

# 'This is why I'm doing a lot of exercise' — a qualitative study of participant's experiences of the Sophia Step Study

Jenny Rossen <sup>1,2</sup>, Helena Löf <sup>1,2,3</sup>, Agneta Yngve <sup>4</sup>, Maria Hagströmer <sup>5,6</sup>, Kerstin Brismar <sup>7,8,9</sup> and Unn-Britt Johansson <sup>1,2</sup>

<sup>1</sup>Department of Health Promotion Sciences, Sophiahemmet University, Stockholm 11486, Sweden; <sup>2</sup>Department of Clinical Science and Education, Karolinska Institutet, Stockholm 11883, Sweden; <sup>3</sup>Division of Health Care Education and Supplementary Education, Mälardalens University, Höskoleplan 72123 Västerås, Sweden; <sup>4</sup>Department of Food, Nutrition and Dietetics, Uppsala University, Uppsala 75236, Sweden; <sup>5</sup>Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm 14152, Sweden; <sup>6</sup>Functional Area Occupational Therapy and Physiotherapy, Karolinska University Hospital, 17176 Stockholm, Sweden; <sup>7</sup>Department of Molecular Medicine and Surgery, Karolinska Institutet Stockholm 17176, Sweden; <sup>8</sup>Rolf Luft Research Center for Diabetes and Endocrinology, Karolinska University Hospital, Stockholm, Sweden; <sup>9</sup>Sophiahemmet Hospital, Stockholm 11486, Sweden

**Introduction:** Support for physical activity (PA) is central in diabetes care. The Sophia Step Study is a three-armed randomised controlled trial aiming to evaluate different levels of support for increased PA in prediabetes and Type 2 diabetes. With the purpose to reveal the programme components and the mediating factors from the participants' perspective this paper aims to report a qualitative exploration of adhering participants' experiences after two years' study participation.

**Methods:** Semi-structured interviews were conducted with 18 participants (men,  $n = 11$ , women,  $n = 7$ , prediabetes,  $n = 5$ , Type 2 diabetes,  $n = 13$ , median age 68.5 years) who completed a two-year multi-component ( $n = 7$ ), single-component ( $n = 6$ ) intervention or served as controls ( $n = 5$ ) at a primary care center in Stockholm, Sweden. The interviews were analysed using content analysis with an inductive approach. Sophia Step Study is registered at ClinicalTrials.gov with Identifier: NCT02374788.

**Results:** The participants recalled the frequent study assessments as providing feedback of health outcomes; positive reinforcement; a sense of sentinel and a personalised approach. Group meetings, pedometers and health check-ups were valued as resources for increased awareness and motivation of PA; establishment of new routines and control over the own health. The long program duration allowed for maintenance of awareness and routines for PA

**Conclusion:** Adhering participants in theory-based interventions, but also in the control group, identified key mediators to support for PA. Feedback of results, personalised encouragement, emotional support and self-monitoring should be regarded in self-management of PA to optimise patient motivation and outcomes.

**Keywords:** Experience, Physical activity, Prediabetes, Sophia Step Study, Type 2 diabetes, Qualitative method, Self-management

## Introduction

Physical activity (PA) has beneficial effects on diabetes and cardiovascular disease and should serve as a cornerstone in diabetes care.<sup>1–3</sup> Health-enhancing PA is recommended to be performed on a regular basis, preferably daily.<sup>2</sup> This requirement places effort on the individual; integrating PA in the daily routines has been expressed as burdensome and stressful.<sup>4</sup> Indeed, a large number of Swedes with Type 2 diabetes are inactive.<sup>5</sup> To support self-management of PA in Type 2 diabetes pedometers, group counselling, motivational interviewing and prescribed exercise are evidence-based methods, recommended to be used.<sup>6–9</sup> The effects of these methods in Type 2 diabetes have been evaluated by their effect on increasing PA and improving clinical variables. To date, there is limited research on how individuals experience such interventions.

