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# Supporting Chronic Disease by Text-messaging: Perceptions and Reactions to 'Sweet Talk'

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#### Abstract

#### **Objectives**

To explore the attitudes and experiences of young people with Type 1 diabetes who received 'Sweet Talk', a novel behavioural support intervention delivered by an automated, text-messaging system, which schedules messages according to individual patient profiles and diabetes self-management goals.

#### Design

Qualitative study of participants' experience of 'Sweet Talk' using semistructured interviews.

#### **Subjects**

61 young people aged 8-18 years with Type 1 diabetes, recruited from the Tayside paediatric diabetes clinics, who had received the 'Sweet Talk' text-messaging intervention for one year.

#### Results

82% of the participants felt that 'Sweet Talk' had helped their diabetes self-management, and 90% wanted to continue receiving messages at the end of the study. In accordance with the theoretical framework of the intervention, participants' responses indicated that 'Sweet Talk' provided patients with valued tangible, informational, companionship and esteem social support, which young people felt had a positive impact on their diabetes self-management. Key perceived strengths were informational and companionship support while repeated messaged were cited as a key

limitation. Interviews also provided suggestions for the future development of the system.

#### Conclusion

Automated scheduling of personalised text-messages offers an acceptable, valued and effective means of delivering a novel form of 'push' support to adolescents with diabetes. This innovative method of delivering ongoing support and communication between clinic visits appears to have engaged the classically difficult to reach, motivated positive self-care behaviours and engendered a sense of community amongst the target group. 'Sweet Talk' could be readily adapted for other chronic disease models and other age groups. Strengths and weakness of the intervention identified in this study may help to guide the development of future text-messaging support interventions.

# Introduction

Poor adherence with medication is a significant problem in chronic disease management <sup>1</sup>. Monitoring of prescription encashment has demonstrated that around a third of young people with Type 1 diabetes collect less than one third of their prescribed insulin requirements <sup>2</sup>. Optimal diabetes self-management also requires significant lifestyle modifications including frequent blood glucose testing and careful attention to diet and exercise. Concentrating on novel technologies and therapeutic developments may be a 'mistaken priority in diabetes research', and instead there should be a focus on what helps people follow self-management advice, including medication adherence <sup>3;4</sup>. This is reflected in current guidelines for the management of Type 1 diabetes, which recommend that young people should be offered intensive insulin therapy (IIT) to optimise glycaemic control as part of a comprehensive support package <sup>5;6</sup>.

Self-efficacy and social support theories predict self-management behaviours and adherence <sup>7-10</sup>, but conventional support groups and behavioural interventions rarely engage young people <sup>11</sup>, and require considerable health professional resources. There is, therefore, a need to find ways of supporting, educating and motivating young people with T1D <sup>12</sup>. The challenge is to develop validated, innovative support systems that appeal to young people and encourage uptake of IIT, and these must be practical and feasible to deliver within existing national health resources.

Teenagers are typically early adopters of new technology, so may be attracted by e-health strategies<sup>13</sup>. Given the high rate of ownership and use of mobile phones among young people<sup>14</sup>, text-messaging appears to be an obvious medium for delivering a low-cost personalised, patient-centred support intervention<sup>15</sup>.

Our group therefore developed 'Sweet Talk', a novel social support network for young people with diabetes, using text-messages to deliver a theoretically guided behavioural intervention. The intervention is informed by social cognitive theory which states that health behaviours are influenced by selfefficacy <sup>15;16</sup>, which in turn is motivated by goal setting and social support <sup>7-9</sup>. The theoretical framework of the 'Sweet Talk' intervention is outlined in Figure 1. 'Sweet Talk' is centred on a web-based text-messaging system, designed to automatically schedule messages based on patient profiles (age, gender and treatment regimen) and personal self-management goals agreed in clinic <sup>17;18</sup>. The 'Sweet Talk' system contains a database of text-messages containing information, tips and reminders, and categorised according to the main diabetes self- management tasks of insulin injections, blood glucose testing, healthy eating and exercise. Participants receive a weekly textmessage reminder of their personal goal and a daily text-message from the database. In addition participants received occasional text 'newsletters' relating to topical issues, and designed to engender a sense of community (e.g. stars with diabetes). Sweet Talk was evaluated in a three-group randomised control trial<sup>18</sup>. A control group continued on conventional insulin therapy and conventional support, and two groups received 'Sweet Talk'

support, one group continuing on conventional insulin therapy and one group changing to intensive therapy.

