Research: Educational and Psychological Aspects

A novel exploration of the support needs of people initiating insulin pump therapy using a social network approach: a longitudinal mixed-methods study

C. Reidy[1] ⓘ, C. Foster[2] ⓘ and A. Rogers[1] ⓘ

[1]National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Wessex School of Health Sciences, Faculty of Environmental and Life Sciences, University of Southampton and [2]Macmillan Survivorship Research Group, School of Health Sciences, Faculty of Environmental and Life Sciences, University of Southampton, Southampton, UK

Abstract

Aims   To establish what practical and emotional means of support are required on initiation of insulin pump therapy and how needs change over time, using GENIE, a social network intervention.

Methods   The study's longitudinal design used semi-structured interviews, surveys (PAID, CLARKE) and HbA_{1c} values at time of pump initiation, and at 3 and 6 months. Interviews used GENIE to capture participants' expectations and experiences of pump therapy and associated support and resources. Thematic analysis was used with sequential, time-ordered matrices.

Results   A total of 16 adults undertook 47 interviews. A total of 94 services, resources and activities were acquired, while tally, frequency and value of network members increased over time. The novelty of pump therapy impacted on participants' self-management needs. Key themes included: 1) the independent nature of managing diabetes; 2) overcoming the challenges and illness burden associated with pump use; 3) the need for responsive and tailored emotional and practical support; and 4) useful resources when incorporating pump therapy. GENIE was thought to be novel and beneficial.

Conclusions   A social network approach determined what resources and support people with diabetes require when incorporating a new health technology. Visualisation of support networks using concentric circles enabled people to consider and mobilise support and engage in new activities as their needs changed. The novelty of pump therapy creates new illness-related work, but mobilisation of personally valued flexible, tailored support can improve the process of adaptation.

Introduction

There is a drive from policy makers to prioritising self-management support in long-term conditions [1] and increased momentum from NHS England and diabetes voluntary organisations to consider the emotional well-being of people with diabetes when promoting self-management support [2,3]. The need for self-management support is heightened when new health technologies, such as insulin pump therapy in type 1 diabetes, are introduced, requiring renewed knowledge, confidence and resources [4]. However, few diabetes support interventions explore or address improving self-management abilities or engagement with

health services together with social support networks, yet for people with long-term conditions, social networks can provide an important means of mobilising, mediating and accessing support for health and well-being [5].

The WHO now lists 'social support networks' as a determinant of health [6]. Network members located in the personal community of someone with a long-term condition are sources of emotional, practical and illness-related 'work' [7] and have been associated with improving self-management [8,9]. Personal communities of social support can range from members who are healthcare professionals, family, friends, community groups, objects (e.g. a bicycle), or even pets, which have been known to provide emotional support [10]. A personal community which represents a diverse range of relationships and network member type (including so called 'weak ties') [9] can be especially beneficial; for example, network members can be distributors of health literacy [11]. As such, interventions that seek to

What's new?

- The need for self-management support is heightened when a new technology is introduced, requiring new or renewed knowledge, confidence and resources and much fine-tuning over time.

- The intervention in the present study offered a positive disruption to self-management by prompting reconsideration of network members and how they impact on self-management as well as an avenue to connect to new activities and sources of support.

- Social support mapping demonstrated a rich range of network members, ranging from partners, to family members, peers, pets, community groups, friends and objects, (for example, bicycles, glucose monitors) of varying types, numbers, frequency and value.

- There was a return on investment for non-judgemental, accessible self-management support and education provided by specialist pump clinics.

enhance an individual's personal community of social support and access to wider resources and local support are likely to complement self-management strategies [12].

Kennedy *et al*. [8] implemented a web-based social support and networking tool named GENIE (Generating Engagement in Networks Involvement) in an isolated population of people with diabetes. The tool mapped and reflected personal network members and signposted local sources of support. This resulted in an increase in participants' capacity for and confidence in managing their diabetes. Bandura's social cognitive theory, which focuses on social influence and the dynamic and reciprocal interactions between the individual, the environment and behaviour, underpins this approach. Social cognitive theory considers the unique way individuals acquire and maintain behaviours while also taking into account interactions with the wider social environment [13]. The need for a responsive network when managing a long-term condition has been illustrated in the recent development of a scale to measure collective efficacy, CENS [14]. Measurement of collective efficacy can be a unique predictor of loneliness or an indicator of a network with the potential to provide responsive support and resources.

There is growing interest both in the role network members can play in self-management of diabetes through sustaining learned self-management practices in day-to-day life [15,16] and in the impact that diabetes-related technology has on close network members [17]. The World Diabetes Day theme for 2018/2019 is 'family and diabetes', which aims to promote the role of family members in self-management [18]. Wiebe *et al*. [19] evaluated the social context of managing diabetes, exploring how social relationships are a central element in diabetes management. They suggest use of interventions that

focus on the relational work (e.g. the complex communication and negotiation) involved in social relationships, and engagement of networks to enable access to resources as and when needed. Even when focused on healthcare professionals, social networks have been thought to improve the rate of recovery after strokes [20], where being part of a network of extended clinical expertise allows a widening of boundaries and both contribution and access to new knowledge. In terms of implementation, Kennedy *et al*. [8] found that GENIE both enhanced support for people to self-manage and was acceptable and implementable in a UK setting when delivered through lay health workers in the community. However, while there is more interest and evidence for the role of personal communities in the self-management of diabetes, there is a lack of research exploring the range and value of network members involved in self-management of type 1 diabetes, or of network members and resources of value when integrating a new health technology.
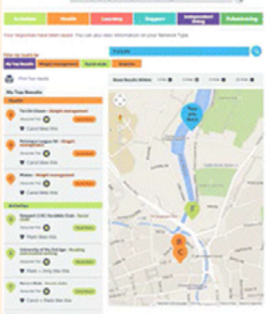
In the present study, we explored, through GENIE, the support and resource needs of people with type 1 diabetes incorporating pump therapy over the initial 6-month period. We considered the ways in which participants valued this support and resource and how these needs shifted over time, and whether the intervention was deemed acceptable.