The Sophia Step Study is a theoretically based three-armed randomised controlled trial aimed to evaluate a single- and a multi-component intervention designed to support patients with prediabetes and Type 2 diabetes to increase their PA level.<sup>10</sup> The study is ongoing, recruiting participants in waves and planned to be completed by January 2020. In a program of such long duration process evaluation becomes essential; to evaluate whether the program components are implemented and if the program is accepted. Yet, it is important to explore participants' perspectives on the strengths and weaknesses of a program.<sup>11</sup> In addition, what we as researchers have evidence for as active ingredients might not be conclusive with what the patient's experience. To understand the mechanisms for behaviour change it is imperative to reveal the program components and the mediating factors from the participants' perspective. In behaviour

Correspondence to: Jenny Rossen, Department of Health Promotion Sciences, Sophiahemmet University, Stockholm 11486, Sweden. Email: jenny.rossen@shh.se  
© 2018 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

DOI 10.1080/20573316.2018.1437940

change trials, the control set-up is challenging as deciding to sign up for a research study and being assessed regularly may induce behaviour change per se. This makes the translation to practical care challenging and it is important to be aware of the thoughts that being a part of a research study may have.<sup>12</sup> Sophia Step Study included a rigorous assessment schedule and the control group participants can therefore be considered as a being offered a brief intervention. Qualitative inquiry assists in highlighting implementation factors, informal patterns, unexpected interactions as well as the subtle effects that taking part of a research study may have and is useful as a part of process evaluation.<sup>11</sup> The aim of this paper is to report a qualitative exploration of adhering participants' experiences after attending two years of the Sophia Step Study.

## Methods

### Intervention

The Sophia Step Study is a theory-based primary care PA intervention comprising several components.<sup>10</sup> Participants were randomised to one of three intervention arms (Figure 1).

### Participants

Patients diagnosed with prediabetes or Type 2 diabetes who fulfilled the inclusion criteria for Sophia Step Study<sup>10</sup> were recruited at a primary care centre in Stockholm, Sweden. Inclusion criteria for the main study were; 40–80 years of age and ability to communicate in Swedish, either having prediabetes (HbA1c > 39–<47 mmol/mol and/or fasting glucose >5.6 mmol/l) or diagnosed with Type 2 diabetes with a duration of >1 year. As this study aimed to explore experiences from participants adhering to each intervention arm, a criterion-based selection was applied. Inclusion criteria were ≥60% attendance at group counselling sessions, ≥80% of days with registered steps and attendance at ≥75% of study assessments.<sup>13</sup> In spring 2016, 59 of 62 enrolled participants had completed the two-year assessment schedule of Sophia Step Study. Out of these 36 meet the criteria's as adherers and were eligible for interview. Convenience sampling was applied by contacting eligible participants list wise. In all, 22 participants were

contacted for an interview by telephone or email until maximum variation was reached in terms of intervention group, sex and diagnosis (prediabetes and Type 2 diabetes). Two could not attend the interviews and two others had been taken ill and cancelled on the same day or on the day before the interview. Table 1 depicts the demographics of the 18 interviewed participants. Range duration of Type 2 diabetes was 3–25 years and of prediabetes 3–4 years.

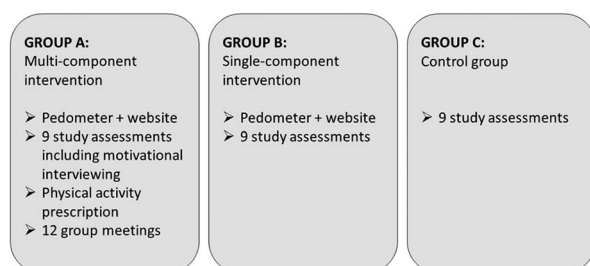
### Data collection

A semi-structured interview guide (Supplemental Table 1) was developed based the study purpose and the design of the intervention program.<sup>10</sup> Face-to-face individual interviews were conducted during January–April 2016 by the author HL. The interviews took place within 2–12 weeks after study completion in a private room near the primary care centre. The recorded interviews, which lasted 8–44 minutes effective time, were transcribed verbatim by the author U-BJ. Transcription validity was assured by HL and UBJ through reading the text while listening to the audio records.

