ORIGINAL ARTICLE



Patient satisfaction with stoma care and their expectations on mobile apps for supportive care

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Abstract

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Aim: Self-efficacy in stoma care is essential, as it reduces morbidity and psychosocial problems. Mobile applications (apps) may optimise patients' self-efficacy. This article investigates patients' satisfaction with stoma care, their attitudes towards a supporting app aiming to promote self-efficacy and evaluate which functionalities are desired.

Method: A survey was sent to members of the two stoma-related patient associations in the Netherlands. Associations between patient characteristics, satisfaction concerning received stoma care, and willingness to use an app were evaluated.

Results: The survey was completed by 1868 patients. Overall satisfaction was scored as 6.6, with shortfalls reported in the preoperative information provision, stoma site selection, and postoperative care. Patients of older age, who were unaware of getting a stoma, had an ileostomy, a low quality of life or psychosocial problems, were less satisfied. An app was expected to be of added value by 59.4% of the patients having a stoma for less than three years, compared to the significantly lower 43.8% expectation rate of the remaining study population (p < 0.001). Moreover, patients with a high frequency of physical or psychosocial problems expressed higher levels of interest.

Conclusion: Patients were only moderately satisfied with their received stoma care. A supportive app is most likely beneficial for patients who had a stoma for less than three years, were in an acute situation, and/or have stoma-related problems. Most patients prefer information via internet or on paper, although apps may offer additional benefits. It is important to acknowledge digital literacy and to council patients appropriately about the benefits and help them to use apps.

KEYWORDS

app, colorectal, colostomy, digital, ehealth, ileostomy, mhealth, mobile health, satisfaction, stoma, surgery, urostomy

INTRODUCTION

It has been estimated that over 750,000 people in the United States have an ostomy [1]. In the Netherlands, this number is estimated to be 40,000 [2]. For some patients, a stoma may improve quality of life [3]. For others, having a stoma may negatively impact one's self-image and daily functioning, resulting in reduced quality of life [4-6]. Coping with a stoma may result in insecurity, leading to various psychosocial problems [7]. Patients who are unable to manage their stoma well are at risk of encountering stoma-related morbidities, such as skin irritation, leakage, parastomal hernia, or prolapse, with an incidence varying from 20% to 80% [8, 9]. Patients with a

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high self-efficacy in stoma care had fewer psychosocial problems and stoma-related morbidities [10, 11]. Hence, tailored patient education and guidance are essential for improving patients' ability to cope with a stoma and their quality of life.

Providing targeted and adequate stoma care can be challenging. Even when a stoma is given in an elective situation with patients receiving proper counselling, they may be unable to retain and replicate the given information due to the shock of having to undergo an operation and the news of getting a stoma. Hence, even if counselling is well done, it is very important for patients to have access to stoma-related information. Several educational stoma care programmes have been described in the literature, all of which have shown positive results in terms of psychosocial skills, self-efficacy, and quality of life [12, 13]. Surprisingly, it is largely unknown whether the current preoperative information routine and stoma care yield sufficient patient satisfaction and whether patients' needs are met. A mobile application (app) may provide a sustainable solution fitting patients' individual needs, situations and daily routines, and stimulating self-management [14-16]. Apps may offer important benefits, such as personalisation of information, connectivity or monitoring functionalities, wound-care videos, and information availability on a hand-held device. However, understanding patients' opinions on current stoma care and their specific needs in care and their preferred pathway of information is necessary. Only then, it becomes clear whether there actually is a need for improvement and additional support, and moreover, in what format.

METHODS

Study design

A national retrospective survey study was conducted in cooperation with the two Dutch stoma-related patient associations ("Stomavereniging" and "Stichting Stomaatje"). This study was conducted according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [17]. Ethical approval was waived by the local Ethics Committee of Amsterdam UMC.

