


BMJ Open Associations between diabetes duration and self-stigma development in Japanese people with type 2 diabetes: a secondary analysis of cross-sectional data

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ABSTRACT

Objectives To examine the associations between self-stigma and diabetes duration in a sample of Japanese people with type 2 diabetes.

Design A secondary analysis of a cross-sectional study.

Setting Two university hospitals, one general hospital and one clinic in Tokyo, Japan.

Participants Outpatients with type 2 diabetes aged 20–74 years and receiving treatment from diabetes specialist physicians (n=209) completed a self-administered questionnaire.

Primary and secondary outcome measures Self-stigma was measured as the primary outcome. Patient Activation Measure, body mass index and haemoglobin A1c were measured as secondary outcomes.

Results One-way analysis of covariance showed significant differences in self-stigma levels between the five groups of diabetes duration (≤ 5 years, 6–10 years, 11–15 years, 16–21 years and 22 years or more) after controlling for age, gender, education, marital status, diabetes treatment (insulin use) and diabetes-related complications, $F(4,198)=2.83$, $p=0.026$. Multiple comparisons using Bonferroni correction showed statistically significant differences in self-stigma levels between the groups with ≤ 5 years (95% CI 59.63 to 69.73) and 11–15 years with diabetes (95% CI 71.12 to 80.82; $p=0.020$). The highest mean level of self-stigma was observed in the group having diabetes for 11–15 years.

Conclusions Self-stigma was associated with diabetes duration and was lowest after diagnosis and gradually increased, with its highest levels being observed in those having diabetes for 11–15 years. Self-stigma takes time to develop and gradually increases in individuals as it is learnt through direct experiences of diabetes-related stigma after self-administering treatment in everyday social situations.

INTRODUCTION

In recent years, researchers worldwide have shown interest in diabetes-related stigma, with a number of studies focusing on this topic.^{1–5}

Strengths and limitations of this study

- This study is the first to examine the associations between self-stigma and diabetes duration using a secondary analysis of cross-sectional data.
- This study's strength includes its analysis of self-stigma development in a sample of outpatients with type 2 diabetes mellitus (T2DM) with varying lengths of time since diagnosis.
- The duration of living with T2DM was classified into five groups by diabetes duration quintiles: (1) ≤ 5 years, (2) 6–10 years, (3) 11–15 years, (4) 16–21 years and (5) ≥ 22 years to capture at different stages of disease management.
- Our findings have generalisability as the study sample reflected varying types of patients from four different types of medical facilities (two university hospitals, a general hospital and a clinic).
- Owing to the limitations of this study's cross-sectional design, causal inferences regarding the relationships between self-stigma and diabetes duration cannot be made.

Goffman published his pioneering study in 1963 on the concept of stigma, and since then, it has been redefined and reworked by sociologists and social psychologists.^{6–12} *Stigma* has been generally defined as any attribute likely to put an individual at odds with societal norms, resulting in negative stereotyping, prejudice, blame, rejection, status loss and discrimination.^{6–12} It is known that the onset of type 2 diabetes mellitus (T2DM) and the progression of its complications are interconnected with both environmental and genetic factors.^{13 14} Nevertheless, T2DM is conventionally evaluated using an external perspective (eg, diet, exercise) rather than an intrinsic genetic-based method.^{1 3 15}

From a stigmatised person's viewpoint, stigma can be understood as taking three forms.^{16–20} First, *experienced stigma* refers to a person experiencing discrimination due to social unacceptability.^{16 19} Second, *perceived stigma* occurs when a person fears shameful, discriminatory situations and/or detrimental treatment because of their condition.^{16 19} Third, *self-stigma* is when people are aware of negative stereotypes, prejudices, and discrimination regarding themselves, agree with them, and direct these negative and biased beliefs, feelings and behaviours internally.^{17 18 20}

