 | 65 |

control over the individual. In contrast, individuals outlined purposive strategies to include or exclude certain network members who were perceived as being more or less helpful. Collective efficacy was most frequently obtained through a respondent's partner changing their lifestyle, especially in cooking and eating, to make life easier for the partner with diabetes. Certain reactions to T2DM were universal – individuals who went into hypercontrol using strict diet and medication regimes to master their diabetes, those who denied they had problems and those whose diabetes was subsumed by other medical conditions or problems. These reactions meant network support for diabetes was avoided or underutilized.

The differential impact of socio-economic context and relevance of austerity

In *Bulgaria* (BG), financial austerity often dictated network dynamics particularly in regard to paying for medicines and special diabetic

diet, where the family made sacrifices. Where this was performed by adult children, they were able to impose a certain amount of control over their parents in a reversal of roles. Those who did not have access to or avoided this type of support often sought alternatives to expensive medicines through seeking out advice on diet or supplements from other sources. There was some dissatisfaction with health-care professionals and negotiation with them to obtain cheaper medicines. However, in *Bulgaria* compared to elsewhere, health professionals' advice was taken more seriously and sought more frequently.

My family, they might eat potatoes or beans, but for me because this is what the diet states – chicken. (BG19, male 60)

Similar to *Bulgaria*, in *Greece* (G), financial austerity led to stronger dependence on family support, but unlike *Bulgaria*, most people are co-located within a domestic environment.

Table 3 Examples of case summaries of navigation, negotiation and collective efficacy

| ID and demographics | Summary of navigation, negotiation and collective efficacy |
|---|--|
| BG1, Female age 58, working part-time | This is a woman, who had been living and caring for her mother, and for her brother's children, because he had been a widower for long time. To do SM activities, she relies on a girlfriend who also has diabetes type 2 and who is stimulating and encourages her to solve everyday problems. They visit GPs and medical specialists together and take part in the activities organized by 'The club. . . [for disabled]', because 'one has the need to do culture' |
| GR8, Female age 75 Lives with her ill husband Former farmer | The participant was diagnosed with diabetes 2 years ago. She got examined whilst on a trip abroad when she felt ill. Her relatives acted immediately and transferred her to Athens for further examination. When her husband had a respiratory attack, her neighbours who are employed at the hospital ran to help and prompted him to go straight to hospital. It was there that they discovered that he too suffered from diabetes. Her daughter made an appointment at a specialized hospital for him to receive heart surgery which had already been damaged by the diabetes. They have developed common dietary habits and do agricultural chores so that they get exercise |
| NL26, Male, age 73, lives with partner and two children | This 73-year-old male has roots in Suriname but has lived for a long time in the Netherlands. He is well-educated and lives with his partner and two children. He does a lot of volunteering, for example coaching his son's football team, driving a taxi bus for elderly and is part of several commissions. Typical for his relationship with others is his open attitude about his disease. He involves everyone by explaining to them that he has diabetes and what they should do if something happens to him. This way of <i>negotiating</i> differs from many others who are not very open about their disease. When it comes to the management of his disease, he has full confidence in professionals, but <i>negotiates</i> between his GP and internist at the hospital in the way that he chooses treatment at the hospital. <i>Collective efficacy</i> can be found in his volunteering where he helps others, but also receive support and information. Also being part of a family (especially his spouse) provides him with support to manage his disease |
| N207, Female 45 years, married, on sick leave | N 207 had diabetes in a pregnancy in 1996. Her disease was not properly treated until 2000. Much diabetes in her family, her sister, mother and grandmother. She has <i>navigated</i> to try and manage her illness, but has had great challenges regulating her diabetes, and medication has little effect. She has changed her diet and lost weight, but still struggles with high blood glucose. She feels she has had bad follow-up in health care. She also has trouble with her back and with fibromyalgia. She has much pain and concerns about her condition. She claims she has injuries on her inner organs because of much use of pain killers. She is isolated and avoids social arrangements because of her diabetes and because she is tired and her condition varies from day-to-day. Before she got ill she used to be active. She has a dog she goes for walks with, and she tries to use a treadmill, but she is challenged by pain. She draws a picture of a challenging and hopeless situation. |
| SP4, Male age 64, lives with mother who is dependent | She has college education on ICT, but has been on sick leave for 4 years This newly kidney-transplanted patient reflects on the involvement of several members of his network achieving as a result <i>collective efficacy</i> , to the point that his diabetes has little impact on his life. He has performed some <i>navigation</i> work in terms of making judgements of who he might contact in case of emergency, but does not need to do much <i>negotiation</i> as the support that his family provides him with in terms of diet and help in contexts where he does not feel as autonomous, supplements these needs. For example, his brother is a blood donor, so he helps him with the needles. He also accompanies him to the consultation every time. And his sister cooks for him |