This article reports on a qualitative evaluation of 'Sweet Talk', which explored young peoples' attitudes and responses towards this novel text-messaging support system and its integration into their daily lives.

# SUBJECTS and METHODS

#### **Subjects**

Paediatric patients attending clinics in Tayside, Scotland, were invited to participate if they were aged between 8 and 18 years, had had Type 1 diabetes for more than a year and were on conventional insulin therapy (CIT; 2 or 3 daily injections of pre-mixed insulin). Patients with serious social problems, severe learning difficulties and needle phobia were excluded. Patients were recruited between October 2002 and February 2003 to a 12month study. The Tayside Committee on Medical Research Ethics approved the study and a standardised form was used to obtain informed consent from patients and their families. Participants were randomised to one of three groups: Group 1, a control group continued on CIT and received normal support (n=28), Groups 2 and 3 received 'Sweet Talk' either with conventional therapy (Group 2, n=33) or intensive therapy (Group 3, n=31). Details of the baseline demographics of the participants are shown in Table 1. All participants received a mobile phone. One participant from Group 2 moved away from the area during the study. The semi-structured interview was administered to 61 out of the 63 young people who had received 'Sweet Talk'.

#### Methods

'Sweet Talk' recipients were interviewed (by VF) at the end of the study in the hospital, usually in the presence of their parents. A semi-structured interview tool was used which required a combination of closed and open-ended answers. Interviews were based on topic guidelines shown in Table 2. Field notes were kept and the transcripts analysed with NVIVO software.

Transcripts were coded into the four broad social support categories identified in the literature (tangible, informational, companionship and emotional)<sup>8</sup>, facilitated by the coding system used in the Diabetes Social Support Interview<sup>19</sup> (Table 3). Data generation and analysis continued until saturation, *ie* no new themes were emerging. VF and AG independently performed qualitative content analysis of participant responses. This process was facilitated by NVivo textual analysis software.

# **RESULTS**

Results of the randomised controlled trial have been published previously. This demonstrated a significant improvement in self efficacy in the group receiving the intervention and improved blood glucose control in a subgroup also receiving intensive insulin therapy, while questionnaires revealed that most participants believed the system had improved their self-management and wanted to continue using it after the study<sup>18</sup>.

The qualitative analysis of interview transcripts is reported here.

There was 86% agreement in the coding of participant responses performed by VF and AG, using the analytic framework in Table 3.

## **Social Support Categories**

Tangible or Instrumental Support

Young people identified a number of practical benefits of different types of messages including the self-management task reminders, clinic reminders, ease of contacting the diabetes team and ordering supplies (Table 4).

Participants gave numerous examples of reminders sent by 'Sweet Talk' related to the main diabetes tasks of insulin injections, blood glucose testing, healthy eating and exercise, and reported that these had positively influenced their self-management behaviours. Responses also indicated that young people valued 'Sweet Talk' as a means of contacting the diabetes team between clinic visits. The majority appreciated the text-message reminders before each clinic visit (77%).

#### Informational Support

The informational content was identified as the most useful aspect of the text-messaging support system, particularly messages containing information about the main diabetes self-management tasks (Table 5). Other useful information related to diabetes facts, research developments and role models with diabetes. The text-messages also provided information about new products to aid diabetes self-management, such as blood glucose meters, and this was welcomed by a number of respondents. Three young people spontaneously mentioned that they liked to store the messages, indicating

they valued the message content, one disliked having to delete messages when his in-box was full. However, eleven participants did not feel that the informational content of the messages was helpful, and confirmed that diabetes knowledge alone does not predict adherence behaviour. During interviews it also became apparent that participants discussed the content of the text-messages with their families.

Some aspects of the text-messaging system irritated young people; receiving the same message repeatedly was mentioned by 20% of participants. A small number of participants also described some messages as irrelevant (n=1), annoying (n=1), or patronising (n=1).

#### Companionship Support.

The interviews revealed that the text-messaging service was successful at promoting a sense of 'community' with other young people with diabetes (Table 6). Efforts were made to engage people in the text-messaging system, to develop a sense of 'ownership' of the system. This included asking participants to share ideas on a variety of subjects, for example how to stay active over the winter. This exchange of ideas seemed to be appreciated by some young people. Sending a text-message 'newsletter' on topical issues engendered a sense of a wider community of people with diabetes, providing positive role models. For example, when the film star Halle Berry won an Oscar, a text-message was dispatched to participants letting them know she has diabetes. This message generated a flurry of text-message responses from participants at the time and three people mentioned it specifically many months later during the semi-structured interview.