Methods

Design

The mixed-methods design consisted of longitudinal interviews combined with questionnaires, HbA_{1c} values and GENIE intervention outcomes (mapping of network members onto concentric circles and activity uptake; Table 1). After providing informed written consent, participants took part in a semi-structured interview shortly after pump initiation (baseline), at 3 months (T2) and at 6 months (T3). This involved working through GENIE (with an adapted database populated with type 1 diabetes- and insulin pump-specific resources, local activities and services; Table 1), followed by reflective questions about GENIE. The semi-structured interviews provided a dynamic method which enabled the exploration of participants' experiences, needs, values and perspectives. The interviews initially explored the individuals and groups that contribute to the participant's personal network, how these network members contribute to self-management (at each time point), and further elaboration of the meaning and contribution of relationships within this network. The interviews also explored the nature of the context and content of the illness work that network members undertake in terms of supporting integration of pump therapy as well as their interest in social activities. The preferred activities that arose from GENIE were discussed, as well as the ways and means in which the participant may access these new activities. All

Table 1 GENIE elements

Elements	Details	Theory of how it works
Filter questions	The process starts with questions to provide details of the user's context. This includes postcode, gender, age and health condition.	• Providing filter questions allows tailoring of suggestions and helps to reduce choice at the preference stage.
Concentric circles: Stage 1	Social network members (family, friends, groups, professionals) are represented and mapped, depending on subjective importance, onto three concentric circles. Details of relationship and frequency of contact are recorded. • Support work can be: illness-related (taking medications and measurements, understanding symptoms, making appointments); everyday (housekeeping, child rearing, support for diet and exercise, shopping, personal care); or emotional (comforting when worried or anxious, well-being, companionship).	• To explore everyday relationships and how network members contribute to support. • To note change over time. • To provide a visual image to enable engagement. • To help people become conscious and reflexive of contributions made by others to self-management support • As starting point for a discussion about how to extend existing support, access support from new sources, or change existing practice.
Typologies: Stage 1	Feedback and a summary is provided on network types: Diverse - family, friends, and community groups with *regular frequent contact*; Friend and/or family centred – mainly friends and/or family members with *regular contact and support*; Friend and/or family contact – some mostly friends and/or family members with *limited or patchy support*; Isolated or professional contacts only	• To help people become conscious and reflexive of network structure and availability of self-management support • Act as a prompt for healthcare professionals and others to take action where there are obviously fragile networks
Preferences: Stages 2,3,4	The user co-produces and owns the network map. Choices are tailored using a series of questions and based on preference and enjoyment rather than on health-based need. For example, the facilitator prompts by asking: 'Are there things you used to do that you don't do anymore? What stopped you from continuing to do these things?' This gives clues about how to identify the most relevant type of support, the likely barriers they may encounter, and how to encourage them to restart these activities. Network members are selected as potential buddies to accompany them to new activities. Asked to select the three activities or resources they are most interested in and agree to try them out. The locations of the activities are displayed on a Google-based map.	• Non-intrusive methods are more effective than highly directive approaches which often fail because they do not deal with existing relationships to negotiate time and space for new activities (intimidating to attempt by oneself) or needing help with transport. • The user is made a capable and willing to reciprocate participant. • To reduce choice and complexities arising from information overload counterproductive for learning, social engagement and social support particularly where there is poor health literacy.
Links to VCOs: Stages 2,3,4	The preference questions link to community resources in a pre-created database (populated with type 1 diabetes and insulin-pump-specific resources, local activities and services). Categories in the database include: activities and hobbies, health, learning, support, independent living and volunteering	• Diverse networks which include VCOs enhance health and well-being through providing access to new acquaintances for advice, support and links to resources are often missing where there is reliance on strong family ties. • Support from VCOs is non-clinical. • Specific benefits for people who are isolated.

VCO, Voluntary and Community Organisation. Information taken and adapted from Kennedy *et al*. 2016 [8].

interviews were digitally recorded and transcribed verbatim for analysis. The quantitative outcomes captured an overview of changes while incorporating the device, while the qualitative responses provided more depth about the nuances of these relationships and lived experiences.

Ethics

Ethical approval for this study was granted by the National Research Ethics Service (Reference 17/NS/0089).

Setting

The study took place between January 2018 and September 2018 in insulin pump clinics at three NHS trusts in the south of England. A total of 43 interviews were conducted face-to-face and four by telephone.

Population sample

Purposive sampling was used by each clinic to search their clinic database for potential participants who met the inclusion criteria, i.e. individuals who had been diagnosed with type 1 diabetes for >6 months, were aged >16 years and were due to initiate insulin pump therapy. A recruitment pack, including the study participant information sheet (which outlined the study and the topics that would be covered in the interview), and invitation letter were sent in the post or given by a clinician during a clinic visit. Participants were purposefully sampled to ensure a range of ages, marital status, sex and employment status in order to reflect differing perspectives.