### Data analysis

Manifest content analysis with an inductive approach was used to analyse the transcribed material, with the purpose to summarise and portray the content.<sup>14–15</sup> Question by question for each study group was treated as the unit of analysis.<sup>15</sup> The analysis process was made stepwise, starting by reducing the material to meaning units responding to the study purpose while keeping the core content. The meaning units were further condensed and subsequently labelled with codes. The codes were abstracted into main- and sub-categories by repetitive and methodical discussions of their similarities and differences among the authors.<sup>15</sup> The answers from the first and fifth interview questions were also deployed to describe reasons for participating and reflections on group allocation. Following the analysis differences and similarities between the three study groups was explored. Three researchers (JR, HL and U-BJ) independently listened to all recorded interviews and read the transcribed interviews, discussed, reflected and reached consensus upon the categories and collaborated in choosing quotations representing the findings.<sup>15</sup> Interviews and content analysis were performed in Swedish. The results and quotations were translated into English and verified by a professional translator.

Participants were randomized to:



**Figure 1** The three intervention arms with including intervention components.

**Table 1** Participants' demographics.

Total	Group	Diabetes	Gender	Age	BMI	University education
18	A: 7 B: 6 C: 5	72%	39% women	58–77 years	20–36 kg/m <sup>2</sup>	50%

## Results

From the analysis two main categories and five sub-categories were abstracted. Figure 2 describes the main- and sub-categories and Supplemental Table 2 displays quotations representing the findings.

### Professional management

In all groups, participants expressed confidence about the overall professional management of the study. The participants experienced the study as well tailored to people having prediabetes and diabetes by the provision of qualified guidance and resources for increased motivation and person-centred support. An intrinsic value of being part of a research study was expressed.

*Health check-ups and feedback* The participants referred to the study assessments as health check-ups that provided feedback on health outcomes; were experienced as encouraging; gave a feeling of control and of being in secure hands. The participants described the value of meeting a professional who was competent, who listened, who assisted in understanding the results and who had expectations of the results. Many participants expressed a feeling of emptiness at the completion of the study and called for more frequent check-ups as part of standard care.

*External resources supporting motivation to engage in PA* Group A and B participants experienced the pedometer and the accompanying step registration as a surprisingly simple method and a powerful motivator to perform

PA. The device assisted in becoming aware of the daily PA level and pattern, in setting goals and taking control over daily physical activities. The participants appreciated following their registered step level over time on the website and to compare their performance to that of others. The device assisted in relating the actual activity level to the individual step goal and reinforced reaching the goal. Group A participants emphasised the group meetings as an overall source of inspiration for PA. The meetings provided information, presented opportunities for sharing of experiences and advice and served as a platform to receive peer support and be each other's role-models. Participants in both group B and C expressed a desire to meet peers and share experiences.

Some frustrations were also expressed. One participant expressed a need for stricter management of the group sessions and some had experienced problems with the pedometer and suggested using more modern forms of step counters. Some irritations were also expressed over group participants that failed to register on a timely basis or not at all.

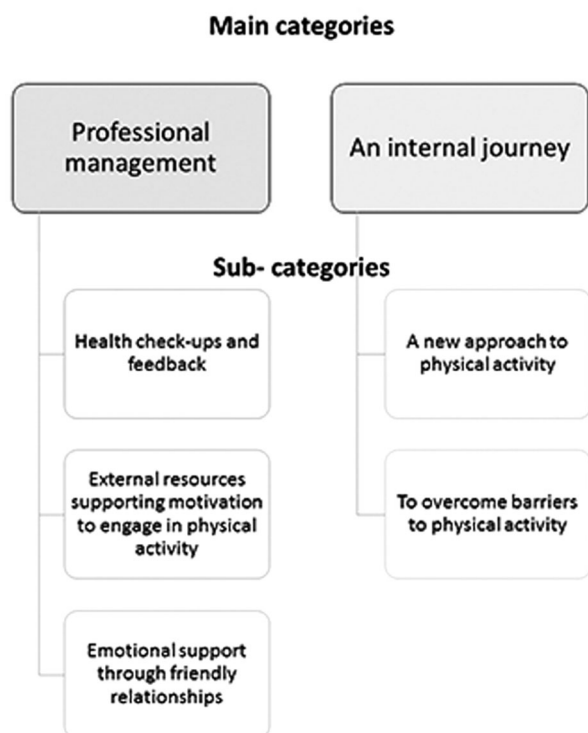
*Emotional support through friendly relationships* Meeting a professional with an interactive and open communication at the study assessments was a source of important emotional support. The feeling of being cared for, seen and watched over was important and the participants felt that the professionals were not overly enthusiastic or pushing.