Table 3 Continued

| ID and demographics | Summary of navigation, negotiation and collective efficacy |
|--|---|
| UK12, Female age 75, lives alone, voluntary work | This very actively networked woman is an example of the work needed to plan and obtain <i>collective efficacy</i> from a network. She has worked hard during her life to navigate, negotiate and maintain a supportive network which allows her to be a 'good patient' and keep her diabetes under control. She lives in a retirement complex. The support is very reciprocal as she gives a great deal of support to others, for example neighbours and young people in a skills swap group. Her network provides activities which promote well-being, exercise and lifelong learning. She <i>navigates</i> this through a series of hubs which all give connections to other resources/activities: sports centre, library, the retirement complex (warden and place for groups to meet). She needs to <i>negotiate</i> her network, for example daughter-in-law who can give her 'slots' when she can provide help; being aware of the sensitivities of her sons (she tries to protect them from her serious health episodes); and neighbour who gives her cakes – has to teach her why she is starting to refuse these. She has negotiated support from her HCP by being a 'good patient' and her pharmacist is used to provide information on medicines |

For those without family networks, the health centres played a strong supporting role. Many participants had family members who had diabetes and they appeared fairly fatalistic about their condition. The cost of biomedical monitoring, for example blood glucose strips meant many, although encouraged, did not test their blood sugar on a regular basis.

In the *Netherlands* (NL), support was often 'outsourced' to professional carers as people had the facilities and funds to do this. There was opportunity for diverse networks and reciprocity relevant to network negotiations shaped by norms that help was not directly asked for and receiving help from others necessitated giving something in return. Giving support was generally apparent throughout the interviews, for example recent immigrants had to work to fill the gaps in network support due to missing families – this was often performed by volunteering to work in their local community.

I planned to call her this morning, because she called me last week for my birthday. That means this week it is my turn. (NL3, female 61)

Financial difficulties were not a problem for *Norwegians* (N), and there were strong social norms around diabetes being due to unhealthy lifestyles commensurate with health promotion messages, media interpretations of diabetes and

cultural of idioms of a healthy and active nation. For people who had difficulties maintaining sufficient physical activity to achieve weight loss, there were indications of support from close family networks, but tendencies to keep the diagnosis hidden in broader networks led to struggles to gain wider support because of assumptions about 'self-infliction'. Nonetheless, there was potential for engagement with network support as some were active in social organizations and Diabetes Association groups.

In *Spain* (SP), there were several struggling networks as family needs were prioritized over diabetes management. In some cases, the family did not provide support when it might have been expected, there may be a gender factor here – older women often did not get the support they expected from their family whereas men did (especially when widowed or divorced).

In the *UK*, there was more health system imposed care which led to devolving of responsibilities. Nurses at GP practices were charged with regular monitoring of biomedical indicators which left many with the view that everything was under control and no lifestyle change was needed. Financial struggles in the UK were at the level of negotiating social security benefits and being able to afford and access fresh

food. Many UK respondents told moral identity stories about other people they knew with poor diabetes management (reverse of Norwegians and their 'self-blame').

By taking these properties and nuanced differences into account, further insights into the capacity of networks to support self-management of diabetes were obtained, which applied to all countries. Four themes concerning networks were found: generative networks, proxy networks which imposed aspects of management on individuals (impositional or authoritarian), avoidant networks and struggling networks.

The nature of network support activated positive collective efficacy

Generative networks were generally diverse and operated to benefit an individual through support work being provided and sought from many actors in the network. We have taken a diverse network to be one where family, friends and organizations were named within an ego respondent's network.