Data analysis

The widely used, reliable scales [21,22] routinely collected in the selected clinics were self-administered. The Problem Areas In Diabetes (PAID) scale was developed to measure emotional distress in people with diabetes and has 20 items which use a five-point Likert scale (range 0 to 100), where higher scores reflect greater emotional distress. The CLARKE survey is an eight-item measure of hypoglycaemia awareness. A score of ≥ 4 suggests lack of hypoglycaemia awareness. The PAID, CLARKE and HbA_{1c} results were collected by the clinic at baseline and T3. The differences in HbA_{1c} values and PAID scores between baseline and T3 were compared using Wilcoxon signed-rank tests.

Participants completed concentric circles of network members and preference questions for activities on the GENIE database at baseline, T2 and T3. Changes in the number of network members, frequency of contact (days per year) and value of contact (on a scale of 1 to 3, with 3 being most valuable) of each network member were collated and compared over 6 months. Uptake in activities, and the type of activities were also recorded. Statistical data were analysed using IBM SPSS software, v.25.

Longitudinal qualitative interview data were subject to trajectory analysis, which focuses on changes over time using sequential, time-ordered matrices [23], combined with thematic analysis. Thematic analysis was guided by Braun and Clarke's well-established five-step framework [24]. The first step required familiarisation with the data through multiple readings, while, as the second step, an initial list of ideas about what was in the data was generated and initial codes were collated from the data. The third step was where themes began to emerge, when we refocused and refined the analysis of the initial ideas and codes at the broader level of themes. The themes were explored and reviewed for refinement in the fourth step, which included comparing and contrasting the similarities and difference between themes, interviews and contexts. Step five was where the themes were finally defined and named.

Results

We conducted 47 interviews with 16 participants. Purposeful sampling worked relatively well in this instance, with opportune natural variety amongst pump starters, and with a high response and participation rate from those approached in clinic (80%). One participant (P8), however, was lost to follow-up at T3. Participants had a mean age of 38 years and a mean duration of diabetes of 27 years, and 11 (69%) were female (Table 2 and Table S1 present individual characteristics). A Wilcoxon signed-rank test

Table 2 Baseline sociodemographic characteristics of participants

Insulin pump users	
Mean (SD; range) age, years	37.63 (15.62; 21–65)
Sex: female	68.75 (11)
Ethnicity: white British	87.50 (14)
Income (average UK = £26,500)	
Lower than average	56.25 (9)
Average	25 (4)
Higher than average	18.75 (3)
Marital status	
Never married or formed a civil partnership	43.75 (7)
Married or in a civil partnership	43.75 (7)
Divorced	12.50 (2)
Work situation	
In paid full time work (full- or part-time)	56.25 (9)
Retired from paid work	25 (4)
In full-time education or training	12.50 (2)
Long-term sick/disabled	6.25 (1)
Education level: degree level or above	43.75 (7)
Mean (SD, range) time since diagnosis, years	27.06 (12.81; 11–45)
Diabetes-related complications[*]	50 (8)
Hospitalisation for hypoglycaemia or diabetic ketoacidosis?	56.25 (9)

Eye damage, background retinopathy/treated retinopathy/neuropathy/cardiovascular disease/other complications.
Data presented as % (*n*), unless otherwise stated.

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indicated that the average HbA$_{1c}$ of participants was lower at 6 months than at baseline (average rank of 8.5 vs average rank of 1.5) and that the observed difference between both measurements was significant (P=0.001). The Wilcoxon signed-rank test also indicated that PAID scores were lower at 6 months than baseline (average rank of 9.1 vs average rank of 4.0) and that the observed difference was significant (P=0.001; Table 3). There was no statistically significant improvement of hypoglycaemia awareness; however, hypoglycaemia awareness improved from 75% of participants to 81% as a result of one participant regaining hypoglycaemia awareness.

GENIE concentric circles

The number, frequency of contact and value of network members increased over time from baseline to T3 (Table 4). The majority of network members at each time point were family members (41%), followed by friends (15%) and healthcare professionals (15%). Unsurprisingly, healthcare professionals had a relatively low frequency of contact compared with their (high) value (Table 4). The most commonly cited healthcare professionals were pump therapy clinicians (Fig. S1) and, while there was a significant decline in frequency of contact (which included face-to-face contact, emails, texts and phone calls) over 6 months (P=0.006), the value of these clinicians did not change significantly (P=0.361; Fig. 1).

Some participants experienced a decline in partner contact and value over time where two participants broke up from long-term relationships (Fig. 2); however, contact with family members remained relatively stable. Most described more contact with mothers than fathers, and while partners were the network member most frequently communicated

with, mothers were valued nearly equally (Fig. 2). In addition, while children were often seen more frequently than a sibling(s), a particular sibling was especially valued. These relationships were discussed in more detail in the qualitative interviews.

GENIE preference elicitation

The preference elicitation encouraged engagement and uptake of a range of activities and resources, whereby a total of 94 new activities were undertaken (a mean of 5.88 per participant; Table 5). Participants had a particular interest in online support, resources or social media (with 50 reported activities undertaken). Participants were also keen to undertake exercise and a total of 24 exercise-related activities were reported. These interests were explored in more detail in the qualitative interviews.

Semi-structured interviews

The matrix table (Table 6) demonstrates the progression of needs over time. This process captured substantial life changes and disruption during this period. Four key themes were identified. Table S2 presents some of the quotations which elaborate on the themes identified: (1) the independent nature of managing diabetes; (2) overcoming the challenges and illness burden of the pump; (3) the need for responsive and tailored emotional and practical support; and (4) useful resources when incorporating pump therapy.