Development of the questionnaire

The questionnaire used in this study was based on the consumer quality index stoma care (CQISC) which assesses the medical status of patients with stoma and their experiences with overall healthcare [18]. The questionnaire was compiled by our research team and included clinical experts in stoma care and stoma patient associations. The questionnaire consisted of three parts: (1) patient characteristics and medical status, (2) current stoma care including possible improvements and patient satisfaction, and (3) patients' experiences with mobile technology, assessing the needs for the desired functionalities of an app. Satisfaction was evaluated with the satisfaction concerning stoma care questionnaire

What does this paper add to the literature?

Although stoma care is critical to patients' quality of life, it is largely unknown whether current stoma care yields sufficient patient satisfaction and meets patients' needs. This study showed that patients were only moderately satisfied with received care and a mobile app is considered an important addition by many patients.

(SSCQ), which was validated to evaluate perioperative stoma care [19]. The SSCQ contains three domains: "preoperative care and information", "postoperative care and guidance", and "contact with stoma nurse" with a total of 20 questions (total score: minimum of 20 and maximum of 100).

Study population

The two patient associations sent invitational e-mails to their members. The members of the Dutch Stoma Association, "Stomavereniging", were already part of an active panel, regularly participating in patient-related surveys, and received a closedunique and personal invitation link. Members of the Dutch Patient Foundation "Stomaatje" received an open—not unique-invitation link. The inclusion criterion was patients with a stoma (e.g., ileostomy, colostomy or urostomy), which was also stated in the invitation e-mail and the introduction of the survey. Most members of both associations had a stoma; however, a minor portion also had an ileoanal pouch. Patients with a pouch that did not have a stoma were excluded from the analysis if they returned the survey. To our best estimate, approximately 5270 patients (including patients with a pouch) were invited to complete the survey.

Data collection

Potential participants received an open or closed invitation and possibly one reminder to complete the web-based survey using SurveyMonkey®. Data was collected between 21 February and 17 March 2020. Collected data were anonymized by the Dutch Ostomy Association, and subsequently provided for analysis.

Statistical analysis

Statistical analyses were performed using SPSS (version 27). Descriptive statistics were used to assess baseline characteristics. Missing data were accounted for using imputation by chained equations for variables with missing data. The pooled results of the five multiple iterations were used for the analysis. For further analysis, the frequencies of 10 potential physical and nine potential



psychological problems were respectively added together, so the total scores ranged from 10-50 and 9-45. Multiple linear regression analysis was performed to investigate the association between the patient characteristics and patient satisfaction. As recall bias for patient satisfaction may be strongly present, the analysis was also conducted separately for each time group (<1 year, 1–3 years, 3-5 years, 5-10 years and >10 years having a stoma). Multinominal logistic regression analysis was conducted to investigate whether willingness to use an app could be predicted by patient characteristics, satisfaction, or experience with mobile technology. To discriminate between patients' willingness and unwillingness, we trichotomised the outcomes to "willing" (with choices "very willing" and "willing"), "neutral", and "unwilling" ("unwilling" and "very unwilling"). The reference category for the logistic analysis was the neutral option. For both regression analyses, all determinants were chosen a priori, based on the literature and expectations. Dummy variables were created for nominal and ordinal variables and measured relative to their default reference categories (the highest frequency in this study population or the most clinically relevant). A stepwise backward selection method was used to correctly select and remove covariates that were not associated with the outcome. Therefore, only the significant variables ($p \le 0.05$) remained in the prediction model.

RESULTS

A total of 1868 patients who met the inclusion criteria completed the web-based survey; 1692 via closed invitation (response rate 40%), and 198 via open invitation (estimated response rate 19%) Thirteen patients with a pouch but without a stoma were excluded from the analysis. The baseline characteristics are summarised in Table 1. Most patients were male (n=1011, 54.1%), had a colostomy (n=983, 56.3%) and had an operation indication related to a malignant disease (n=1116, 59.7%). The mean age was 67.5 years. Most patients had a stoma for at least five years (n=1141, 61.1%). The most frequently reported physical and psychosocial problems were leakages, skin issues, stomal hernias, fear of leakages, sexual problems, and insecurity (Figure 1,2). As expected, stoma nurses were the main source of information and stoma-related questions. Stoma nurses were mainly contacted regarding stoma materials (47.0%), leakage (42.6%), and skin problems (37.0%).