**Emotional and Esteem Support** 

Young people reported that the text-messages provided praise and encouragement, which positively influenced their self-perception and engendering a positive outlook regarding their diabetes (Table 7).

Patients were also asked to provide suggestions for improving the 'Sweet Talk' service, and examples of their responses are illustrated in Table 8.

# **Discussion**

Health may not be the primary concern of many young people and therefore health professionals need to 'go where they are ...as a stepping stone to health issues' 12. By harnessing a technology integral to youth culture to deliver a behavioural support intervention, 'Sweet Talk' has engaged a classically difficult-to-reach group in a patient-centred diabetes and technology specific approach.

This study therefore addressed an important and previously under-explored subject in health research and provides important insights into young people's views of a text-message based support intervention for diabetes. In particular, it provides insights into the ways of effectively building relationships between young people and professionals using the emerging and rapidly evolving format of mobile phone communication. Its strengths lie in the fact that it is underpinned by social support theory and is professionally moderated

(thus obviating the possible negative effects of peer-to-peer interventions in this group <sup>20</sup>), but it is also driven by social relationships that engage young people and help improve self-efficacy.

In general participants responded positively, with a high study participation rate, the majority reporting that it had helped them manage their diabetes and wanting to continue receiving messages at the end of the study. Content analysis of responses indicated that patients perceived that 'Sweet Talk' had provided support that mapped on to the four social support domains identified in the literature; tangible, informational, companionship and emotional social support. Social support is defined as 'information leading the subject to believe that he is cared for and loved, esteemed and a member of a network of mutual obligations. Importantly, such social support has been identified as a significant factor contributing to health, and can be a powerful facilitator of behaviour change. The informational and companionship support were valued most highly by participants, consistent with findings from disease specific websites. The information as adolescents can experience difficulties accessing safe internet support networks and high quality health information.

Qualitative evaluation provides important insight into the impact of social support on outcomes in this challenging age group with diabetes. A recurring theme in this research was that 'Sweet Talk' delivers a unique form of regular, personalised 'push' support to patients that can be monitored by the health care team. Access is not limited to motivated patients that typically engage in

behavioural interventions or support groups<sup>20;22</sup>, which can contribute to health inequalities<sup>24</sup>. Supportive parental involvement in diabetes care is important throughout adolescence<sup>25-27</sup>. While 'Sweet Talk' was not designed as a family intervention, during interviewing it became apparent that content of messages was frequently discussed with parents, suggesting it may have provided collateral health effects by creating a useful platform for non-confrontational discussions about diabetes<sup>28</sup>.

'Sweet Talk' is an 'imagined community': Participants derived benefit from hearing about other people's experiences, without expending time and effort, and having the potential embarrassment of aligning themselves with other 'diabetics' and support groups. Peer support can have a detrimental affect on young peoples self management if adverse coping behaviours are recommended<sup>10</sup>, but professional moderation of 'Sweet Talk' messages ensured reliability and appropriateness of content<sup>21</sup>. Despite this, the intervention remains patient-centred. 'Sweet Talk' provides an opportunity for contact, but young people determine how they wish to use it, and control the timing and nature of interactions, which also creates a paradox: the text-messaging system achieved a sense of intimacy, by delivering personalised messages to a private mobile phone, but intrusiveness was avoided because there was no obligation to open messages at a certain time, or at all, providing a means of opting out, even in such a 'push' support intervention.

The 'Sweet Talk' intervention has demonstrated that text-messaging can be used as a medium to deliver a behavioural intervention, engage young people

with diabetes, and provide a novel form of 'push support'. Little is known about the characteristics of interactive health technologies that successfully engage patients<sup>29</sup>. This study addresses this issue, by focusing on participants' perceptions of the strengths and weaknesses of the current system, and can be used to guide future interventions. Young peoples' suggestions for improving the 'Sweet Talk' service included specific ideas for message content, using new generation mobile phone technology to send pictures and animation, and increasing the messages that shared peoples' experience of diabetes. The spectrum of responses reflects that adolescents are individualistic<sup>30</sup>, and vary in the type of support they find beneficial<sup>18;31</sup>. Increasing the database of messages to minimise repetitions is a priority. Creating a patient sub-editorial group would utilise the valuable skills and experiences of young people<sup>32</sup>, enhancing reciprocity and ownership of the 'Sweet Talk' system, to provide message content that better reflects their needs and wishes. The new generation of mobile phones could be exploited to deliver more sophisticated versions of the 'Sweet Talk' intervention. Further research should also attempt to integrate such text-messaging interventions into other health informatics system<sup>29</sup>, and incorporate detailed cost-effectiveness assessments<sup>33</sup>. The 'Sweet Talk' message database could be easily adapted to suit other chronic disease models and to engage other age groups.