Independent nature of managing diabetes

Many participants articulated how they have to manage diabetes for and by themselves. Baseline discussions featured

Table 3 Participant clinical outcomes

| Participant	HbA$_{1c}$ baseline, mmol/mol (%)	HbA$_{1c}$ T3, mmol/mol (%)	HbA$_{1c}$ change	PAID score baseline	PAID score T3	PAID score change
1	59 (7.5)	46 (6.4)	−13 (−1.1)	1	5	+4
2	72 (8.7)	70 (8.6)	−2 (−0.1)	17	6	−11
3	68 (8.4)	60 (7.6)	−8 (−0.8)	11	5	−6
4	68 (8.4)	65 (8.1)	−3 (−0.3)	50	35	−15
5	51 (6.8)	53 (7.0)	+2 (+0.2)	30	10	−20
6	67 (8.3)	60 (7.6)	−7 (-0.7)	6	4	−2
7	98 (11.1)	75 (9.0)	−23 (−2.1)	38	5	−33
8	85 (9.9)	81 (9.6)	−4 (−0.3)	59	16	−43
9	60 (7.6)	53 (7.0)	−7 (−0.6)	22	8	−14
10	80 (9.5)			46	51	+5
11	64 (8.0)	60 (7.6)	−4 (−0.4)	11	13	+2
12	62 (7.8)	57 (7.4)	−5 (0.4)	9	6	−3
13	86 (10.0)	74 (8.9)	−12 (−1.1)	14	13	−1
14	56 (7.3)	49 (6.6)	−7 (−0.7)	69	33	−36
15	68 (8.4)	60 (7.6)	−8 (−0.8)	10	8	−2
16	68 (8.4)	63 (7.9)	−5 (−0.5)	30	16	−14
Average/Total	68.74 (8.4) ±13	61.73 (7.8) ±10	−7.01* (−0.6)	26.75 ±20	14.30 ±14	−12.45†

*P <0.001.
†P<0.005.

Table 4 Changes in numbers, frequency of contact and value of network members

|	Count of network members			Frequency of contact (collective days per year)			Value of contact		
	Baseline	T2	T3	Baseline	T2	T3	Baseline	T2	T3
Healthcare professional	24	23	19	520	380	52	52	52	43
Family members	64	57	64	12021	12177	12049	155	163	153
Friends	24	26	27	2020	1763	2164	44	47	55
Pets	6	9	8	1877	3285	2607	12	20	18
Fitness activities	12	16	19	624	1025	1534	24	37	46
Groups	6	12	14	497	1082	825	10	23	23
Health technology	5	10	10	1150	2984	2984	13	26	26
Social media	3	4	4	469	521	521	6	7	7
Colleagues	6	6	8	1524	1524	1901	11	11	13
Object	3	3	4	742	734	1099	7	7	10
Education	3	2	3	20	8	373	3	2	4
Other	2	3	3	369	373	20	4	7	5
Total	158	171	183	21833	25856	26129	341	402	403
Mean (SD) per participant	10.20 ±3.29		12.20 ±3.75*	1354.73 ±790.99		1747 ±933.29[†]	22.13 ±1.83		26.73 ±9.92[‡]

*$P= 0.017$.
[†]$P= 0.018$.
[‡]$P= 0.033$.
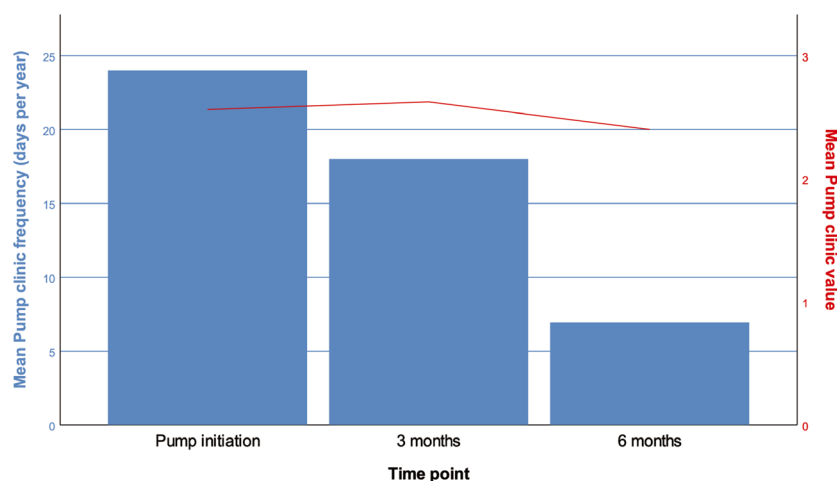
FIGURE 1 The frequency of engagement with the pump clinic over time vs value of the pump clinic.

this topic quite heavily compared to T2 and T3, probably because this was the start of conversations about what support and resources were required or desired for self-management. Participants expressed the centrality of independence and responsibility in their self-management, such as the constant personal calculations of carbohydrates, exertion, current and future bolus requirements, hormones, stress levels and potential dawn phenomenon effects on blood glucose levels. However, there were many discussions about how this effort was frequently undermined by the sheer lack of understanding of the lived experience, or

passing of judgement on self-management from others (family members, friends, colleagues, strangers or clinicians). There was a narrative of unwillingness to ask others for help, as if admitting defeat, or a perceived lack of capability of others to help (often from experience).

Most participants described either trying to be 'positive' and 'not think/talk too much about bad things', or not thinking too much about potential complications. Considering who provides support to self-manage, and how, did seem like a novel task and evidently not something that had been considered before by most.