Weak-tie connections

One of the key characteristics of such networks is that they are generative of active weak-tie connections. An example of this is UK12 who obtained collective efficacy from a diverse network which allowed her a normal independent lifestyle with diabetes. UK12 lived in a retirement village overseen by a warden but had a very active life within and outside the village with a vast circle of networked family, friends, voluntary colleagues and groups. She drew on her network to obtain more health-related resources, in particular by having organizations in her network; useful weak-tie connections for self-management support were generated.²⁶

I'm looking for more, all the time ... I'm getting ideas at the moment because when I go to the sports centre they've got loads of activities for older people like me and other illnesses, not just diabetes, they cover everything there. It's a fantastic place and there's a cafe you can get a meal, it's quite a social event so you know all these things (UK12, female 75)

Making use of collective efficacy

These types of networks generate healthy changes in behaviour in other network members. It was often the case that an ego respondent's partner (usually female) was key in making changes sustainable and was instrumental in building them into everyday life. An example of this is where the family engages in change to a more healthy diet:

When my wife sees me have something that's not good for me, she tells me 'you shouldn't, that's not good for you' ... The meals are the same for all at home. (SP9, male 44)

Other examples of generative networks included those where group exercise was a component.

We are trying to exercise together, all of us ... We aim to create a large group and include family and kids and socialize very often, so it becomes a big group and better habits. (N1, female 35)

Being able to be reciprocal was an important factor, and networks can allow skills to be shared to the benefit of others:

When I had to reduce weight, I went to a weight loss group at 'X' ... When they realized that I was a cook I was engaged to take part in cooking courses and things like that for overweight people with diabetes who have challenges with their intake ... (N305, male 47)

Proxy networks

Here, work related to the management of T2DM by others in the network on behalf of the individual (substitution/proxy work). When health-care professionals provide an external authority to participate, this runs opposite to the responsabilization agenda. Networks here were often family centred or focussed on health professionals.

Close bond connections

Close bonds were needed so as to have legitimacy for negotiation on behalf of someone and act as a continuation of the self (different

to weak ties). Families and close friends often acted for the individual to provide support, motivation, monitoring and reminding. This could be beneficial when the network comes together to make changes collectively, for example around diet. In some countries, most notably Bulgaria, children supported their parents financially.

My children have booked me a private doctor. I don't know how much it costs – they won't tell me. And if I haven't gone to the private clinic for a long time, they call me ... My family takes my illness into consideration, they even monitor me. When I go to visit them my children make efforts to cook diet food (BG11, female 81)

Diet changes were often dependent on a close 'super-helper' – often the wife of a male who has developed diabetes. The dependence on a super-helper or strong family support again meant that individuals had to do little for themselves. This type of network was often frail particularly when reliant on one key person with few other connections and resulted in or was a result of poorly controlled diabetes.

My daughter always comes with me, I go with her everywhere, she cooks for me avoiding salt. (SP10, male 70)

Non-familiar support

In the UK, the NHS undertakes diabetes management through regular 6-monthly reviews, monitoring and referral to other services. This led many to trust that their care was being actively managed and discussed, with little need to do anything for themselves, in effect they were, at a personal level, coasting along and non-participative with diabetes management. Other examples of proxy networks included where an individual was living in a sheltered home or care facility with routine monitoring by the organization and help readily at hand (most prevalent in the UK and the Netherlands). In Greece, due to the financial crisis, charitable organizations are providing more of such care to the homeless.

We need the homecare support. They apply a bandage, give injections or anything else and come when necessary. Lately I had cataract surgery and therefore I needed to use eye-drops. I couldn't ask my children because they had to work. And that's why I get homecare, they visit me three times a day to apply the eye-drops. (NL 2.2, female 89)

People did devolve control to their network. One example was a retired priest whose parishioners became a substitute family providing food, meals, transport, monitoring and interceding to get him medical help which he seemed to take for granted. The church provided a house and Care Line for emergencies.

Well neighbours and then the primary school insists that I go up every week for the day and have a school dinner, so they sent me school dinners every day, things like that. (UK16, male 81)

Avoidant networks

Help and support (or interference) from a network was avoided for a number of reasons. Many did not like joining groups or organizations. Some individuals felt they had no problems with diabetes and did not need to seek help or tell anyone else because they had everything under control and felt healthy, so any mention of diabetes became an unwanted annoyance.

Lack of discussion and denial

For some, diabetes was a cause of stigma; consequently, discussing their condition with others was difficult. For example, UK24 did not disclose her condition because having diabetes was a source of shame.

You know with diabetics especially with Africans to be frank Africans they don't like saying what they are suffering from, everybody's just hiding what is. A lot of my friends don't know I'm diabetic, and I've been with them for 10 years they don't know. (UK24, female 42)

Respondents also reported problems in discussing diabetes because family members or

work colleagues actively avoided any dialogue. This led to a lack of engagement with diabetes management and struggling to reconcile a normal social life with making healthy choices. Social events involving food were areas where maintaining normal social ties were often more important than attempting to force attention on dietary needs.

