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E-health relationships diabetes: 50 weeks evaluation

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Abstract: Hybrid e-health support was given to 11 insulin-dependent type 2 diabetes mellitus (DM2) patients, with electronic support plus a multi-disciplinary health support team. Challenges were low ICT and health literacy. After 50 weeks, attractiveness and feasibility of the intervention were perceived as high: recommendation 9.5 out of 10 and satisfaction 9.6 out of 10. Technology acceptance model (TAM) surveys showed high usefulness and feasibility. Acceptance and health behaviours were reinforced by the prolonged health results: aerobic and strength capacity levels were improved at 50 weeks, plus health related quality of life (plus biometric benefits and medication reductions, reported elsewhere). Regarding e-health theory, we conclude that iterative skill growth cycles are beneficial for long-term adoption and e-relationships. Next, the design analysis shows opportunities for additional affective and social support, on top of the strong benefits already apparent from the direct progress feedback loops used within the health coach processes.

Keywords: type 2 diabetes; DM2; e-health; lifestyle; monitoring; coaching; blended care; service design.


Biographical notes: Luuk P.A. Simons is a Senior Fellow in the field of persuasive technology, hybrid eHealth systems, eRelationships, self-management and high intensity coaching.

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1 Introduction

Our Western lifestyle plays a large role in the onset and progression of DM2: type 2 diabetes mellitus (Lim et al., 2011). Several lifestyle interventions improved outcomes in type 2 diabetes patients on insulin therapy, most notably: lower blood sugar and lower medication needs (Jenkins et al., 2008; Esposito et al., 2009). However, these are often costly, highly controlled interventions. Moreover, the longer-term (>6 months) sustainability of behaviour changes is limited.

The question is: can we do this on a more ‘do-it-yourself’ and e-supported basis? This would have two advantages. First, since behaviour improvements are implemented within patients’ lives, it improves the chances of sustained health behaviour (Simons et al., 2013). Second, it is cheaper. Since 2010 the Health Coach Program has been used to improve lifestyle and metabolic outcomes (including reduced insulin needs for DM2 patients), via e-support, improved self-management and rapidly improved health behaviours (Simons and Hampe, 2010a; Simons et al., 2015).

To promote rapid health results, a high intensity nutrition, training and coaching (HINTc) intervention of 12 weeks was developed for this patient population, plus lightweight e-support and mostly self-management in weeks 13–50. The intervention combines improving health literacy with active behaviour change support.
This paper discusses follow up results and design lessons after 50 weeks, as part of a larger biomedical study. An important goal of the biomedical pilot study was to promote long-term (>6 months) healthy lifestyle adoption in senior DM2 patients. Even in well-facilitated settings, a majority of interventions lack sustained health effects after six months (Verweij et al., 2011). Moreover, in e-health initiatives, there is always the risk of falling victim to the ‘e-health law of attrition’ (Eysenbach, 2005): meaning that 90% of users are often already lost within a few usage instances.

In this study population, there were additional challenges due to their low average ICT- and health literacy. This exploratory design analysis formulates design lessons based on 50 weeks follow up. We focus on feasibility and attractiveness of the HINTc e-supported lifestyle intervention, plus on formulating design lessons. Given the desire to develop cost-effective long-term e-health support relationships with these types of patient groups, a focus is on long-term e-relationship support lessons. Medical results will be discussed in another paper.

Research questions:

- What are the 50-weeks-follow-up feasibility and attractiveness of the HINTc e-supported lifestyle coaching program; and what are the effects on quality of life?
- What design lessons emerge for long-term e-health and e-relationship support?
- As part of the design analysis we address: efficacy of the service mix deployed in e-supported lifestyle interventions. We combine the 50-week results from our measurements with a design analysis based on an evaluation framework of requirements for ICT-enabled healthy lifestyle interventions.

2 Theory

The e-supported lifestyle program combines coach sessions with electronic dashboarding and self-management. Hybrid programs (face-to-face plus tele-support) have been indicated to be attractive for some time (Demark-Wahnefried et al., 2007; Demark-Wahnefried and Jones, 2008). Finding the right mix between offline and online contacts is an ongoing design research challenge (Pekmezzi and Demark-Wahnefried, 2011). In summary, a hybrid or multi-channel service mix is recommended (De Vries et al., 2008; Sperling et al., 2009; Simons et al., 2002; Simons and Bouwman, 2004; Simons, 2006; Simons and Hampe, 2010a, 2010b), combining electronic and face-to-face interactions. Still, there are many design challenges, given the multitude of options. For a more extensive discussion, see Simons et al. (2014a).