Time point
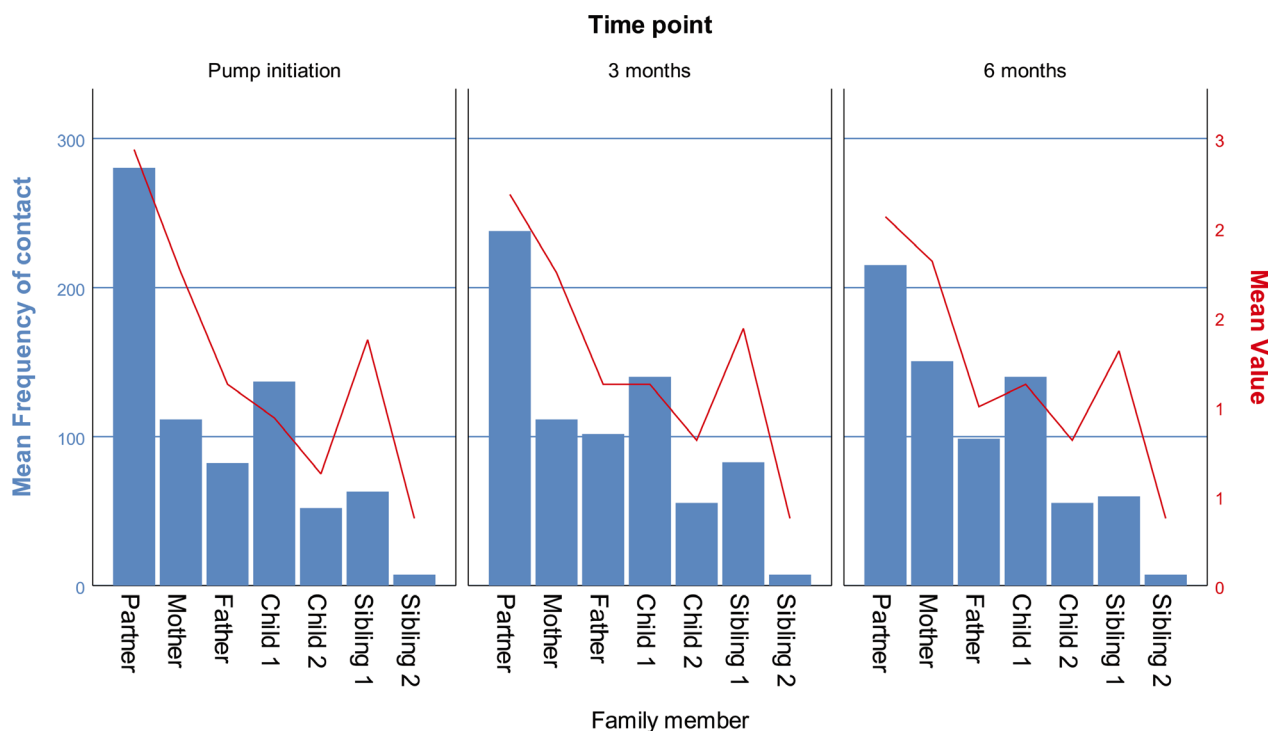
FIGURE 2 Frequency and value of contact with key family members over time.

Overcoming the challenges and illness-related burden of the pump

Most participants spoke of barriers they faced acquiring a pump, yet persevering and continuing to assert their wishes. Numerous participants described wanting better control over their glucose levels and believing that a pump may unlock opportunities for this to be realised. Some participants expressed less confidence acquiring a pump and were encouraged or inspired by partners or family members, or friends who already had the device. Where participants did not assert themselves, close network members supported them to persevere.

The pump was described as relatively easy to use and logical, but requiring new practices to learn and much trial and error initially. At baseline, a third of participants observed and expected that the pump would take time to accommodate and would require experimentation. There were some expressions of fear of consequences for getting it wrong. Other expectations included discomfort of having something attached '24/7', but also optimism about a new tool to help self-management. There was discussion around the associated extra consumables needed, especially from female participants. The physicality of the pump created discussions about how participants were beginning to deal with the size, noise and accessories required and the new-found or increased illness-related work required to place it on their body; however, some baseline discussions involved feelings of invigoration in relation to diabetes, such as a positive disruption to self-management of this enduring condition.

Pump therapy initiation was described by all at T2 as a learning process of challenges and overcoming these, such as where to put the device. T2 also brought challenges to original expectations, including surprise at sleeping being 'okay'. There were incidents of inconvenient alarms, batteries failing suddenly, the remote being slow, clunky or even failing, forgetting to change cannulas regularly, and the increased workload involved in changing equipment regularly. Most participants described feelings of even more invigoration towards their diabetes self-management practices, such as dealing with diabetes all over again but with more tools and revitalised interest. Participants expressed appreciation of access to more advanced features than injections (multi-wave, extended bolus, reduced/increased basal). The device even led the way to an appealing new 'robot' identity.

At T3 nearly all participants were still fine-tuning, but described how trial and error increased their knowledge and confidence and helped them come to terms with not having a perfect solution. Family members or partner suggestions were valued here. 'Tightening up' or mastering long-acting insulin requirements, and 'honing in' on more specific problems (exercise, particular foods, varying working patterns) were also discussed. Life events (e.g. moving home) had an impact for some with regard to being able to incorporate pump therapy as they would have liked and grasp all the new technological options offered. Any matters encountered were resolved through speaking to their clinic, manufacturer helpline or via peer-support. All participants said they were really pleased with the pump, even though it required extra work.

Table 5 Participant uptake of activities

Types of engagement		Total
Online or telephone support/social media	Diabetes information websites	10
	Peer-support group (online)	8
	Pump accessories website or blog	8
	Video blogs/instructions	6
	Blogs	5
	Online health forum	2
	Twitter	3
	Googling carb content	1
	Total	50
Health	Walking	7
	Yoga/Pilates	5
	Ice skating/Snowboarding	2
	Team sports	2
	Running	2
	Swimming	2
	Cycling	2
	General exercise/gym classes	2
	Total	24
Activities/groups	Volunteering	3
	Sewing / Baking	2
	History group	1
	Book club	1
	Men in Sheds	1
	Total	8
Other	Carbs and Cals app	4
	Fitbit	2
	Flash Glucose Monitor	2
	Total	8
Learning	Recipes	3
	Diabetes book	1
	Total	4
Total		**94**

Need for responsive and tailored emotional and practical support

Network members that influenced self-management and the ability to incorporate pump therapy included family members, pets, friends, colleagues, employers, groups and healthcare professionals. Life experiences sometimes disrupted support networks and consequent diabetes care.