Group A participants expressed large emotional gains by meeting peers and by an open and honest sharing of experiences, worries and barriers. The group meetings were described as pleasant, with easy and light conversations, a friendly and relaxed atmosphere and led to positive social pressure.

### An internal journey

Study participation, regardless of group affiliation, led to awareness of the importance of daily routines for PA and the participants taking more responsibility for their own health. Strategies to implement new routines and to deal with personal barriers during the study were described as a process, or part of a journey. A personal development was achieved, including struggles for maintenance of new habits to a structured thought about sustainable healthy habits.

*A new approach to PA* Several participants experienced a turning point, e.g. that PA is one of the necessary components for the maintenance of good health. During study participation, new approaches materialised for increased PA in daily life. Both simple strategies (e.g. getting of the bus a stop earlier; new walking routes and doing more household chores) as well as advanced strategies (e.g. investment in a gym membership; completing a crawling course and recruiting a personal trainer) were used. The study duration of two years provided the time required for the changes to root in the



**Figure 2** The content analysis resulted in two main- and five sub-categories.

daily routines. Many participants pronounce that the study became part of daily life, with daily thoughts about how to reach the day-to-day activity goals. The health improvement resulted in a feeling of having taken control over the own health, strengthened the participants' positive approach towards PA and helped to increase participants' intrinsic motivation for maintenance.

*To overcome barriers to PA* Symptoms from other diseases and conditions during the study contributed to participants' concern and frustration. In group A and B, it led to thoughts about not being able to participate in the study as wished or how to reach the PA goals that were initially set. Other issues in daily life could also decrease motivation and overcoming barriers was performed by a continuous internal dialogue. To perform PA was not always fun, but was viewed as something inevitable-as part of the process to achieving a healthy lifestyle. The process was described as a personal development requiring some effort.

### **Reasons for participation, reflections on randomisation and differences between intervention groups**

The main motives for participation were: the nurse invited; saw a need to improve health status and a desire to contribute to research. Group A participants expressed the randomisation as winning the highest prize, articulating a gratitude to be in a group format that enabled sharing experiences with others. Group B participants were generally pleased, and some were thankful about not being assigned to group meetings because that would have been time-consuming. Group C participants did not express many thoughts about the randomisation although some mentioned an initial disappointment. All participants expressed appreciation of the study assessments, although group A participants predominantly talked about group meetings and a cognitive re-evaluation. Group B participants stressed the pedometer and the social comparison of steps. Group C participants noted that they had received support in the study assessments and were generally pleased to be part of the study despite the allocation.

### **Discussion**

The findings of this study illustrate how participants with high adherence to the respective allocated study arm experience participation in Sophia Step Study.

The participants reflected upon the study assessments as encouraging, adequately pushing and giving a sense of being watched over. Also, participants from group B and C valued the study assessments, meeting someone that confirmed health outcomes, which had expectations of compliance and related to this as personalised encouragement. This was surprising as the assessments were short in time (10–15 minutes) and did not include consultations but merely feedback on health outcome. An

explanation may be that the participants met the same nurse throughout the study. These findings are consistent with research showing that reinforcing efforts are important in increasing PA and that a personalised approach is central in diabetes self-management.<sup>16–18</sup> Diabetes care is an essential emotional and practical resource in dealing with diabetes and the relationship between the nurse and the patient has repeatedly been regarded as an important aspect of diabetes care.<sup>4,17,19–20</sup> In addition, the participants in these intervention groups were given more responsibility for their own health and as such shared decision-making was applied.<sup>17</sup>

The pedometer was designated as a motivational tool for self-monitoring, goal-setting, prompt practice and reinforcing efforts. This confirms previous studies describing the mediating factors of pedometers for behaviour change.<sup>18,21</sup> The findings of this study also recognise and confirm that purposeful group meetings offer additional cognitive and emotional support in the self-management of diabetes.<sup>22,23</sup> Participants in group B and C expressed a wish to meet peers, a wish that has been pointed out in populations with Type 2 diabetes previously.<sup>4</sup> Prescribed PA, a component of the intervention for group A, was not mentioned in the interviews. This lack of acknowledging this component should not be interpreted as not being implemented or not helpful, but perhaps it played an inferior role to the other intervention components.