Key functionalities to increase health motivations and behaviours in this e-supported lifestyle program are (Simons and Hampe, 2010a; Simons et al., 2012, 2014a, 2017):

- Daily logging of insulin and blood sugar levels: for close progress monitoring of the health coaches, physicians and participants themselves.
- Close cooperation with physicians, for rapid medication adjustments initially (avoiding dangerously low blood sugars when insulin dosage is not reduced rapidly enough in the first days), plus medical monitoring/coaching in the following weeks.
- A personal online health dashboard with graphs of progress towards adherence targets on the various health behaviours.
Automated feedback on lifestyle aspects where positive scores have been achieved (nutrition, physical activity, stress management or an overall score).

(Tele)coaching by a health coach, generating online reports on progress towards adherence targets in the personal dashboard.

The (tele)coaching sessions can be flexibly planned, based on convenience and participant preference: during in-clinic visits or phone based from home.

Options to ask questions to the coach: via messaging within the dashboard or via email.

Online schedule indicating upcoming events: group sessions, individual coach sessions (when and where), physical measurements, surveys.

A micro-learning health quiz accessible via smartphone, mail and/or web.

Reading materials in the mail.

Weekly tips via email on health, motivation and self-management.

Besides individual coaching, group sessions are also used in order to stimulate group support, mutual inspiration and encouragement, plus peer education.

It was theorised and tested elsewhere that the design challenge of persuasive technology (Fogg, 2002, 2009; Ghorai et al., 2014; Hamari et al., 2014) for health is not just located in the ICT design, but also in the design of the overall service scape, including health effects and coach relationship (Starr, 2008; Simons and Hampe, 2014b). It should generate positive, mutually reinforcing service experiences across communication channels and activate long-term health motivation and -behaviours, in order to deliver long-term health results. This is reflected in the following design evaluation framework for health improvement ICT solutions (Simons et al., 2014a), see Figure 1.

**Figure 1** Basic requirements when designing ICT-supported healthy lifestyle interventions

![Figure 1](image)

- **Health effectiveness:**
  - Health literacy
  - Health behaviors
  - Health outcomes
  - Quality of life and well-being

- **Coaching performance:**
  - Promoting health actions
  - Supporting self-efficacy
  - Activating intrinsic motivation

- **ICT value adding:**
  - Quality of motivators, triggers, experiences
  - Simplicity: familiar interfaces, ease of use
  - Embedded in and enhancing coach relation

Figure 1 addresses three evaluation domains: health effectiveness, coaching performance and ICT value adding. It helps evaluate the impact of ICT-enabled interventions and will be used as analysis framework for Section 4, results.
3 Methods, study design, and intervention

This is a non-randomised, one arm, pilot intervention study of 12 weeks September–November 2015, plus effect measurement at 50 weeks follow up; approved by the Leiden University Medical Center (LUMC) Ethics Board. The biomedical results will be addressed in a separate paper. The study participants were 11 insulin-dependent DM2 patients. Patients were volunteers and provided written informed consent prior to the study. They were recruited by LUMC from the larger Leiden area in the Netherlands. They were eight men and three women, ages 39–70 years, with widely varying levels of education (although skewed towards the lower end) and of comorbidity.

Challenges regarding design of individual training schedules were posed by all the physical constraints in this group: seven had significant movement restraints (knee- and hip-replacements, cardiovascular blood flow constraints, and stents), five had neuropathy, and seven had cardiovascular disease. On average they had been a DM2 patient for more than ten years and they were motivated for trying lifestyle improvements.

Technology acceptance model (TAM) surveys (Venkatesh and Davis, 2000) were used at weeks 4, 12 and 50 to assess intervention feasibility and attractiveness. In this study, TAM is only used qualitatively, as a tool for user evaluation, not to make technology acceptance calculations or predictions. For this purpose, its eight independent variables provided us with a wide range of user evaluation insights, compared to the four independent variables of UTAUT (Venkatesh et al., 2003).