Patients' view on stoma care received

The patients were moderately satisfied with the stoma care they received. The mean total SSCQ score was 72.4 (\pm 13.6), which was converted to 6.6 on a scale of 0–10. The SSCQ score of the five "time having a stoma" groups showed no difference. This may be explained by the fact that stoma care has not improved over the years or that recall bias may disguise possible improvements. A total of 40.6% of the patients indicated that they did not need any additional support

TABLE 1 Baseline characteristics.

TABLE 1 Baseline characteristics.	
Variable	Total n = 1868
Gender	
Male	1011 (54.1%)
Female	857 (45.9%)
Age (mean, standard deviation)	67.5 (11.6)
Nationality	
Dutch	1837 (98.3%)
Other	31 (1.7%)
Level of education	
Low	824 (44.1%)
Medium	325 (17.4%)
High	719 (38.5%)
Family situation	
Single without children	240 (12.8%)
Single with children	152 (8.1%)
With partner and with children	636 (34.0%)
With partner without children	818 (43.8%)
Other	27 (1.4%)
Current self-reported quality of life	
Bad	34 (1.8%)
Moderate	302 (16.2%)
Good	970 (51.9%)
Very good	426 (22.8%)
Excellent	137 (7.3%)
Stoma type	
Colostomy	983 (56.3%)
lleostomy	461 (26.5%)
Urostomy	300 (17.2%)
Other	124 (6.6%)
Time having a stoma	
<1 year	169 (9.0%)
1–3 years	291 (15.6%)
3–5 years	269 (14.4%)
5–10 years	507 (27.1%)
>10 years	632 (33.8%)
Permanent or temporary stoma	
Permanent	1630 (87.3%)
Temporary	238 (12.7%)
Indication for surgery	
Malignancy	1121 (59.9%)
Benign	749 (40.1%)
Aware of stoma before surgery	
No, acute situation	260 (13.9%)
Stoma was unexpected or unlikely	286 (15.3%)
Yes, elective surgery	1322 (70.8%)
Hospital	
Regional hospital	1415 (75.7%)
University hospital	453 (24.3%)

TABLE 1 (Continued)

Variable	Total n = 1868				
Satisfaction concerning stoma care questionnaire (SSCQ) (mean, standard deviation)					
Total score	72.4 (13.6)				
Domain preoperative care and information	17.6 (5.2)				
Domain postoperative care and guidance	30.9 (7.4)				
Domain contact with stoma nurse	23.8 (4.6)				
Internet use for information regarding stoma					
Never	600 (32.1%)				
Yearly	538 (28.8%)				
Monthly	571 (30.6%)				
Weekly	124 (6.6%)				
Daily	33 (1.8%)				
Mobile technology experience					
Excellent experience	362 (19.4%)				
Much experience	661 (35.4%)				
Some experience	598 (32.0%)				
Little experience	188 (10.1%)				
No experience	59 (3.2%)				
Use of mobile apps					
Yes including medical apps	380 (20.3%)				
Yes but no medical apps	1127 (60.3%)				
No apps	88 (4.7%)				
No mobile phone	272 (14.6%)				

Note: Continuous data are presented as mean \pm standard deviation and categorised data as frequencies and percentages.

or care, and 63.8% reported that further improvements were unnecessary. However, additional care was most desired after hospital discharge, and the most frequently reported potential improvements were preoperative information provision (16.9%), stoma site selection (14.1%), information about stoma-related problems (20.3%), and stoma materials (19.4%).