For participants who had long-term partners, the latter were cited as the closest sources of support within a personal community. They were often described as being central to emotional and practical support, but there were also some conflicting reports of criticism and lack of understanding about diabetes in general. Some partners attended pump initiation and clinic appointments, providing another ear to remember the complex information, and would seek out further support on behalf of their loved ones. This was especially helpful with the extra work required by the pump (more blood glucose checking, more information to retain, more appointments). They also provided or supplemented support where the participant had to provide support to others, e.g. children and older parents. As time went on, partners were especially valuable when participants were sick or needed extra support. Over time some participants reflected that their partners had been on this journey of adaptation too. Single participants relied more heavily on close friends and close family members, and expressed concerns over their safety concerning hypoglycaemia, especially at night.

Mothers were often described as calming, encouraging and supportive, although sometimes anxious or judgemental. Sometimes mothers were considered more helpful than partners for emotional support and diabetes management. In some cases the roles had reversed where parents now knew much less about diabetes-related experiences or regimen, and so could provide less technical and practical support than before. Fathers were generally deemed 'less helpful' than mothers, usually due to providing less communication and emotional support and less interaction with diabetes management growing up, but not by all. Sometimes fathers were described as a calming presence and sometimes offering humour.

If participants had any family members who had diabetes as well, it was apparent that they provided support or understanding that only others with diabetes could offer. Other important network members included children, nieces/nephews, grandparents and siblings. Some participants turned to their close siblings or children for emotional support. For one participant who was single and retired, her children were her main source of support. Family members often provided consistent and reliable support. Over half of participants had pets and most described their pets at baseline as highly valued network members. Some added their pet in later after reflecting on what/who was in their personal support network.

Friends were valued for taking part in activities and for offering non-judgemental or emotional support. There was no expressed expectations for friends to understand diabetes intricately, but some participants did talk about valued friends treating them 'like normal', rather than those who 'do not understand diabetes'. Support or flexibility in the work place or whilst in education was valued, e.g. when undertaking night-shifts, or during hypoglycaemia. Colleagues being interested, and looking out for those starting pump therapy or supporting them if needed during hypoglycaemia were appreciated. Work colleagues could be in a position to be helpful 'weak ties'. However, there were also reports of managers or colleagues being unhelpful, rude or obstructive.

There were extensive and in-depth discussions about support from clinicians, especially at pump clinics. At initiation of pump therapy clinicians were considered important, but there was a perceived need to create trust and reliable support. Group education sessions were appreciated by most participants, but with a request for one-to-one sessions to address more intimate issues. At baseline the clinic held the key to understanding discrete and important features of the pump. New pump users relied on the expertise and chosen delivery of that integral expertise. This did not appear to be in conflict with independent self-

Table 6 Time ordered matrix of themes

Themes	Time 1	Time 2	Time 3
The independent nature of managing diabetes	Establishing independence and feelings of self-efficacy and responsibility heavily featured at baseline discussions	Occasional mention of independence.	Some mention of independence but more comfortable discussing and reflecting on the support others provide or impact others have on self-management.
Overcoming the challenges and illness-burden of the pump	Excited, dubious, wondering how they will place it on their body and other practical concerns.	Describe "new lease of life". More lived experiences and cyborg identify. More advanced features being used. Describe taking on difficulties. Easier to tell people than multiple daily injections. Pumps = new illness work. Some problems. Huge array of in-depth descriptions of experiential pump experiences.	More routine. More reflective about how pump has helped them. More descriptive of how and why went on pump. Solutions of consolations to pump issues. Discuss what is resolved and what is still left to be resolved. Some say that the pump has helped them tobe more interested in type 1 diabetes self-management.
The need for responsive and tailored emotional and practical support	Partners most referred to followed by mothers who were seen less but provided highly valued support.	Changes in support. Tested relationships. Shifts (in circles) where has had the opportunity to reflect.	Remember additional people/weak ties who help. Most important support discussed. Comments from colleagues/family members that they are more relaxed now. Changes consolidated (less shifts in circles).
	Initial impressions of pump clinic. Describe past negative experiences. Most GPs not deemed helpful.	Experiences of calling clinic. Tried and tested support. Negative experiences with GP described – especially re: prescriptions. Very happy with pump clinic.	Happy with pump clinic even those there are less engagements necessary with clinic-happy to "know they are there".
Useful resources when incorporating pump therapy	Peers: Not much experience of this as yet for most but distinct support described by others.	Peer-support: Discussed much more and in-depth. Some bad experiences. Otherwise peer-support added to circles.	Peer-support: Used a lot for tips.
	Resources: Not many resources at this point except YouTube for some. Describe interests or barriers to activities.	Resources: Trying out different support – especially emergency and practical support (accessories and resources – manual/online information). Described what helped and tried and tested approaches (YouTube, peer-support). Described increase in activities.	Resources: Still discussing struggles with positioning on the body. Like downloaded results. New activities taken up. New technology (e.g. Libre) and interest in future technology.

management but was complementary when non-judgemental, supportive, consistent and accessible. This created positive engagements and collaborative relationships, enabling participants to integrate pump therapy into their lives gradually, and in ways that were not fully captured by most former clinicians. Most participants did not consider their general practitioner as a self-management network member, yet 100% cited their pump clinic. However, a couple of participants spoke of important relationships with their general practitioner or practice nurse, who had created highly valued sustainable and trusting relationships and responsive emotional support.