# What is already known?

Supportive social networks facilitate adherence to diabetes self-management routines. Adolescents may be reluctant to engage with traditional support groups and e-Health solutions offer a promising alternative.

#### What this study adds

Automated scheduling of personalised text-messages offers an innovative, acceptable and effective means of delivering support to adolescents with diabetes, which appears to positively influence diabetes self-management behaviour and could be easily adapted for other chronic disease models.

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Contributors: The study was conceived and designed jointly by all the authors as part of a PhD project by VF, supervised by SG and CP. VF performed the semi-structured interviews and VF and AG analysed the transcripts. All

authors contributed to the writing of the paper and approved the final draft.

VF is the guarantor.

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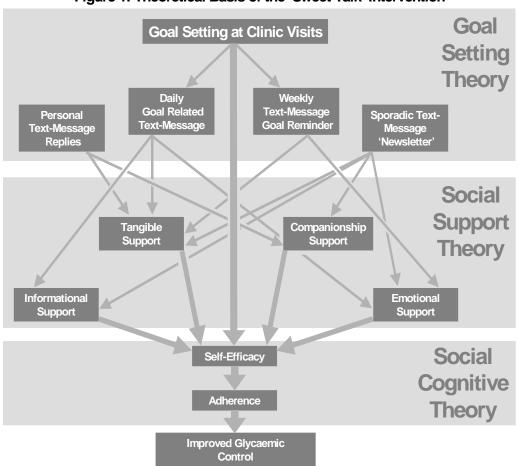


Figure 1: Theoretical Basis of the 'Sweet Talk' Intervention

Table 2: Baseline Clinical and Psychosocial Demographics of Patients in the 'Sweet Talk' Study Groups

Variable	Group 1 (n=27)	Group 2 (n=33)	Group 3 (n=31)
Male Sex	17	15	17
Age (years)	12.7 (10.5 – 14.8)	14.1 (11.7 - 15.6)	12.6 (11.2 – 15.4)
Carstairs Deprivation	-2.13 (-3.73 – 0.73)	-1.48 (-3.01 – 1.03)	-1.76 (-3.23 - 0.93)
Score†			
Ethnicity (non-white)	1	1	1
<b>Duration of Diabetes</b>	3.2 (1.7 - 6.7)	4.8 (2.6 - 8.6)	5.4 (2.9 – 7.7)
(years)			
BMI SDS	0.38 (-0.44 – 0.83)	0.13 (-0.55 – 1.0)	0.44 (0.04 – 1.04)
HbA <sub>1c</sub> (%) at study start	10.1 (9.2 - 11.2)	9.8 (8.6 - 11.5)	10.0 (9.0 – 11.4)

Data are absolute numbers or median (interquartile range)

† Postcodes were used to obtain Carstairs Deprivation Scores, which were based on results from the 2001 census. Higher score represents higher level of deprivation.

No significant differences in categorical variables using chi-2 test or continuous variables using two-sample t-tests were identified.

BMI SDS – Body mass index standard deviation scores from 1991 reference values.

## **Table 1: Semi-Structured Interview Questions**

- What did you think about the content of the messages?
- How did the messages make you feel?
- Do you feel that the text-messaging system helped you look after your diabetes?
- Did you find the clinic visit reminder helpful?
- Did you find any messages particularly annoying?
- Did you find any messages particularly helpful?
- Do you have any suggestions to improve the text-messaging service?
- Do you want to continue receiving messages at the end of the study?