Multivariate linear regression analysis showed that the satisfaction score was significantly associated with the patient-related factors: sex, age, and education; the care-related factors: hospital type, stoma permanency, and preoperative unawareness of stoma; and the postoperative factors: quality of life and frequency of psychosocial problems (Table 2). Preoperative awareness, quality of life, and frequency of psychosocial problems mostly influenced satisfaction. Hospital type and stoma permanency did not have a clinically relevant influence. The stratified analysis for time having stoma yielded two additional variables which were not significant in the general regression analysis; patients with an ileostomy had significantly less satisfaction in the group "stoma less than 1 year" and patients with a benign operation indication had significantly less satisfaction in the group "stoma 3-5 years" (Table 3). The other yielded variables differed in significance between the groups and it was notable that the influence of a high education was substantially increased in the group "stoma less than 1 year".

Patient preference regarding e-health

Of all patients, 39% stated that they consulted the internet at least once a month to search for information regarding their stoma. This percentage was 64.8% for patients with a stoma of less than three years. Patients stated that their most preferred way of consulting information would be using the internet (55.9%), on paper (46.3%), or via a yet to be developed mobile app (33.5%). The preference for an app increased to 47.4% for patients aged 50 years or younger. Experience with mobile technology was moderate to high for the majority of patients (86.8%), and this was also largely present in patients above 80 years of age (70.9%). A mobile app would be expected to be of benefit for them, as reported by 47.6% of the patients, as they expected it to help them cope with a stoma. However, this percentage was significantly increased for patients with a stoma less than three years, 59.5% compared to 43.8% of the remaining study population (p < 0.001). Table 3 presents the patients' preferences for the functionalities of an app, in order of popularity. Most items were assessed as useful, except for a sensor measuring stoma production. The most popular items were advice on stoma-related problems and information on stoma care, stoma materials, instructions at discharge, and lifestyle (Figure 2).

The multinominal logistic regression analysis in Table 4 showed that willingness to use an app was significantly influenced by experience in mobile technology, frequency of psychosocial and physical problems, time having a stoma, and the independent domains of SSCQ. Patients who had a stoma for less than 3 years were more willing to use an app. Other cutoffs of time having a stoma were studied but were not significant or more clinically relevant. Interestingly, patients with a high satisfaction score on the SSCQ domains: "preoperative care and information" and "contact with stoma nurse" were more willing to use an app.

DISCUSSION

Although stoma care is of critical importance to the well-being and quality of life of patients, it is largely unknown whether current stoma care yields sufficient patient satisfaction and meets patients' needs. It is necessary to understand patients' perspectives and evaluate whether additional support to improve patient care is desired, and in what format. An app may provide a sustainable solution fitting patients' individual needs, offering possible benefits such as push notifications and peer support additional to information on paper. Assessing determinants influencing the willingness to use an app is essential to ensure proper design and implementation.

Overall, patients scored their satisfaction with their received stoma care as 6.6 (scale of 0–10). Patient satisfaction was mostly influenced by being unaware of the chance of getting a stoma, indicating improper preoperative counselling, or an acute situation in which counselling could not take place. Patients who received a stoma in an acute situation were significantly less satisfied. These patients did not have or had limited preoperative counselling, and immediate

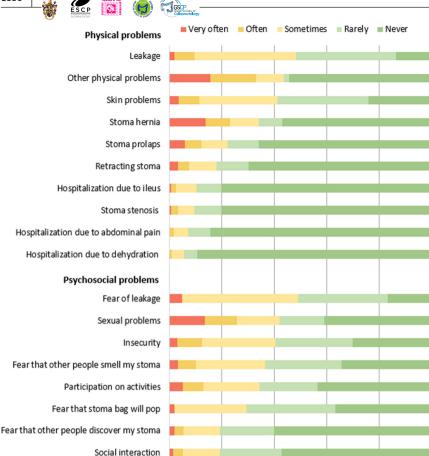


FIGURE 1 Patients' self-reported physical and psychosocial problems related to their stoma.