Furthermore, user satisfaction evaluations were used plus the RAND SF-8 health related quality of life survey (Ware and Gandek, 1998). Besides, a standardised sit/stand test is used to assess strength (Csuka and McCarty, 1985) and an Astrand (1976) test for endurance.

a Study inclusion criteria
- DM2 treated by insulin therapy with or without oral blood glucose lowering drugs
- BMI >= 25 kg/m²
- age 30–80 yrs
- Dutch language and basic computer competence (for use of email and web-based dashboard).

b Exclusion criteria
- recent (<3 months) myocardial infarction
- uncontrolled blood pressure (SBP > 170 mmHg and/or DBP > 100 mmHg, 2 out of 3 measurements)
- any chronic disease other than type 2 diabetes hampering participation (at the discretion of the investigator)
- low motivation to participate (score 2 ‘weak’ or 1 ‘very weak’ on a 5-point scale)
- alcohol consumption of more than 28 units per week at present or in the past
- psychiatric disease (as defined by DSM-V)
- claustrophobia
• metal implants or other contraindications for MRI.

3.1 The e-supported lifestyle intervention HINTc

An extensive e-supported lifestyle program is offered, which combines coach sessions with electronic dashboarding and self-management, plus electronic health tips and a digital health quiz game. Intensive coaching is offered for four weeks with the purpose of generating self-propelling behaviours and capabilities. In week 1 a low-calorie approach is taken to enable rapid alleviation of fatty liver conditions. The support in weeks 5–12 is more lightweight, with group sessions at the end of weeks 6, 8 and 12, weekly electronic tips and a digital health game. The support in weeks 13–50 is: sustained e-tool support, plus 6-weekly group coach sessions for sharing and discussing each other’s progress and challenges, for reinstating health literacy lessons and for social group support.

As an umbrella overarching the personalised coaching per participant, the general lifestyle advice follows the guidelines of the Harvard Epidemiology and Nutrition Group for nutrition and physical activity, with specific modifications for diabetics. The guidelines are to increase intake of vegetables and low sugar fruits (each 2.5 servings/day or more), to choose whole grains instead of refined grains, to limit sugar and other high glycaemic load foods, to have one daily serving of nuts and/or legumes, to limit intake of red meat and processed meat, to limit intake of trans and animal fats, and to have no more than 2 (male) or 1 (female) alcoholic beverages/day. Physical exercise guidelines are: at least 60 min/day moderate intensity activity (like walking or gardening) and at least $3 \times 30$ min/week intensive activity, which was also supported with group training sessions at the LUMC location three times per week (Borg level 12–14). Stress management guidelines are: relaxation exercises for >10 min/day.

4 Results

We discuss several types of results. We address answers to the first research question: What are the 50-weeks-follow-up feasibility and attractiveness of the HINTc e-supported lifestyle coaching program, including the positive feedback provided by the improvements in quality of life and physiology (insulin medication, blood sugar, physical stamina)? And to answer the second research question (‘what design lessons emerge for long-term e-health and e-relationship support?’), we analyse efficacy of the service mix deployed in e-supported lifestyle interventions, following the framework of Figure 1 from Theory.

First, regarding attractiveness and feasibility, satisfaction and recommendation were not only high after four weeks (8.7 and 9.0 out of 10 respectively) and 12 weeks (9.1 and 9.0 out of 10 respectively), but also after 50 weeks: 9.6 and 9.5 out of 10 respectively. This is in contrast with usual patterns where the initial enthusiasm of the first weeks wanes after three months. Regarding ‘health related quality of life’ as measured with the RAND SF-8 an interesting pattern emerged over the 50-week period, as illustrated in Figure 2.

The physical health score moved from an average of 50.1 at start to 66.6 at week 4 to 73.1 at week 12, to 62 at week 50, with 76.2 as the Dutch average (standard deviation: 13.5). In other words: for physical health the average score increased almost two standard
deviations in the first 12 weeks (due to better eating and training). After 50 weeks a gain of one standard deviation remains. Mental health went from 68.9 at start, to 82.4 at week 4, to 80.6 at week 12, to 71 at week 50, with 77.6 as the Dutch average (standard deviation: 13.7). Experienced mental health seems to peak at week 4. This coincides with the large positive surprise that the patients experience in the first four weeks: fast improvements in fitness, quality of life, medication, self-efficacy, health literacy, fun and group support, plus a hope for a better future. In the following period between weeks 4 and 12 there is a continued building up of strength and fitness, losing weight, building patterns/habits and gaining longer-term self-efficacy. After 12 weeks, group training stops and patients are much more on their own. Patterns diverge between patients, with some continuing to improve further (health behaviours and outcomes), whereas others decline.