Perceived stigma occurs in individuals with T2DM *before* their diagnosis and affects a wide range of individuals' health behaviours.^{1 21–26} For example, avoiding screening tests, refusing a diabetes diagnosis, delaying treatment and concealing a diagnosis from family members are forms of perceived stigma.^{1 21–26} In contrast, self-stigma occurs in individuals with T2DM during disease management. Empirical research has demonstrated that increased self-stigma negatively impacts the quality of patients' interactions with healthcare professionals and their self-management behaviours,²⁷ specifically patients' activation to engage in self-care, which it affects directly and indirectly through self-esteem and self-efficacy.^{2 28 29} Activating patients to engage in self-care is critical for increasing patients' ability to gain the knowledge, skills, confidence, and behaviours required to manage their illness.^{30 31} A recent prospective longitudinal study reported that patients' activation is associated with their diet and exercise behaviours as well as a reduction in body mass index (BMI), weight and glycated haemoglobin (HbA1c) among people with T2DM.³² Given these evidences, we elected to include patients' activation to engage in self-care, BMI and HbA1c as secondary outcome variables in this study.

Limited research has examined when self-stigma develops during the disease management process. Many studies on diabetes-related stigma have overlooked the differences between self-stigma and perceived stigma, especially the components distinctive to self-stigma resulting in patients internally directing their negative attitudes and behaviours.^{27 33 34} People with T2DM are unlikely to begin applying negative attitudes and behaviours internally immediately after diagnosis. Based on the existing research, we hypothesised that self-stigma needs time to develop, such that its level is the lowest at the time of diagnosis and the early stages of treatment. Therefore, this study aimed to examine the associations between self-stigma and diabetes duration in people with T2DM using secondary data analysis of our previous cross-sectional study.²

METHODS

Participants

We conducted a secondary analysis using cross-sectional data from a self-administered questionnaire for outpatients with T2DM receiving treatment from diabetes

specialist physicians at hospitals in Tokyo, Japan. The eligibility criteria for the participants included (1) being diagnosed with T2DM, (2) being aged 20–74 years, (3) speaking Japanese as a native language, (4) having no problem with cognitive functions and (5) requiring no urgent medical procedures on the day of completion of the questionnaire at the physicians' discretion.

A detailed description of the study procedures has been published previously.² After a clinic visit, physicians used a consecutive sampling method, and distributed a letter explaining the survey questionnaire to their eligible patients after screening for the inclusion criteria based on patients' medical records. Thus, except for the patients having an exclusion criterion, including cognitive impairment, physicians distributed the letter to *all* their patients on the corresponding day of recruitment. The research staff spoke to the patients who received the letter in a separate, private room at the hospital and explained the purpose of the study to patients who met the eligibility criteria. Only patients who provided written informed consent participated. The research staff distributed the questionnaire to participants and asked them to answer it individually.

As for the sample size, this study was a secondary data analysis of our previous study²; thus, a post hoc power analysis was conducted using G*Power (V.3.1) to calculate the actual power ($\beta=0.25$) and effect size (0.23) on the basis of a one-way analysis of covariance (ANCOVA), a two-tailed $\alpha=0.05$, a final sample size of 209 and six covariates.

Measures

The following items were investigated using a self-administered anonymous questionnaire: age, gender, height, weight, diabetes duration (years), education (years), marital status, diabetes treatment (eg, oral hypoglycaemic agents, insulin injection and other injection therapy) and their HbA1c level on the day they completed the questionnaire, which was written down directly from the blood test result. BMI was calculated using patients' height and weight. Both BMI and HbA1c were used as secondary outcomes to understand the clinical characteristics by their diabetes duration. Diabetes-related complications were calculated by the research staff based on patient-report with reference to the Diabetes Complications Index.³⁵ Participants took approximately 15–20 min to complete the whole questionnaire. Additionally, the questionnaire included scales measuring self-stigma and patient activation.

Self-stigma

Self-stigma was measured as the primary outcome. To assess self-stigma levels, we used a reliable and validated instrument—the Japanese version of the Self-Stigma Scale (SSS-J).^{18 20} The scale consists of 39 items evaluated on a 4-point Likert scale ranging from *strongly disagree* to *strongly agree* (rated from 0 to 4), with total scores ranging from 0 to 117 points as a continuous variable. Higher

Table 1 Participants' sociodemographic and clinical characteristics (n=209)