postoperative care by a stoma nurse or a stoma-competent ward nurse could be limited, for instance, for patients who underwent surgery at the weekend. Hence, these patients missed much information and counselling, most likely to be given in an elective situation. In addition to acute situations, other variables also influenced satisfaction. The perioperative clinical condition and mental state may also negatively impact patients' perception of the actual received stoma care in the immediate pre- and postoperative phase. In addition, patients who underwent surgery for a benign indication with underlying chronic disease reported lower satisfaction. These patients may have had a more severe and/or lengthy disease course or recovery, possibly influencing their reported satisfaction. In addition, patients who received an ileostomy were less satisfied. These patients likely experience more frequent changes in stoma materials, leakages, peristomal skin problems, and water/electrolyte imbalances, all of which impact daily life. Although these two associations were significant only in the two subgroups of the stratified analysis, they were expected to substantially affect patient satisfaction. Overall, men showed higher patient satisfaction than women, which is comparable with literature and may be explained that men and women value aspects of care differently [20-22]. Older and highly educated patients were generally less satisfied. This may be explained by the fact that younger patients are likely to experience fewer comorbidities and complications, be more active, and participate in their own care;

0%

20%

40%

60%

80%

100%

Other psychosocial problems

thus, young patients may have a more positive perception of the received care. Patients with decreased quality of life or psychosocial problems showed lower overall satisfaction. The psychological state may affect the patients' expectations and experiences [23, 24].

Although most patients had a stoma for many years, they still consulted the internet regularly to search for information regarding their stoma and how to cope with it. A mobile app may be a good alternative for internet (or responsive websites), offering additional functionalities such as personalisation of information or peer contact, and information on a hand-held device is considered to be both easily accessible and convenient by many. Surprisingly, our study showed that most patients prefer to have additional stomarelated information via the internet or on paper, which raises the question if an app is a needed addition for all patients. As reported in this study, patients with no or limited experience with mobile devices are significantly hesitant to use an app for their personal stoma care. It is important to acknowledge digital literacy, especially, since healthcare information and accessibility are digitalising fast and, in many aspects, with most hospital patient portals are now electronically operated. Patients may be still unaware of benefits of apps as described above, or just not used to accessing medical information via apps, as there is simply not much out there for them. An app is expected to be most commonly used by patients with a sufficient smartphone experience, and who had a stoma



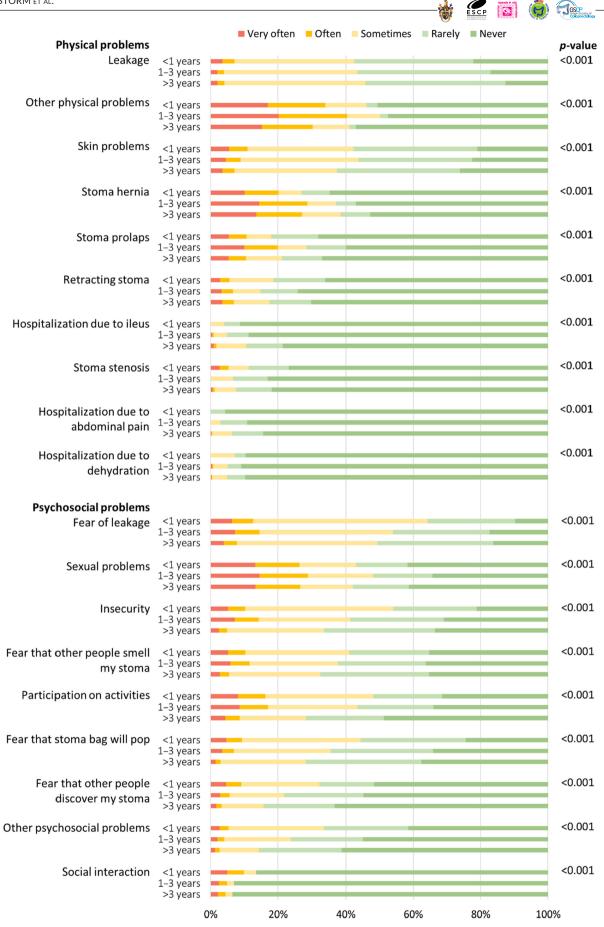


FIGURE 2 Patients' self-reported physical and psychosocial problems regarding their stoma, stratified on years of having a stoma.