At T2, many participants discussed issues with regard to acquiring essential pump prescription items. The clinic became especially important when participants experienced general healthcare professionals not understanding type 1 diabetes. Participants also expressed appreciation of the clinic staff having honest and potentially difficult conversations with them. The current clinic was described as 'more

friendly', with former clinics disparaging and 'less supportive'. Most participants spoke about speaking to the clinic for practical tips since pump initiation and the value of these opportunities.

At T3 participants shared experiences of reaching out for help. If participants had not contacted the clinic they usually had a list of items to discuss and troubleshoot at follow-up appointments. Clinics were now opportunities for troubleshooting rather than the participants 'having to go' or 'being judged' when there. They were utilised well and the resources available in clinic were appreciated.

Useful resources when incorporating pump therapy
Many participants wanted more information about developments in diabetes technology or self-management tips. Information and support were sought and desired from a variety of sources, including the pump manual, manufacturer helpline, social media and apps. Social media use included social networking sites (namely Facebook, Twitter,

Instagram), blogs, video-blogs (YouTube), and diabetes websites. Social media was prominent in baseline discussions and continued throughout, and it became apparent that social media provided convenient access to information and peer support. Peers were deemed useful for practical and emotional support by many (both online and offline) and were integral to their support networks because of the uniqueness of knowledge (about diabetes) held by peers. Most participants mentioned being a 'lurker' rather than an active participator, but appreciated reading others' comments, especially when they did not know others with type 1 diabetes. Video blogs helped relieve anxiety by visualising complex new pump tasks. A few participants conveyed how being on pump therapy felt more like being part of a community, where peers seemed more accessible. However, not all peer communication on social media was deemed useful, with potential exposure to negative self-management practices or unwarranted advice.

The pump manual assisted with troubleshooting at T2 for many participants, and access to this comprehensive information reduced the need for additional contact with the clinic. The helpline featured heavily in follow-up interviews. Participants expressed reassurance in knowing there was an emergency point of contact, and as time moved on, with half of participants having contacted the helpline, they were further reassured to know it was also reliable and useful.

At T2 and T3, new activities had commenced and participants spoke of activities they had undertaken as a result of GENIE. Participants mentioned engaging with various health, exercise or carbohydrate-counting apps. Exercise in general was deemed important, with walking and yoga or pilates particularly of interest, although undertaking personally chosen activities in general was referred to as supporting both physical and mental health and reducing insulin requirements through keeping active. An example of this was one participant who joined 'Men in Sheds', which provided the opportunity to get back into recreational work as an electrician, work he had been forced to stop professionally because of heart problems. He felt this not only improved his mental health but his physical health too. However, barriers to undertaking activities for participants, either old or new, included anxiety about meeting new people, groups not catering to diabetes-specific needs (for weight loss or exercise) or feeling unable to do an activity previously enjoyed, although this was also a drive to take up interests again.

Reflections on the social network intervention

GENIE prompted conversations about various elements of living with type 1 diabetes and a pump, personal interests and what support was present or absent. All participants identified personalised activities through GENIE. GENIE also enabled participants to reflect on and express what they desired to help them manage, and why.

Concentric circles

All participants enjoyed engaging with the concentric circles activity, appreciating having a novel visual image of their support and the reflective nature of the task. Most participants reported the usefulness of a visual reflection of their support network, which led to re-evaluation of current network members and reconsideration of support received, and identification of further sources of support. The reflective space within GENIE enabled novel reflection and illumination of the mechanisms in which network members do or do not support or engage in self-management tasks when integrating a complex new technology. Identified mechanisms included: modelling of behaviour (e.g. peer-learning, sharing of practical tips); persuasion (e.g. network members encouraging pump therapy or self-management techniques); providing information, support, or even criticism and social pressure; and engagement with more diverse activities and connections.

Preference elicitation

Participants' mostly described how GENIE offered specific and tailored preferences and an element of safety in searching for online or local groups and activities; however, some participants said that they did not want to be directed to resources and did not feel the need to be encouraged to do any activities, preferring instead to take up activities on their own. Conversely, some of these participants did express specific reasons for not taking up activities, such as lacking a companion to attend activities or lack of confidence attending groups alone.

Modifications were also suggested, including making GENIE available as an App, more explanations about particular activity options and network interactions, adding clarity to what the preference entails rather than being over-generic, and offering more language options.

Delivering GENIE

Some participants suggested accessing GENIE within the clinic setting, offering the opportunity to reflect on their diabetes self-management and preferred activities in a focused clinic rather than during busy day-to-day life. Other suggestions included access via local diabetes groups for convenience, or having a drop-in space during clinic.

Discussion

At the centre of a diagnosis of type 1 diabetes is the individual living with diabetes. Participants were keen to establish their own levels of responsibility and capabilities in managing their diabetes, but there was also evidence of engaging with the network of people, objects and resources around them to support self-management during adaptation to a new health technology. This study offered the opportunity to explore the network and resources around people in

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the process of incorporating a pump, from the point of initiation to 6 months later. This exploration used a social network tool, GENIE, to offer personalised, tailored opportunities and signposting to additional support and resources. Using concentric circles within GENIE, the present study cohort demonstrated a rich range of network members of varying types, numbers, frequency and value.