Need for hypercontrol

A need for hypercontrol of diabetes was also a characteristic of avoidance networks. Avoidance was often aimed at avoiding health-care professionals and 'progressing' to insulin. Hypercontrol was achieved through regular and in some cases obsessive blood sugar monitoring and a vigilant approach to diet. Individuals with such attributes often related stories of people they knew who had suffered severe consequences of diabetes (such as amputation, loss of sight or death). Hypercontrol constituted moral identity work individuals modelled what they did on the alleged 'poor control' of others.²⁷ In other cases, hypercontrol was seemingly associated with strong identification with personal responsibility.

Patient's wife She used to think it was Ok to have her cakes and stuff and then she could take this other tablet that would bring it back down again, and she's ended up on insulin, so that was a lesson wasn't it for us.

Patient That's why I make sure that it's alright, I don't want to go on insulin, not them needles anyway. (UK9, male age unknown)

Struggling networks

Struggling was a characteristic of networks where the 'ego' respondent did not know anyone else with diabetes, would not involve family, where the family refused to engage or where there were other life priorities.

Hidden nature of diabetes

Engaging with collective efficacy was problematic because diabetes is a hidden condition.

SP7 exemplifies how support was needed but difficult to negotiate:

No, my family doesn't help me. I am responsible for health issues at home ... I ask them to support me a bit more, taking the cakes out of my sight, but they're all tomboy-like and take little care of me. They don't see a disease in my diabetes, I'm telling you, they don't see it at all ... So in that sense I don't have anybody, anybody that tells me: 'hey, you're exceeding yourself, don't eat that'. (SP7, female 60)

Having restricted networks also led to struggling with health priorities because of limited and sometimes poorly understood examples of health behaviours. G4's mother also had diabetes, but she got annoyed rather than helped by her mother's breaches which made it difficult for her to diet. Furthermore, she believed that however much she dieted, diabetes would not go away; she had the living example of her aunt who

got to 45 kilos and she still has diabetes. (G4, female 49)

Prioritizing other problems

Financial worries and other health conditions often overwhelmed people meaning that diabetes management suffered. G6 had had heart surgery and was unable to work with only very limited support from his wife and son. Only intervention by the health practice prevented serious consequences.

They issued me a social security number because we didn't have enough (money) for medication, because I don't even receive pension ... (G6, male 59)

A complicated family life with many calls on an individual's time meant adding in activities such as exercise was felt impossible.

I have three children, a husband who works three shifts ... it's just too easy to say 'now, you have to start exercising; exercise every day!' So you commute 20-miles each day, and you have three kids, school, daycare, a man ... (N202, Female 42)

Loneliness was a common problem. Loss or change in circumstances concerning a key

network member led to networks struggling to be supportive and meant negotiations were needed to ensure support was provided.

In the last 2 years things have worsened, because my wife got ill; she was the one who took care of me – she cooked and pleased me with delicious meals, but now she can't anymore and I have to take care of her and of me (alone). Now, my son started helping me – he buys drugs and provides me with insulin (BG24, male 78)

Confused by unhelpful advice

In some cases, contact with health services was unhelpful and confusing because it was not relevant, hard to navigate and access and led to contradictory advice which was sometimes hard to fathom or factor in to everyday life. Advice which was perceived as nagging and judgemental was not helpful for people who were struggling.

Some are completely fanatical about it; 'You need to lose weight! You need to lose weight!'... Well I am struggling with diabetes type two, but ... I think in a way that one should beware not to attack a person. (N202, female 42)

Discussion

The findings presented here make a novel contribution to understanding how self-management support works by providing insight into the diverse way in which networks operate or are mobilized (or not) for those living with diabetes. We found that social networks play a key part in supporting people with diabetes and that network support can be enacted in various ways with differing implications for individuals. We found that certain networks generated support. It appears that in these networks, the person with diabetes or others in their network undertake significant navigation work to connect with a range of resources and actively negotiate to obtain the best type of support. Collective efficacy apparent amongst network members seemed to encourage or facilitate the undertaking of 'healthy' practices, and when there was any

opportunity to be reciprocal, then health and well-being activities were more likely to be engaged in. Other types of networks were more problematic. Proxy networks were identified, where network members undertook much of the work related to diabetes and individuals devolved responsibility to others including health service professionals. This was most obvious in the networks of frail older people who received social care from external agencies. In some cases, children had renegotiated their roles within the family to navigate their parents through the health system and to monitor diet and medication. Avoidant and struggling networks where support was not available from network members or engaged with resulted in no or underutilized collective efficacy and struggles to maintain control. Diabetes management was often subsumed by other priorities in life. Individuals who tried to achieve hypercontrol often cited others with poor diabetes management as negative role models they had to navigate away from.