Figure 2  Physical and mental health (RAND SF-8) in weeks 0, 4, 12 and 50 (n = 11)

Second, some of the physiological improvements of the first 12 weeks were sustained at 50 weeks (a more detailed analysis will follow in a separate publication, based on more reliable and extensive biometric and clinical measurements): average 8% weight loss (was 9% at 12 weeks), roughly 20% lower fasting glucose and 65% lower insulin medication (was 20% lower and 71% lower respectively at 12 weeks, based on data in self-monitoring tool).

Clearly, the results in the first 12 weeks helped motivate patients and provided positive feedback that they were on the right track. Still, given the goal of long-term (50 weeks) health results, it is positive to see that the 12 week results are largely sustained through to week 50.

The two measures for physical endurance and strength showed interesting differences over time. Endurance measure VO2max first increased +36% at week 12 and was +27% at week 50. Strength (measured via 30 sec sit/stand test) on the other hand was +23% over the 12-week period and further improved to +44% (week 50). Of the 11 participants, 7 have continued intensive exercise in weeks 12–50.

Third, the TAM user evaluations of week 12 and 50 shed some further light on patients’ experience and appreciation of the intervention, see also Table 1.
The TAM (Likert scale 1 to 7, strongly disagree to strongly agree, with several negatively coded items) user evaluation at weeks 12 and 50 shows three main patterns. First, these patients were relatively positive at 12 weeks and 50 weeks about all TAM constructs. Aspects that scored particularly high were: usefulness and the support offered by the multidisciplinary health team.

Second, some patients were not ICT-literate and clearly had trouble with e-tools like the health quiz of food/exercise logging. See Simons et al. (2016) for a more extensive discussion on their differences in ICT adoption, which became apparent in the first 12 weeks.

Table 1  TAM user evaluation (n = 11, weeks 12 and 50)

<table>
<thead>
<tr>
<th>TAM construct</th>
<th>Week 12 score (out of 7)</th>
<th>Week 50 score (out of 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Usefulness</td>
<td>All items ≥ 6.8</td>
<td>All items ≥ 6.6</td>
</tr>
<tr>
<td>2 Effortless</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Lowest (5.0): Health quiz</td>
<td></td>
<td>• Lowest (4.8): Food guidelines</td>
</tr>
<tr>
<td>• Lowest (5.0): Food/exercise logging in dashboard</td>
<td>5.1 Food/exercise logging in dashboard</td>
<td></td>
</tr>
<tr>
<td>3 Opinion of social circle</td>
<td>All items ≥ 6.3; except ‘other patients’: 5.4</td>
<td>All items ≥ 6.3; except ‘other patients’: 6.0</td>
</tr>
<tr>
<td>4 Support</td>
<td>All items ≥ 6.0</td>
<td>All items ≥ 6.0</td>
</tr>
<tr>
<td>5 Affect</td>
<td>All items ≥ 6.4</td>
<td>All items ≥ 6.5</td>
</tr>
<tr>
<td>6 Ability</td>
<td>All items ≥ 6.0</td>
<td>All items ≥ 5.7</td>
</tr>
<tr>
<td>7 Trust</td>
<td>All items ≥ 6.2</td>
<td>5.8 Privacy? Rest: 6.5</td>
</tr>
<tr>
<td>8 Valuation (e)support elements</td>
<td>6.9 Personal trainers</td>
<td>6.7 Start menu/diet</td>
</tr>
<tr>
<td>‘What helped most to build health behaviours?’</td>
<td>6.8 Health literacy</td>
<td>6.6 Health literacy, personal trainers, group sessions</td>
</tr>
<tr>
<td></td>
<td>6.7 Daily e-log sugar/insulin</td>
<td>6.5 Support health coaches, physicians</td>
</tr>
<tr>
<td></td>
<td>6.7 Support health coaches</td>
<td>6.4 Start workshop</td>
</tr>
<tr>
<td></td>
<td>6.6 Support physicians</td>
<td>6.6 Lowest (4.6): Homework physical exercise</td>
</tr>
<tr>
<td></td>
<td>6.6 Support/advice via mail</td>
<td>6.4 Lowest (5.6): Health quiz, week tips, homework physical exercise</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Future use intention</td>
<td>6.7 Daily e-log sugar/insulin</td>
<td>Only 3 items (rest not applicable);</td>
</tr>
<tr>
<td></td>
<td>6.6 Regular training/exercise</td>
<td>6.6 Healthy eating</td>
</tr>
<tr>
<td></td>
<td>6.6 Ask advice health coaches or physicians</td>
<td>6.4 Regular training/exercise</td>
</tr>
<tr>
<td></td>
<td>Lowest (5.0): Food/exercise logging in dashboard</td>
<td>5.8 Use tips and health quiz to increase health literacy</td>
</tr>
<tr>
<td></td>
<td>All other items ≥ 6.0</td>
<td></td>
</tr>
</tbody>
</table>
Third, we observed that over the course of roughly weeks 12 to 50, focus of participants shifted, also visible in their TAM scores. After initial focus on tools and start up challenges, focus later shifted to health literacy, plus sustaining healthy food and exercise patterns. In hindsight (at week 50), participants started appreciating the intensive start menu and start workshop more, the exercise support continued to be highly valued, plus sustaining healthy patterns in weeks 12 to 50 was top of mind: see the high scores for these elements in TAM constructs 8 (valuation of support elements) and 9 (future use). On the level of social support and maintaining a healthy lifestyle focus, the group spontaneously organised monthly meetings together, outside of the hospital setting.