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	В	SE B	95% CI		p-value
Constant	94.41	2.73	89.03	99.79	<0.001
Gender					
Male ^a	-	-	-	-	-
Female	-2.44	0.66	-3.74	-1.14	<0.001
Age	-0.14	0.03	-0.20	-0.08	<0.001
Education					
Low ^a	-	-	-	-	-
Moderate	-0.54	0.92	-2.37	1.29	0.559
High	-1.75	0.69	-3.09	-0.41	0.011
Quality of life					
Bad	-2.69	2.39	-7.39	2.01	0.261
Moderate	-2.23	0.90	-4.07	-0.53	0.011
Good ^a	-	-	-	-	-
Very good	2.45	0.77	0.96	3.96	0.001
Excellent	4.49	1.21	2.13	6.89	<0.001
Hospital type					
Regional hospital ^a	-	-	-	-	-
University hospital	-1.87	-0.81	-3.47	-0.26	0.024
Stoma					
Permanent ^a	-	-	-	-	-
Temporary	-2.13	0.95	-3.99	-0.27	0.025
Aware of stoma					
No, acute situation	-7.20	1.01	-9.22	-5.18	<0.001
Unexpected or unlikely	-2.33	0.91	-4.12	-0.53	0.011
Yes, elective surgery ^a	-	-	-	-	-
Frequency psychosocial problems (range: 9–45)	-0.50	0.05 -	-0.61	-0.40	<0.001 _

TABLE 2Association of patientcharacteristics and overall satisfactionconcerning stoma care.

Note: R² 0.161, Adjusted R² 0.155 F 27.4 Sig. ANOVA < 0.001.

Abbreviations: *B*, beta coefficient for total SSCQ score; CI, confidence interval; SE, standard error; SSCQ, satisfaction concerning stoma care questionnaire (SSCQ).

^aReference category.

Bold indicates significance level at *p*-value <0.05.

for less than 3 years, a high frequency of psychosocial or physical problems, or those who are not satisfied with their postoperative care. These patients were significantly more willing to use an app to provide additional information and support. It could be argued that an app would also be beneficial for patients undergoing emergency surgery, who usually receive less care and are, therefore, less satisfied. Although patients with low digital literacy are hesitant to use apps, an app should also suit the needs of those patients and be optimised for use by them. Adequate preoperative preparation and good contact with stoma nurses are important when implementing an app, as patients are more motivated to use an app. It is important to advocate the app as an information source that integrates in normal preoperative counselling.

This is the first study to focus on patient satisfaction concerning stoma care and assess whether e-health may be beneficial. The strength of this study lies in the extensiveness of the questionnaire covering all relevant aspects of stoma care and determinants for an ehealth intervention, and this study had a large sample size (N = 1868). Results may be biased, as participants were members of patient associations who may be more involved in their own stoma care, or perhaps better educated or skilled when compared to their peers who have decided not to join a patient association. Nevertheless, asking all members of stoma societies to give their opinions is the best way to include a significant number of patients, providing the best possible representation of the general stoma population.

This study had some limitations. First, many patient questionnaires had incomplete data owing to the length of the questionnaire. Missing data was increasingly present over the course of the questionnaire. To improve the validity of the results, missing data used in the statistical analysis were corrected by multiple imputation. Second, most patients had a stoma for at least five years. This might implicate recall bias in the assessment of patient satisfaction

TABLE 3 Association of patient characteristics and overall satisfaction concerning stoma care stratified for time having a stoma.