Participant characteristics	n or M	% or SD
Gender		
Men	168	80.4
Women	41	19.6
Age (years)	60.2	10.1
BMI (kg/m ²)	26.3	5.2
Duration of diabetes (years)	13.3	9.4
Primary treatment		
Oral hypoglycaemic agents	123	58.9
Insulin injections	15	7.2
Insulin injections and oral hypoglycaemic agents	44	21.1
Other injectable medications (other than insulin)	14	6.7
Lifestyle	13	6.2
Diabetes-related complications (0–6)*	0.57	0.86
HbA1c (%)	7.3	1.2
HbA1c (mmol/mol)	56	13.1
Education (years)	13.9	2.3
Marital status		
Married	151	72.2
Unmarried/divorced/bereaved	58	27.8

*The Diabetes Complications Index. BMI, body mass index; HbA1c, glycated haemoglobin; M, mean.

total scores indicated higher self-stigma levels. The internal consistency of the SSS-J in this study was 0.96. Sample items of the scale were as follows: 'Being a patient with diabetes takes away many opportunities from me', 'I have negative feelings about myself with diabetes' and 'I avoid interacting with others because I am a patient with diabetes'.

Patient activation

The Japanese version of the Patient Activation Measure (PAM-13) was used as a secondary outcome to understand clinical characteristics by diabetes duration. The scale is a reliable and validated instrument that can assess patients' activation levels for engaging in self-care.³⁶ The PAM-13 can comprehensively measure the patients' activation levels for self-care, such as the patients' knowledge, skills, confidence and behaviours required to manage their illness.^{30 31} Previous studies showed that the scale could predict not only dietary and exercise behaviours but also comprehensive behaviours that include disease-specific self-management behaviours (eg, glucose monitoring, taking medications).^{30 37} We intentionally selected the PAM-13 because it considers both single instances of self-care behaviours and a person's knowledge, skills and beliefs regarding their chronic disease management. The scale consists of 13 items evaluated on a 4-point

Likert scale ranging from *strongly disagree* to *strongly agree*. Total scores ranged from 13 to 52, and the scores were converted to an interval scale score (0 to 100) based on the algorithm by the scale developer.³⁰ The higher the total score, the higher the patients' activation level for self-care. The internal consistency of the PAM-13 in this study was 0.85. Sample items of the scale were as follows: 'I am confident that I can follow through on medical treatments I may need to do at home' and 'I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising'.

Statistical analyses

This study was a secondary analysis of cross-sectional data collected in our previous study.² The dataset was generated by AK, YF, SF, AI, YO, RS, KU, TY, TK and HH, and some of the data are openly available in Dryad.³⁸ For descriptive statistics, we calculated continuous data using means and SD and categorical data using frequencies and percentages. Participants were classified into the following five groups by diabetes duration quintiles: (1) ≤5 years, (2) 6–10 years, (3) 11–15 years, (4) 16–21 years and (5) ≥22 years. Next, we calculated the mean and 95% CI for self-stigma, PAM-13, BMI and HbA1c of each group. We compared each diabetes duration group for differences in their levels of self-stigma, PAM-13, BMI and HbA1c, using ANCOVAs after controlling for age, gender, education, marital status, diabetes treatment (insulin use) and diabetes-related complications as possible confounders based on our previous study.² When significant main effects were found, we conducted multiple comparison tests with Bonferroni corrections. The significance level was set at p<0.05. We used SPSS V.23.0 (SPSS Japan) to conduct all analyses.

Patient and public involvement

No patients were involved in designing this study, recruiting participants or conducting the study. However, they were informed that the research team would disseminate the final study findings to them and the public.

RESULTS

We asked 259 outpatients with T2DM to participate in the study at four medical facilities (two university hospitals, one general hospital and one clinic) in Tokyo, Japan and obtained written informed consent forms from 218 (participation rate 84.2%). Of these, 217 completed the questionnaire (one declined). We excluded five participants who chose *strongly disagree* for all 39 items of SSS-J from the analysis because it was uncertain whether the scale was able to measure what it was originally intended to assess. We also excluded three participants who chose *strongly agree* for all 13 items of the PAM-13 from the analysis as per the instructions from the scale developer.³⁰ Therefore, the final analytic sample included 209 participants. There were no missing data both in the scales and participants' demographics.