The final set of study results address research question 2, what are lessons for long-term e-health relationship building. As a basis, we use an efficacy evaluation of the hybrid e-support mix deployed, at 50 weeks follow up. Table 2 shows the authors’ evaluation using the theory framework of Figure 1.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Authors’ design evaluation at 50 weeks follow up, on design requirements of Figure 1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health effectiveness</strong></td>
<td><strong>Coaching performance</strong></td>
</tr>
<tr>
<td><strong>Health literacy</strong></td>
<td><strong>Promoting health actions</strong></td>
</tr>
<tr>
<td>++ Better than the low literacy start, but much forgotten at wk 50 by some.</td>
<td>++ (e)coach mix promoted steps forward for all.</td>
</tr>
<tr>
<td>– Increased falling back into certain old beliefs at wk 50.</td>
<td>+/- Increasing variance after 12 weeks.</td>
</tr>
<tr>
<td><strong>Health behaviours</strong></td>
<td><strong>Supporting self-efficacy</strong></td>
</tr>
<tr>
<td>+/- At week 50: Improved behaviour, but large variance.</td>
<td>+ Sustained self-efficacy at 50 weeks, except for two patients with major life/health events and low compliance week 12–50.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health outcomes</strong></td>
<td><strong>Activating intrinsic motivation</strong></td>
</tr>
<tr>
<td>++ Biomarkers and medication.</td>
<td>++ Getting results and feeling better. Continued high satisfaction at wk 50.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Quality of life</strong></td>
<td><strong>Fit with coach processes</strong></td>
</tr>
<tr>
<td>+ At wk 50 better than start.</td>
<td></td>
</tr>
</tbody>
</table>

Notes: Authors’ opinions, 5-point scale from – – to ++.

Table 2 contains several lessons. First, looking at health effectiveness, we see mixed results. Biologically, there are large, positive effects for all 11 participants, even at 50 weeks. Even despite the large health, education and psychology differences within the group. However, regarding health literacy and self-management competence, the large
differences that were observed at the start, became increasingly pronounced during the 50 weeks follow up. This relates to the second column: coaching performance. Promoting health actions and intrinsic motivation worked relatively well. But with those patients that have less self-management skills, it is hard to maintain coaching effectiveness in the 12 to 50 weeks period. Third, regarding ICT value adding, it was good that there was a variety of e-tools, given the large differences in the patient group regarding ICT literacy and preferences. The simple mail-based tool for sugar/insulin monitoring was highly valued by all. And for the multi-disciplinary coach team the e-tools were very useful for progress monitoring and pro-active coaching. See Section 5, design lessons and implications for practice, for further reflection and improvement ideas on e-tools.