Some participants enrolled because they wanted to contribute to research. This may have contributed to an external motivation at the start, but an intrinsic motivation was demonstrated during the study. The two-year duration admitted maintenance of awareness and routines.

Strengths of this study are the application of an inductive approach, an initial broad interview questions and inclusion of control group participants that permitted an exploration of indirect effects of participating in a research study.<sup>12</sup> The authors have varied pre-understanding and involvement in the intervention, which enriched the discussions and analysis. The choice of involving HL for all interviews and for performing the content analysis strengthened the objectivity as she was not familiar with the theoretical background of the Sophia Step Study. The risk of missing or interpreting the results too rapidly was reduced by triangulation and close collaboration between the researchers and the process of agreeing on the categories assured credibility.<sup>15</sup>

The small number of participants studied could be a limitation. However, the interviews gave repetitive answers and there was no reason to include more participants. Some of the interview questions (3–4, 6–8) are rather guided, which indeed was steering the answers. The purpose was to reveal thoughts about the intervention components and to evaluate the program. This was also the reason for the initial selection of individuals in that a criterion-based sample was used in this study including only compliers from group A and B. The



experience of non-compliers and drop-outs is planned to be investigated in a separate study since it is imperative to carefully explore barriers, constraints and support needs of those not fully completing a program. Variation in the participants in terms of sex, intervention group (A, B and C), diagnoses, disease length, BMI and education increases the transferability of the findings. However, the study was restricted to patients who adhered to the interventions and belonging to a health care centre in central Stockholm, Sweden, and hence further research is needed for other population groups.

## Conclusions

Adhering participants in theory-based interventions, but also in the control group, identified key mediators to support for PA. Feedback of results, personalised encouragement, emotional support and self-monitoring should be regarded in self-management of PA to optimise patient motivation and outcomes.

## Acknowledgements

The authors thank all patients who participated in the individual interviews.

## Declaration of interests

The authors report no declarations of interest.

## Funding

This work was supported by the Sophiahemmet Foundation; The Swedish Diabetes Foundation; King Gustav V and Queen Victoria's Order of Freemasons Research Foundation; Vårdalstiftelsen; Skandia; and The Sibling Svensson's Foundation for Medical Research. None of the funding bodies have had any role in the design of the study, data collection, data analysis, interpretation of data nor in writing the manuscript.

## Author contributions

AY, KB, MH, JR and U-BJ designed the Sophia Step Study. JR, HL and U-BJ developed the study design for this qualitative study. Data collection were made by HL and data analysis performed by JR, HL and U-BJ. JR drafted the manuscript and all authors critically reviewed and revised the manuscript and approved the final version.

## Ethical considerations

Participation was made on a voluntary basis and participants were informed that they could resign participation without giving any reason. Informed consent was collected from all participants before the interviews. Anonymity and confidentiality of the participants were assured. Ethical approval was obtained from the Regional Ethical Review Board in Stockholm, Sweden (2012/1570–31/3 and 2015/2075-32).

## ORCID

Jenny Rossen  <http://orcid.org/0000-0003-4920-252X>  
 Helena Ljöf  <http://orcid.org/0000-0002-7018-2706>  
 Agneta Yngve  <http://orcid.org/0000-0002-7165-279X>  
 Maria Hagströmer  <http://orcid.org/0000-0002-4607-8677>  
 Kerstin Brismar  <http://orcid.org/0000-0002-5241-514X>  
 Unn-Britt Johansson  <http://orcid.org/0000-0003-3309-136X>