Table 2 Means, 95% CIs and one-way analyses of covariance of self-stigma levels, PAM-13 scores, BMI and HbA1c levels of the five different groups of diabetes duration

Measure	Group	n	M	95% CI		F	P value	Partial η^2
				LL	UL			
Self-stigma*	≤5 years	44	64.68	59.63	69.73	2.83	0.026	0.05
	6–10 years	50	70.22	65.71	74.73			
	11–15 years	42	75.97	71.12	80.82			
	16–21 years	32	74.62	69.03	80.22			
	≥22 years	41	71.22	65.97	76.48			
PAM-13†	≤5 years	44	53.50	50.58	56.42	0.48	0.748	0.01
	6–10 years	50	50.94	48.33	53.55			
	11–15 years	42	51.67	48.86	54.47			
	16–21 years	32	51.96	48.73	55.20			
	≥22 years	41	51.18	48.14	54.22			
BMI (kg/m ²)	≤5 years	44	28.19	26.74	29.64	2.07	0.086	0.04
	6–10 years	50	26.23	24.93	27.52			
	11–15 years	42	25.41	24.01	26.80			
	16–21 years	32	25.95	24.35	27.56			
	≥22 years	41	25.76	24.25	27.27			
HbA1c (%)	≤5 years	44	7.41	7.08	7.73	0.36	0.837	0.01
	6–10 years	50	7.22	6.93	7.51			
	11–15 years	42	7.32	7.00	7.63			
	16–21 years	32	7.28	6.91	7.64			
	≥22 years	41	7.14	6.80	7.48			

Means were calculated after controlling for age, gender education, marital status, diabetes treatment (insulin use) and diabetes-related complications.

*The Japanese version of Self-Stigma Scale (SSS-J).

†Patient Activation Measure.

BMI, body mass index; HbA1c, glycated haemoglobin; M, mean; PAM-13, Patient Activation Measure.

Table 1 shows participants' sociodemographic and clinical characteristics. The mean age of the participants was 60.2 years (SD=10.1, range 23–74), and the proportion of men was 80.4% (n=168). The mean duration of diabetes was 13.3 years (SD=9.4, range 0.1–51.0) and the mean score on the Diabetes Complications Index was 0.57 (SD=0.86, range 0–4). About 60% of participants used hypoglycaemic agents without insulin and other injections. Participants reported having a mean education of 13.9 years (SD=2.3, range 9–18), and about 70% of the participants were married.

Table 2 shows the results of ANCOVAs for differences in self-stigma, PAM-13, BMI and HbA1c by diabetes duration. Figure 1 shows the mean self-stigma levels by diabetes duration group. The ANCOVA showed a significant difference in self-stigma levels between the five groups after controlling for age, gender, education, marital status, diabetes treatment (insulin use) and diabetes-related complications, $F(4,198)=2.83$, $p=0.026$. The lowest mean self-stigma level was observed in the diabetes group with ≤5 years and increased in order from 6–10 years to 11–15 years of diabetes. The highest mean

self-stigma level was observed in the group with 11–15 years of diabetes and decreased in order from 16–21 years to 22 years or more. Multiple comparisons using

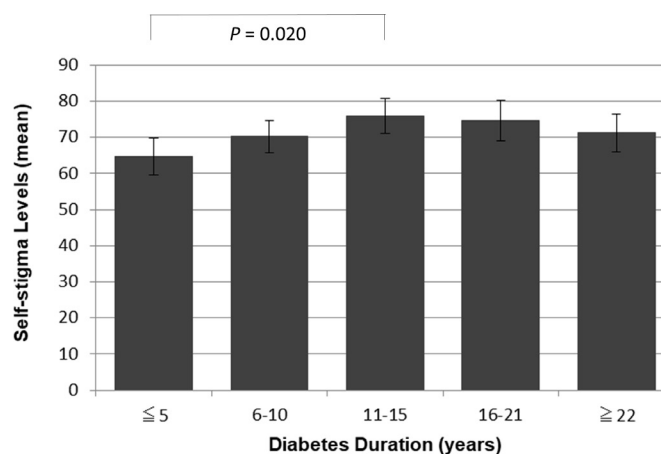


Figure 1 Mean self-stigma levels (SSS-J) of diabetes duration (n=209) groups. Self-stigma, The Japanese version of Self-Stigma Scale (SSS-J).