5 Design lessons and implications for practice

Several lessons can be learned from this study in relation to the intensive healthy lifestyle approach and in relation to the suitability of hybrid e-health support. Plus, we will address options for improvement.

First, it is interesting to see in this HINTc intervention that satisfaction is high initially (at 4 and 12 weeks) and stays high or even seems to grow (during at least the first 50 weeks), even though large lifestyle changes are requested from the participants. Our interpretation is that contributing factors for this satisfaction are: gains in self-efficacy and health literacy, seeing results plus feeling results, which activates intrinsic motivation. In other words: the large and growing benefits that patients experience. The benefits, besides medication reduction, are also clearly visible in the increased scores on the physical and mental health dimension of the RAND SF-8 quality of life survey.

Implication for practice: Aim for large and rapid health benefits in (ICT-supported) health interventions. This helps for motivation (Simons et al., 2014a) and bio medically (Ornish, 2008). ‘Moderation kills us’ is the quote from professor Ornish to summarise the fact that for patients with serious health conditions, an ounce of prevention is not enough. More than a pound of lifestyle is needed in order to effectively reverse their problems and create real hope for the future, given the progressive nature of their (lifestyle related) diseases.

Second, based on qualitative feedback from the participants, it appears that several new, healthier food and exercise patterns started to become ‘the new normal’ already after four weeks into the intervention, remaining ‘normal’ for participants at week 12 and 50 as well. Still, this is also an area where increasing differences between participants were observed in weeks 12–50. Although this pilot group is too small to draw large conclusions, we observed that several patients were quite sensitive to health beliefs from their social context. So what their peers considered normal and (thus?) healthy behaviours, were gradually perceived by these patients as normal behaviours too. Even though it was behaviour that got them ill in the first place, or though they had learned to know better in the first 12 weeks of the program.

Implication for practice: It takes serious strength of mind and heart to continuously ‘know better’ than your peers, during a long period of multiple months (or even years). Apart from involving the partners from the start, additional follow up support (social, educational, or even medical authority) to empower and reconfirm patients in the right
health beliefs is highly valuable to protect them against social norms from their less healthy social contexts.

Third, opinions varied regarding the suitability of most of the e-tools provided (like the health quiz, the email week tips, food and exercise logging). In the short-term of the first few weeks, virtually all tools were used by virtually all patients. After several weeks, usage patterns diverged. Two factors appeared important in determining adoption and use of these tools: availability of time, plus ICT literacy, with the latter appearing most important: four participants expressed an aversion to using computers. On top of that, individual preferences are important. For example, one participant continued daily food logging for over 50 weeks (whereas all others stopped after week 12), because he liked this form of explicit monitoring. Two other participants continued using the health quiz throughout the 50 weeks (the rest did not). Several others continued reading week tips and other health content during the 50 weeks follow up. Clearly, user preferences for the various e-support tools differed, which is a pattern we observed in other intervention groups as well (Simons and Hampe, 2010a; Simons et al., 2012, 2014b).

Implication for practice: It is advisable to have a portfolio of several e-tools, even if they address overlapping support goals, in order to achieve maximum ICT-support benefits within participant groups.

Fourth, the exception to this varied e-tool adoption pattern was the simple, daily mail reminder Tool for sugar/insulin inputs, also described in Simons et al. (2016). This tool was used daily again by the patient group in weeks 48–50 to assemble user pattern data (the tool was not used in between, since care was handed over to their General Practitioners). We think that the combination of high simplicity with high usefulness was the key to its high adoption. The tool was an important basis for the coaching from the multidisciplinary support team. In conclusion: e-support was not only useful for the patients, but especially for the care givers, providing them with more extensive views on patient status and progress.

Implications for practice: First, aim for a very high degree of simplicity. Blood sugar and multi-daily insulin medication were monitored with standard, trigger-based emails (e.g., ‘please provide your evening inputs’) and with only a simple, secure link leading to their personal landing page which showed the previous inputs plus the requested inputs. This simplicity was explicitly valued by participants (and email use was perceived to be simpler than App use), plus it lead to high compliance rates (>90%). A second implication is that a real added value of these inputs as a basis for day-to-day lifestyle advise and medication changes, seems to protect against the ‘e-health law of attrition’ (Eysenbach, 2005, see also Section 1). Preferably, e-health tools need to do more than monitoring plus semi-standard feedback like ‘you did well’ or ‘a personal best!’ For these patients, their situation is a complex puzzle. Thus, using their inputs for really educating them is valued a lot.