By sensitizing the analysis to the mechanisms of network support, and unpacking how negotiations and navigation are enacted within networks, it has been possible to gain a greater understanding of the dynamics of networks and thus, why some elements of networks are helpful and improve people's capacity to cope and why some have more negative consequences. A value judgement that collective efficacy is a good thing holds true in some circumstances, but not in others. A theoretical premise is that where networks are generative, there is greater likelihood of better integration of diabetes management with daily life, improved health practices and thus better health outcomes. Conversely, where network support is avoided and navigation and negotiation are the struggles, diabetes management is not integrated into everyday life and individuals attempt to attain hypercontrol or just give up. A novel finding of this analysis is that networks can provide a proxy or substitution for control where there is inactivity of the ego. Networks may not always be helpful, and

negotiating appropriate support can require a great deal of effort and work by both the individual and members of their personal network.

This cross-national analysis has shown that the nature of network support for people with T2DM varies in some respects according to context but that the underlying characteristics are not tied to a particular national context. Contextual differences between countries were evident in how network support operated and was expressed. This was most evident in relation to financial constraints and austerity measures, the monitoring and motivations available within the health systems and the wider national messages around diabetes.

Limitations

Limitations are that the transcripts were not fully translated into one language – there were only sufficient resources to provide English translation of selected exemplar quotes. This may have led to a limited understanding of the richer context underlying the full individual narratives. Similarly to Brannen and Nilsen, we have considered the national level to be a context of the study rather than the unit of analysis.²⁸ The national differences helped to provide a depth and a thicker description to explain and understand the role and dynamics of networks in SMS. Another limitation is the tension between the biographical interview and the aim of exploring network properties; we attempted to overcome this by construing the interviewee as an ego respondent of the network. Ideally, a snowballing technique to obtain the views of others identified in the ego's network would have allowed a fuller understanding of the network dynamics, but time and resources did not allow this. However, snowballing has most often been used for quantitative analysis of networks.

There is other literature which attempts to explain how networks operate to provide support. The notion of suffusion,¹⁴ has been shown to be in accord with the findings presented here – family members take on specialized roles within networks which overlaps with

that of health professionals in providing monitoring and motivation for health behaviour. Other research has also shown that children take on the parenting role in providing care and financial support.²⁹ Weak ties were a noticeable and valued feature of generative networks which accords with other findings on the durability and moral acceptability of such resources.²⁶

Conclusions

These insights into the network properties associated with management of diabetes have implications for development of interventions and care and offer a new way of thinking about self-management support and how it can be sustained and built into personal networks; provision of self-management support should not be limited to the patient. People with active, generative networks can be identified and encouraged to continue developing and maintaining these contacts. Where there are frail proxy networks or evidence of struggling and avoiding contacts, then steps need to be taken to connect people with additional support and families can be helped to link relatives to more diverse resources. A proxy network can be an appropriate solution, but some of these networks are fragile, and support may need to be renegotiated when a key helper is lost from the network. Tools to help the identification of network typologies and address support needs are being developed.³⁰

Conflict of interests

No conflict of interests have been declared.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Guidelines for biographical interviews.