Participants expressed an initial liminality when introduced to pump therapy, which required an increased need for practical and emotional support and reassurance. As time went on, participants' confidence grew to trial new methods to integrate, relate to and wear the pump. Qualitative results highlight the complexity and nuances of social relationships. Partners and mothers were frequently highlighted as sources of integral support. This occurred even when these network members also created sources of anxiety or judgement. Pump therapy was also a source of new anxiety for network members, but, as time went on, this anxiety decreased. Participants who had been diagnosed in childhood discovered a new imbalance of expertise and experience in the management of diabetes between parent and (now adult) child. Where parents could no longer provide technical or practical support or knowledge they provided vital and valued emotional support.

It was not expected that all healthcare professionals (e.g. general practitioners, pharmacists) would know a lot about type 1 diabetes, but language did matter; participants expected to be spoken to with some respect regarding their capabilities. This could be the difference between clinicians being a viable option to turn to for support or any form of collaborative relationship and not. While frequency of contact with clinicians decreased over 6 months, other sources of support, resource and activities were gained. There appears to be a return on investment for the non-judgemental, accessible self-management support and education given by pump clinics. Specialist clinic support at the outset provided reassurance and skills, which enabled participants to self-manage more confidently. However, these clinics do not seem to represent the majority of diabetes clinics where there are concerns around the effectiveness and appropriateness of communication methods and approaches in the delivery of diabetes healthcare [3]. It has been noted that interactions with healthcare professionals can elicit distress when they do not acknowledge limitations to managing type 1 diabetes and (unintentionally) disempower patients to self-manage through unrealistic expectations [25]. Recent research also shows that clinicians do not feel confident, or familiar in approaching or delivering psychosocial support to meet the needs of people with diabetes [26]. These clinics represent a model of good practice for the delivery of structured education and healthcare. Accessing support on their own terms was important for participants and any contact with clinicians was carefully selected, preferring to manage on their own where possible. Participants' demonstrated determination and capability to self-

manage, but were keen to collaborate with engaged clinicians to address concerns.

Users expressed a desire to access GENIE conveniently and in an accessible setting (such as a drop-in service in clinic or in local groups). Kennedy et al. [8] found that those in lay roles provided the best fit for facilitation of GENIE, and so implementation may benefit from using peers as volunteer facilitators (or 'peer support workers'). Peer facilitation offers a combination of informational, instrumental and emotional support, whilst bridging the gap where healthcare professionals are not equipped to approach or deal with day-to-day self-management tasks and requirements [27]. With training and support, peers can potentially, and economically, bridge this gap using established communication and behavioural strategies (e.g. preference elicitation, goal setting) [27]. For example, Small et al. [28] found that telephone self-management support interventions that were delivered by lay and peer support workers significantly improved HbA_{1c} level and self-management behaviours.

This study captures this unique process of changing needs over time and an avenue to respond to these changing needs. Providing an opening to help people with diabetes navigate their social network and means to personalise support and resources as and when they needed through GENIE appears to have allowed identification of new ways to support self-management and more smoothly incorporate a new health technology. In addition, facilitation of personally tailored activities was not only acceptable to participants, it also provided opportunity and social restructuring to open up new opportunities. The use of a social network intervention offered a positive disruption to self-management through novel considerations of network members and how they impact on self-management. In addition, the pump offered positive disruption through offering something new with which to approach self-management. Suddenly there was a reason or a potential to try new techniques (e.g. variable night-time background insulin to manage the dawn phenomenon). However, there are distinct technicalities to consider with the pump that created increased illness work and burden for new pump users. People with type 1 diabetes are 'super-users', experts in their own diabetes, and so in reality it is then a case of tapping into tailored support when it is deemed necessary.

An increase in social network size should not be viewed as an end in itself, but the means to support people to achieve other recovery goals. It is worth noting that, while the tool does not intervene directly with maladaptive networks or network members, it does incite change within the individual through engagement with the facilitator and renegotiation of existing network members, and also through an increase in network and variety where there is a potential for further sources of support outside of the relationships in existence before engaging with the tool. In addition, while peer support and social media featured strongly in this tool, these are not desired by all, and there are concerns over how and

when social media are used by people to self-manage [29]. It is also worth pointing out that, while purposive sampling sought a diverse range of participants, women did represent the vast majority of participants in this study (69% vs 31%). However, while the male voice is not as well explored here, there is a national (UK) disparity between men and women in uptake of pumps more generally (61% vs 39%) [30]. In addition, although reductions in HbA_{1c} levels were achieved as well as some improved awareness of hypoglycaemia, we cannot know whether this was a direct result of engaging with this social network intervention, or whether this would have occurred regardless. Nevertheless, this study provides rich descriptions of the complex and conflicting process that occurs when integrating a new health technology to manage a long-term condition and as a potential means to support navigation of self-management support.

In conclusion, using a social network intervention, GENIE, provided the opportunity to explore the specific needs of people with type 1 diabetes who are using a new health technology. However, access to such an intervention must also be a choice and not a 'one-size fits all' model. Whether participants were confident or actively seeking more support, there was value in offering them the unique opportunity to reflect on the current status of their support network and to consider what options they may wish to employ in future. In this instance, social networks offered varying and rich opportunities for support which amalgamated over time and in response to life events and changes in circumstances. It would be valuable to widen the scope of this tool to target other people with diabetes, especially those experiencing any form of isolation, new health practices (diagnoses, new health technology) or going through any form of transition. While this tool was deemed acceptable and enlightening, more work needs to be done to consider implementation and whether the improvements experienced by participants in this study can be demonstrated on a larger scale.

Competing interests

None declared.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Table S1 Participant baseline characteristics.
Table S2 Quotations from semi-structured interviews.
Figure S1 Count of healthcare professionals by type.