Fifth, besides e-tool support, the group effects and the multidisciplinary support team were highly valued. The patient group took the initiative to organise several social events together during the weeks 12–50 period and every six weeks there was a 1-hour gathering at the hospital again with the support team. The hospital team meeting was valued socially, but also for health literacy and practical support. These group effects fostered high levels of interpersonal commitment, which is important for long-term relationships and something that is more challenging to achieve with e-tools.
Implication for practice: Using peer group support as part of health interventions is currently underutilised in hospitals, but merits further adoption (for reasons of cost effectiveness and attractiveness for patients, see also Section 6).

Finally, for future improvements, several innovation opportunities emerge:

1. First, in the coaches’ professional opinion, strength and endurance improvements could have been significantly larger with more effective training. Thus, in the next diabetes lifestyle project better training equipment will be used. Moreover, this will be equipment which provides progress feedback every training session.

2. Second, a training progress feedback loop will be used also outside the collective group trainings, with a mail-based self-management monitoring tool similar to our sugar/insulin tool. So that even after completion of the group training period together, the coaches can continue monitoring and guiding patients better, in order to enhance their exercise progress.

3. Third, regarding building long-term e-relationships, it would not be correct to label the phase of 12 to 50 weeks as ‘maintenance’. Patients are continuously renewing their patterns, experiences and lessons. All in relation to health literacy and health competence. Better (e)support is needed for these renewed learning processes. Within long-term e-support relationships, there clearly are patient needs for continued learning, growth and discovery.

4. Moreover, support needs are not just cognitive, but also affective (pride, having fun, giving or receiving encouragements) and social (connecting with others, sharing experiences, showing your best). Recently, a WhatsApp group pilot tested for affective, practical and social support, leading to high user adoption and appreciation (Simons et al., 2018). One of the potentially high-value ideas in this WhatsApp pilot is deploying social media (Schulz, 2014) for peer coaching by ‘super-survivor’ role models from resilience theory, see Section 6 for more details. Once participants start peer coaching others, this can create a win-win-win: they improve their own (role model) behaviours, their ‘coaches’ benefit, plus the task lists of the health professionals become lighter.

5. A limitation of this study is that only insulin dependent DM2 patients were included. This choice excluded an important, large population of DM2 patients which do not use insulin yet and which are motivated to reverse their DM2 progression. This group generally dislike self-pricking for blood sugar monitoring, which hampers self-management, but also hampers participation in these health interventions. Hence we aim for future use of non-invasive glucose monitors like Sridar (2017), which generally have the added benefit of 24/7 logging. As a consequence, barriers to participation are lower and progress feedback will have much better time resolution (roughly every five minutes).

6 Implications for theory

As stated before (Simons et al., 2016) for several of the patients in this group, their learning styles were highly non-cognitive. An (apparent) understanding of health cause and effect seemed to have less impact than experiencing cause and effect. Daily feedback
loops between behaviours and (negatively high) sugar values were useful in this regard. For this group, learning is not very much about explicit awareness, intentions, goals, behaviour and maintenance plans, as postulated in models like health action process approach (HAPA) and i-change (Schwarzer et al., 2010; Wiedemann et al., 2011). For several patients in this group, learning appears to follow mental models of impulse purchasing in marketing: first acting, then experiencing and opinion forming (Vohs and Faber, 2007). This implies that other combinations of coaching, prescribing and explaining may be more effective for these types of patients than some education- and goal focused strategies commonly used in public health communication.

Next, the term ‘maintenance’ (as used in HAPA for example) seems a miss-qualifier for the longer-term phase of health behaviours observed here (12 to 50 weeks). What we observed was closer to processes of iterative circles, continuous renewal, re-interpretation and discovery. These processes of course include pitfalls for those who have fragile health literacy. The latter group easily tend to fall prey to misbeliefs and misadvise from others around them (patients, family or popular press).