References

- 1 Cayton H. The flat-pack patient? Creating health together. *Patient Education and Counseling*, 2006; **62**: 288–290.
- 2 Rogers A, Bury M, Kennedy A. Rationality, rhetoric and religiosity in health care: the case of England's Expert Patients Programme. *International Journal of Health Services*, 2009; **39**: 725–747.
- 3 Kennedy A, Reeves D, Bower P, *et al.* The effectiveness and cost effectiveness of a national lay led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *Journal of Epidemiology and Community Health*, 2007; **61**: 254–261.
- 4 Vassilev I, Rogers A, Sanders C, *et al.* Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illness*, 2011; **7**: 60–86.
- 5 Chodosh J, Morton SC, Mojica W, *et al.* Meta-analysis: Chronic disease self-management programs for older adults. *Annals of Internal Medicine*, 2005; **143**: 427–438.
- 6 Sun X, Guyatt GH. Interventions to enhance self management support. *British Medical Journal*, 2013; **346**: f3949.
- 7 Franek J. Self-management support interventions for persons with chronic disease: an evidence-based analysis. *Ontario Health Technology Assessment Series*, 2013; **13**: 1–60.
- 8 Dennis SM, Zwar N, Griffiths R, *et al.* Chronic disease management in primary care: from evidence to policy. *Medical Journal of Australia*, 2008; **188**: S53–S56.
- 9 Rogers A. Advancing the expert patient. *Primary Health Care Research and Development*, 2009; **10**: 167–176.
- 10 Blickem C, Bower P, Protheroe J, *et al.* The role of information in supporting self-care in vascular conditions: a conceptual and empirical review. *Health & Social Care in the Community*, 2011; **19**: 449–459.
- 11 Deakin T, McShane C, Cade JE, Williams RDRR. Group based training for self-management strategies in people with type 2 diabetes mellitus. *Cochrane Database of Systematic Reviews*, 2005: art. no. CD003417.pub2.
- 12 Foster G, Taylor SJ, Eldridge SE, Ramsay J, Griffiths CJ. Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews*, 2007: CD005108.
- 13 Reeves D, Blickem C, Vassilev I, *et al.* The contribution of social networks to the health and self-management of patients with long-term conditions: a longitudinal study. *PLoS One*, 2014; **6**: e98340.
- 14 Pahl R, Spencer L. Personal communities: not simply families of fate or choice. *Current Sociology*, 2004; **52**: 199–221.
- 15 Gambert SR, Pinkstaff S. Emerging epidemic: diabetes in older adults: demography, economic impact, and pathophysiology. *Diabetes Spectrum*, 2006; **19**: 221–228.
- 16 Minet LK, Lonvig EM, Henriksen JE, Wagner L. The experience of living with diabetes following a self-management program based on motivational interviewing. *Qualitative Health Research*, 2011; **21**: 1115–1126.
- 17 Fiori KL, Antonucci TC, Cortina KS. Social network typologies and mental health among older adults. *The Journals of Gerontology Series B, Psychological Sciences and Social Sciences*, 2006; **61**: 25–32.
- 18 Litwin H. The network shifts of elderly immigrants: the case of Soviet Jews in Israel. *Journal of Cross-Cultural Gerontology*, 1997; **12**: 45–60.
- 19 Pescosolido BA. Beyond rational choice - the social dynamics of how people seek help. *American Journal of Sociology*, 1992; **97**: 1096–1138.
- 20 Stoller EP, Wisniewski AA. The structure of lay consultation networks: managing illness in community settings. *Journal of Aging and Health*, 2003; **15**: 482–507.
- 21 Perry BL. Coming untied? Narrative accounts of social network dynamics from first-time mental health clients. *Sociology of Health & Illness*, 2012; **34**: 1125–1139.
- 22 Harris PB. Dementia and friendship: the quality and nature of the relationships that remain. *International*

- Journal of Aging & Human Development*, 2013; **76**: 141–164.
- 23 Vassilev I, Rogers A, Kennedy A, Koetsenruijter J. The influence of social networks on self-management support: a metasynthesis. *BMC Public Health*, 2014; **14**: 719.
- 24 Kousoulis A, Patelarou E, Shea S, *et al.* Structure and governance of health and welfare systems relevant to diabetes self-management: a realist review to facilitate a European Project implemented in six countries. *BMC Health Services Research*, 2014; **14**: 453.
- 25 Roberts B. *Biographical Research*. Buckingham: Open University Press, 2002.
- 26 Rogers A, Brooks H, Vassilev I, Kennedy A, Blickem C, Reeves D. Why less may be more: a mixed methods study of the work and relatedness of ‘weak’ ties in supporting long term condition self-management. *Implementation Science*, 2014; **9**: 19.
- 27 Broom D, Whittaker A. Controlling diabetes, controlling diabetics: moral language in the management of diabetes type 2. *Social Science & Medicine*, 2004; **58**: 2371–2382.
- 28 Brannen J, Nilsen A. Comparative biographies in case-based cross-national research: methodological considerations. *Sociology*, 2011; **45**: 603–618.
- 29 Laroche HH, Davis MM, Forman J, *et al.* Children’s roles in parents’ diabetes self-management. *American Journal of Preventive Medicine*, 2009; **37**: S251–S261.
- 30 Blickem C, Kennedy A, Vassilev I, *et al.* Linking people with long-term health conditions to healthy community activities: development of Patient-Led Assessment for Network Support (PLANS). *Health Expectations*, 2013; **16**: E48–E59.