## References

- Kodama S, Tanaka S, Heianza Y, Fujihara K, Horikawa C, Shimano H, et al. Association between physical activity and risk of all-cause mortality and cardiovascular disease in patients with diabetes: a meta-analysis. *Diabetes Care*. 2013;36:471–479.
- Colberg SR, Sigal RJ, Yardley JE, Riddell MC, Dunstan DW, Dempsey PC, et al. Physical activity/exercise and diabetes: a position statement of the American diabetes association. *Diabetes Care*. 2016;39:2065–2079.
- Authors/Task Force M, Ryden L, Grant PJ, Anker SD, Berne C, Cosentino F, et al. ESC Guidelines on diabetes, pre-diabetes, and cardiovascular diseases developed in collaboration with the EASD. *Eur Heart J*. 2013;34:3035–3087.
- Svedbo Engstrom M, Leksell J, Johansson UB, Gudbjornsdottir S. What is important for you? A qualitative interview study of living with diabetes and experiences of diabetes care to establish a basis for a tailored patient-reported outcome measure for the Swedish national diabetes register. *BMJ Open*. 2016;6:e010249.
- Zethelius B, Gudbjornsdottir S, Eliasson B, Eeg-Olofsson K, Cederholm J, Swedish National Diabetes R. Level of physical activity associated with risk of cardiovascular diseases and mortality in patients with type-2 diabetes: Report from the Swedish national diabetes register. *Eur J Prev Cardiol*. 2014;21:244–251.
- Bravata DM, Smith-Spangler C, Sundaram V, Gienger AL, Lin N, Lewis R, et al. Using pedometers to increase physical activity and improve health. *JAMA*. 2007;298:2296–2304.
- van Dam HA, van der Horst FG, Knoops L, Ryckman RM, Crebolder HF, van den Borne BH. Social support in diabetes: a systematic review of controlled intervention studies. *Patient Educ Couns*. 2005;59:1–12.
- Christie D, Channon S. The potential for motivational interviewing to improve outcomes in the management of diabetes and obesity in paediatric and adult populations: a clinical review. *Diabetes Obes Metab*. 2014;16:381–387.
- Hordern MD, Dunstan DW, Prins JB, Baker MK, Singh MA, Coombes JS. Exercise prescription for patients with type 2 diabetes and pre-diabetes: a position statement from exercise and sport science Australia. *J Sci Med Sport*. 2012;15:25–31.
- Rossen J, Yngve A, Hagstromer M, Brismar K, Ainsworth BE, Iskull C, et al. Physical activity promotion in the primary care setting in pre- and type 2 diabetes — the Sophia step study, an RCT. *BMC Public Health*. 2015;15:647.
- Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: medical research council guidance. *BMJ*. 2015;350:h1258. doi:10.1136/bmj.h1258.
- MacNeill V, Foley M, Quirk A, McCambridge J. Shedding light on research participation effects in behaviour change trials: a qualitative study examining research participant experiences. *BMC Public Health*. 2016;16:91.
- Patton MQ. *Qualitative research & evaluation methods: integrating theory and practice*. Thousand Oaks (CA): SAGE Publications; 2015.
- Krippendorff K. *Content analysis: an introduction to its methodology*. Thousand Oaks (CA): SAGE Publications; 2013.
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24:105–112.
- Olander EK, Fletcher H, Williams S, Atkinson L, Turner A, French DP. What are the most effective techniques in changing obese individuals' physical activity self-efficacy and behaviour: a systematic review and meta-analysis. *Int J Behav Nutr Phy*. 2013;10:1–15.
- Powers MA, Bardsley J, Cypress M, Duker P, Funnell MM, Fischl AH, et al. Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American diabetes association, the American association of diabetes educators, and the academy of nutrition and dietetics. *Clin Diabetes*. 2016;34:70–80.
- Horner GN, Agboola S, Jethwani K, Tan-McGrory A, Lopez L. Designing patient-centered text messaging interventions for increasing physical activity

- among participants with type 2 diabetes: qualitative results from the text to move intervention. *JMIR Mhealth Uhealth*. 2017;5:e54.
19. Hornsten A, Lindahl K, Persson K, Edvardsson K. Strategies in health-promoting dialogues — primary healthcare nurses' perspectives — a qualitative study. *Scand J Caring Sci*. 2014;28:235–244.
  20. Ciechanowski PS, Katon WJ, Russo JE, Walker EA. The patient-provider relationship: attachment theory and adherence to treatment in diabetes. *Am J Psychiatry*. 2001;158:29–35.
  21. Tudor-Locke C, Lutes L. Why Do Pedometers Work? *Sports Med*. 2009;39:981–993.
  22. Lidegaard LP, Schwennesen N, Willaing I, Faerch K. Barriers to and motivators for physical activity among people with type 2 diabetes: patients' perspectives. *Diabet Med*. 2016;33(12):1677–1685.
  23. Hughes S, Lewis S, Willis K, Rogers A, Wyke S, Smith L. The experience of facilitators and participants of long term condition self-management group programmes: a qualitative synthesis. *Patient Educ Couns*. 2017;100:2244–2254.