A solution may come from ‘super-survivors’ from resilience literature (Southwick and Charney, 2012) where three levels of competence are distinguished. From the base level up, people can move from low levels of [health] competence and self-efficacy (on occasion ‘falling victim’ to the effects of ineffective behaviours and coping styles) to the middle level of ‘survivor’ where competence and coping levels are quite adequate. But the most interesting step is when previous ‘victims’ become ‘super-survivors’ (Southwick and Charney, 2012), teaching others how to grow. In this process they use their own victim pitfalls/experiences as assets to better understand, empathise and coach others. When certain people in a health group become ‘super-survivors’ this is a win-win: it further stimulates their own health identity and role model health behaviours, plus it provides additional support and inspiration for the other groups members.

Conceptually, super-survivors can be seen as a strong form of advocates, role models, or peer coaches (Prochaska and Velicer, 1997; Southwick and Charney, 2012; Thom et al., 2013). In a follow up WhatsApp group pilot study, these ‘advocate’ roles among participants were indeed found to be attractive and useful (Simons et al., 2018). However, this pilot study had a relatively healthy (non-DM2) worker population, thus the testing of ‘real’ super-survivor DM2 role models is still merited. We hypothesise that the use of super-survivor role models is even more valuable in intensive HINTc settings where

a there is more at stake for the participants
b they have more group interaction moments.

Finally, successfully being a super-survivor role model for others requires quite some skill, self-efficacy (Lippke et al., 2009), plus opportunity. Thus, we advise that health professionals actively seek out and guide potential super-survivors in their role, in order to enhance effectiveness.

Finally, 4 of the 11 participants simply disliked using ICT (whether laptop, smart pad or smartphone) for either reading, checking mail or inputting data. Still, the overall-attractiveness of the intervention was judged to be high, because of

a the large benefits
b the extensive practitioner- and group support.
Thus, the e-health law of attrition (Eysenbach, 2005) was bypassed, partly thanks to (social) benefits in the context of the ICT. Plus, some cognitive dissonance may have worked to our advantage: if something is a challenge, then people may appreciate their own achievements and results more. This appears to have helped increase motivation for ICT-adoption as well as the extensive lifestyle improvements. Especially in the longer run, their increased self-appreciation and self-efficacy appears to have helped.

7 Conclusions

Summarising from this study, we can conclude a few key points. First, the 12 weeks of intensive training and coaching sustainably (for 50 weeks at least) improved patients’ health awareness, health behaviours, health outcomes and quality of life. Second, a virtuous cycle was started (as noted earlier in other lifestyle e-health settings, see Simons et al., 2014a): better health literacy and behaviours → better results → better health literacy and behaviours. This helped patients reverse DM2 progression, lowering all from a very high level of insulin therapy to on average 65% lower medication levels 50 weeks later, with two patients able to stop insulin therapy. Third, this is a challenging patient group with some being low in health- and ICT literacy. Following the design analysis, the highly simplified solution we created for secure, daily e-logging for sugar/insulin for this group was relatively useful. All patients used it well and it enabled everybody involved to closely monitor progression. Regarding other e-tools, appreciation and use varied, but their large potential was confirmed by our longer-term support needs analysis, plus the high intervention appreciation.

This preliminary analysis has several limitations. First, this is only a pilot study with 11 participants. So the focus is more on theory generation than on theory validation. Next, the study outcomes could have been very sensitive to participant diversity. Fortunately, the outcomes were sufficiently robust across participants. Second, the 50-week data analyses are not complete yet; more biometric and behaviour data analyses still need to be done. Third, regarding external validity, these study results may only apply to motivated individuals, who volunteer for lifestyle training. Taking responsibility for one’s health is an important requirement for successful lifestyle coaching. Fourth, it can be argued that TAM is not the only suitable instrument for evaluating technology adoption. For example, UTAUT (Venkatesh et al., 2003) is also viable. However, UTAUT was developed and validated in organisation contexts, where functional aspects of information systems adoption (like performance and effort expectations) are relatively important. In consumer/patient contexts, items regarding ‘attitude towards use’ are relevant as well (Carlsson et al., 2006), and those are part of TAM.

Still, on the positive side our results (biological, behavioural, TAM) prove relatively robust across the 11 participants, even though they are diverse in background (education, gender, age, insulin medication levels and co-morbidity, health literacy, coping and learning styles). The pilot provided an opportunity for design analysis regarding the hybrid service mix deployed. Next, it showed opportunities for further long-term e-relationship building, including affective (pride, having fun, giving or receiving encouragements) and social (connecting with others, sharing experiences, showing your best) support.
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References


E-health relationships diabetes