Table 3; Framework of Coding Responses from the Diabetes Social Support Interview<sup>19</sup>

Support Category	Examples of Support
Tangible Support	Do for
	Help out
	Help out insulin reactions
	Remind
	Monitor
	Intrusive facilitation/nag
Informational Support	Provide information, advice or
	suggestions
Companionship Support	Do with
	Co-operate
Emotional Support	Praise/Encouragement
	Acceptance
	Sensitivity to feelings
	Positive outlook
	Watch
	Cheer up
	Show interest in diabetes
	General non-specific support

## **Table 4: Tangible or Instrumental Support**

#### **Goal Related Messages**

"Yes, some of them, check your blood glucose before every meal, tips, reminders" (§ 13.6 yrs / 7.1%)

"Made me test my blood sugars more" ( $\bigcirc$  17.9yrs / 10.0%)

"Reminding me to take my jags and that" ( $\bigcirc$  13.4 yrs / 11.6%)

"I think it helped a bit because it does remind you to try and eat a bit better" ( $\bigcirc$  15.0 yrs / 13.1%)

"Stopped eating as much chocolate" ( $\bigcirc$  16.7yrs / 9.4%)

"Sometimes they reminded you about stuff eating fruit and veg, ideas for exercise, helped out with that". ( $\bigcirc$  17.8 yrs / 7.7%)

"Made me more active during the year" ( $\stackrel{\frown}{\downarrow}$  15.0yrs / 8.6%)

#### **Contact with Diabetes Team**

"I thought it was quite good. A lot of it (was) quite useful. If you had a question it was answered very quickly." ( $\bigcirc$  17.8 yrs / 7.7%)

#### **Clinic Reminders**

"That was helpful. One time I forgot I even had clinic so it reminded us" ( $\bigcirc$  15.0 vrs / 13.1%)

"Nice to know you knew I was coming" (\$\frac{1}{18.4} \) yrs / 9.0%)

"Remembered anyway" (\$\frac{17.2}{17.2} \text{ yrs } / 12.0%)

### **Table 5: Informational Support**

- "Before I didn't know you weren't meant to inject through clothes and everything....I used to do that" (§ 15.4yrs / 10.3%)
- "Full of facts I've never found out before" (3 12.7 yrs / 8.3%)
- "Study curing diabetes helpful didn't know much about it" " (\$\frac{1}{6}.5 \) yrs / 7.2%)
- "Probably learned a lot more about it basically" (\$\frac{1}{0}\$ 16.0 yrs / 9.2%)
- "Good, it helped me and told me what to do" ( $\bigcirc$  13.6 yrs / 10.3%)
- "Let me know new things that could help me" (3 16.6 yrs / 7.4%)
- "Some of stuff I knew and didn't do anyway. No change." ( $\bigcirc$  16.0 yrs, HbA1<sub>c</sub> 11.0%)
- "Quite a lot of messages I knew already so didn't make that much of a difference" ( $\bigcirc$  13.6 yrs / 10.3%)
- "Boring, I knew about it half the time" (3 14.6 yrs / 11.2%)
- "Annoying to get same messages over again" (♀ 16.0 yrs, HbA1c 11.0%)

## **Table 6: Companionship Support**

- "Peoples suggestions were good, like dancing to top of the pops". ( $\bigcirc$  16.0 yrs / 11.0%)
- "You got to ask questions and hear results from everyone else as well" ( $\updownarrow$  13.5 yrs / 6.5%)
- "Liked film stars" ( $\bigcirc$  16.5yrs/8.3%)

#### **Table7: Emotional or Esteem Support**

- "I think it is encouragement to keep going" ( $\bigcirc$  13.5 yrs / 6.5%)
- "Helped quite a lot, ideas, motivational things it is known that complications reduced by looking after it" (318.4 yrs / 9.0%)
- "Done a lot to keep it on track" (3 11.2 yrs / 9.5%)
- "If I get annoyed (with my diabetes), they don't even know, but they send something" (311.8 yrs / 9.0%) Mother added "it gives him some encouragement
- "Yes it sort of me you think about what you're doing the way it said it ( $\circlearrowleft$  15.4 yrs / 10.3%)
- "Got me to keep in line I suppose" (3 16.7 yrs / 7.2%)
- "Did make you want to reach the goal you set for yourself" (\$\times 18.1 \, yrs / 14.8\%)
- "*Positive*" (\$\times 17.9 \text{ yrs } / 10.0%)
- "Really happy because they were trying to look after me" ( $\bigcirc$  11.5 yrs / 10.9%)

## **Table 8: Suggestions for Improvement**

- "More varied topics, more generalised topics" ( $\bigcirc$  16.1yrs / 7.1%)
- "Update on progress with research" ( $\bigcirc$  16.5yrs / 8.3%)
- "Alarms for pump patients what to do" (3 12.7yrs / 8.3%)
- "More about what other people are feeling. I think it helps to know other people are feeling the same as yourself." ( $\bigcirc$  17.9yrs / 10.0%)

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