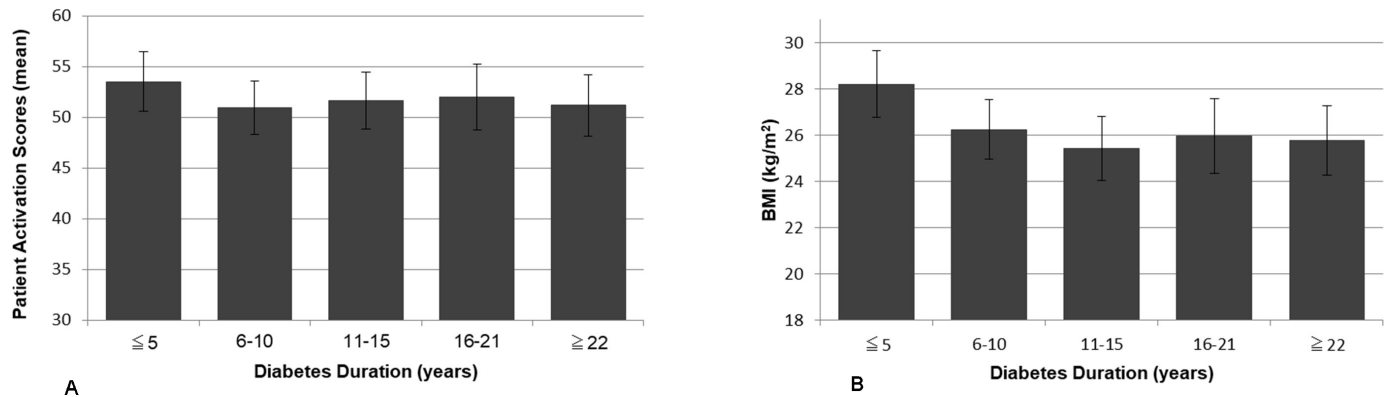


Figure 2 (A) Mean patient activation scores (PAM-13) of diabetes duration (n=209) groups. (B) Mean BMI of diabetes duration (n=209) groups. Patient Activation, Patient Activation Measure (PAM-13). BMI, body mass index.

Bonferroni correction showed that there were statistically significant differences in self-stigma levels between the groups with ≤ 5 years (95% CI 59.63 to 69.73) and 11–15 years of diabetes (95% CI 71.12 to 80.82, $p=0.020$).

Figure 2 shows the mean PAM-13 and BMI by diabetes duration group. The highest mean PAM-13 level was observed in the group with ≤ 5 years of diabetes. There was a tendency for maintaining consistent levels for the rest of the four groups according to diabetes duration, though there were no significant differences in mean PAM-13 levels, $F(4,198)=0.48$, $p=0.748$. The lowest mean BMI level was observed in the group with 11–15 years of diabetes, though there were no significant differences in mean BMI levels, $F(4,198)=2.07$, $p=0.086$. As for mean HbA1c levels, there were no significant group differences, $F(4,198)=0.35$, $p=0.837$.

DISCUSSION

This study examined self-stigma development by diabetes duration using a secondary analysis of cross-sectional data among Japanese people with T2DM. The study's main finding was identifying an association between self-stigma and diabetes duration, with self-stigma being the lowest immediately after diagnosis and gradually increasing to its highest levels in those with a diabetes duration of 11–15 years.

The current findings are consistent with the existing literature on T2DM.^{4 39 40} For example, our findings were consistent with research demonstrating an association between age and diabetes stigma⁴ that found that younger patients, who are typically socially active, were at an increased risk of experiencing socially unjustified and unequal treatment because of their condition compared with older patients.⁴ Similarly, our study found that self-stigma was less likely to occur immediately following a participant's diagnosis but rather developed gradually after receiving treatment and directly experiencing diabetes-related stigma in everyday social life. Moreover, our findings support those by Scheff, who argued that negative stereotypes toward illness are learnt

and reinforced in daily life through socialisation and can ultimately change one's self-perception and social opportunities.³⁹

Interestingly, while self-stigma was highest in the group with a diabetes duration of 11–15 years, self-stigma was shown to decrease gradually for those who had diabetes for 16–21 years and ≥ 22 years. One potential explanation for this gradual decrease is that self-stigma may decrease in patients as they socially adapt to their illness on their own. The age range of the study participants was widely distributed for each group based on diabetes duration (eg, 11–15 years of diabetes: 43–72 years old, 16–21 years of diabetes: 47–74 years old, 22 or more years of diabetes: 52–73 years old). There were six fully retired participants in the group with 11–15 years of diabetes, five in the group with 16–21 years of diabetes and two in the group with 22 years or more of diabetes. Thus, the gradual decrease in self-stigma in the group with 16 or more years of diabetes, was considered more likely the result of illness adaption, rather than effects of older age and/or retirement. This explanation is supported by our previous qualitative research showing that some patients independently adapt to their illness as they discover positive self-representations through diabetes treatment (eg, realising that one does not lack self-control) over time.⁴⁰ Our previous study also showed that people with T2DM took approximately 10–15 years to discover positive self-representations.⁴⁰

It is important to note that perceived stigma does not necessarily require patients' direct experiences and can even occur before diagnosis via surrogate experiences (eg, other patients, family members, colleagues and friends).^{21 22 26} Thus, unlike perceived stigma, this study showed that self-stigma has distinct characteristics in the context of its time of occurrence and the learning pathways since self-stigma cannot be developed secondhand but requires direct experiences. To our best knowledge, this represents the first study to analyse the associations between self-stigma and diabetes duration, and its strength and contributions are in its unique analysis of the development of self-stigma using a sample of people

with T2DM who had lived with a diabetes diagnosis for a long time.

This study had several limitations. First, this study used a cross-sectional design as a part of the secondary analysis of an existing dataset; thus, causal inferences regarding the relationships between self-stigma and diabetes duration cannot be made. Future research should collect prospective longitudinal data to verify the relationships between self-stigma, diabetes duration, and patients' activation to engage in self-care. Second, the study participants were currently being seen and treated by diabetes specialist physicians; thus, participants receiving medical treatment from general practitioners were not included. Therefore, the study results may not be generalised to the entire T2DM population with varying severity levels in Japan. Further studies will be needed in the future for collecting data from people with different T2DM severities who are treated by both specialists and general practitioners.

Conclusions

Despite these limitations, this secondary data analysis identified several distinctive characteristics of self-stigma and contributed to the literature on diabetes self-stigma. Further, the results have important practical implications for clinical practice. Self-stigma was found to develop approximately 10–15 years after diagnosis in individuals with T2DM; thus, self-stigma could be attenuated or prevented using an appropriately timed intervention before patients are at risk of self-stigma. Healthcare professionals can provide some consultation with psychosocial care (eg, psychosocial referrals for patients needing additional support), particularly for patients whose diabetes duration is 10–15 years and who have yet to display proactive self-engagement for their diabetes treatment. Generally, after patients live with diabetes for many years (eg, more than 10 years), physicians expect patients to better understand diabetes and its treatment and to have adapted to their illness. Accordingly, these patients' self-engagement for diabetes treatment has been expected to become increasingly internally motivated and proactive over time. However, in this study, people with T2DM that had a duration of 11–15 years displayed some clinical characteristics that differed from other groups, including lower patient activation levels for self-care and the lowest BMI levels, although these differences were not statistically significant between the groups. Therefore, healthcare professionals should remember that self-stigma can have long-term effects on patients' activation for engaging in self-care that can affect them throughout their lifetime of treatment.

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Contributors AK conceptualised and designed the study. AK coordinated the study acquired, analysed, and interpreted the data, and prepared the paper. HH and TK helped to analyse and interpret the data. AK and HH held primary responsibility for data access. YF, SF, AI, YO, RS, KU, TY and TK made significant contributions to the critical interpretation of the results in terms of important practical content. All authors read and approved the final version of the manuscript. HH and AK accept full responsibility for the work. HH, TK, SF, AI and YO accept full responsibility for the conduct of the study. AK and HH had primary responsibility for the data access. All authors controlled the decision to publish.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and this survey was conducted with prior approval by the Research Ethics Committee of the University of Tokyo Graduate School of Medicine and Faculty of Medicine and each participating medical facility. The secondary analysis conducted in this study was exempt from another IRB approval (Approval No. 3269; 17 September 2013). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available in a public, open access repository. Data are available upon reasonable request. The data that support the findings of this study are available from the corresponding author upon reasonable request. Also, some data presented in this study are openly available in Dryad at <https://doi.org/10.5061/dryad.dncjsxkwd>.

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