	В	SE B	95% CI		<i>p</i> -value
<1 year (n = 169) R ² 0.175, Adjusted R ² 0.144F 1	1.6 Sig. ANOVA < 0.0	01			
Constant	106.53	8.83	89.21	123.86	<0.001
Age	-0.220	0.10	-0.43	-0.01	0.036
ducation					
Low ^a	-	-	-	_	-
Moderate	-1.09	3.07	-7.11	4.93	0.722
High	-6.28	2.60	-11.40	-1.17	0.016
itoma					
Urostomy	0.21	3.27	-12.60	-2.35	0.59
lleostomy	-7.47	2.61	-5.92	6.34	0.004
Colostomy ^a	-	_	_	_	-
requency psychosocial problems (range: 9–45)		0.18	-1.07	-0.37	<0.001
-3 years ($n = 294$) R^2 0.292, Adjusted R^2 0.267 F			1.07	0.07	(0.001
Constant	96.22	6.02	84.35	108.10	<0.001
Gender	70.22	0.02	0-1.00	100.10	(0.001
Male ^a	_	-	-	_	
Female	-5.33	1.61	-8.49	-2.17	<0.001
	-0.15	0.07	-0.28	-0.01	0.034
	-0.15	0.07	-0.28	-0.01	0.034
Quality of life	0.41	2.05	1/ 1/	0.//	0.024
Bad Moderate	-8.41 -2.69	3.95 2.31	16.16 -7.29	-0.66 1.86	0.034 0.245
Good ^a	-	_	-	_	_
Very good	4.81	1.95	0.98	8.64	0.014
Excellent	7.64	3.04	1.68	13.60	0.012
lospital type					
Regional hospital ^a University hospital	- -5.43	- 1.88	-9.16	- -1.70	-0.005
ware of stoma	5.45	1.00	7.10	1.70	0.005
No, acute situation	-6.21	2.30	10.72	-1.70	0.007
Unexpected or unlikely	-0.21	2.30	-4.65	4.21	0.923
Yes, elective surgery ^a	-	-	-	-	-
requency psychosocial s problems (range: 9–45	5) -0.49	-0.49	0.13	-0.76	<0.001
-5 years (n = 268) R^2 0.263, Adjusted R^2 0.240 R^2	= 12.0 Sig. ANOVA <0	0.001			
Constant	81.75	2.72	76.42	87.09	<0.001
Quality of life					
Bad	-4.46	6.25	-16.80	7.88	0.476
Moderate	-0.45	2.19	-4.72	3.85	0.842
Good ^a Very good	- 3.23	- 1.93	-0.55	- 7.01	- 0.094
Excellent	6.64	3.48	9.81	23.48	<0.004
toma indication					
Malign ^a	-	_	_	_	_
Benign	-3.72	1.69	-7.04	-0.42	0.027
ware of stoma					
No, acute situation	-8.63	2.55	-13.67	-3.59	<0.001
Unexpected or unlikely	-4.79	2.39	-9.49	-0.10	0.045
Yes, elective surgery ^a	-	-	-	-	-
requency psychosocial problems (range: 9–45)		0.13	-0.68	-0.180	<0.001
-10 years ($n = 515$) R^2 0.148, Adjusted R^2 0.143	F 29.1 Sig. ANOVA <	0.001			
onstant	86.31	1.83	82.72	89.91	<0.001

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TABLE 3 (Continued)

	В	SE B	95% CI		p-value
	_		, , , , , , , , , , , , , , , , , , , ,		p 1414
Aware of stoma					
No, acute situation	-9.34	1.78	-12.86	-5.81	<0.001
Unexpected or unlikely	-2.41	1.67	-5.70	0.89	0.151
Yes, elective surgery ^a	-	-	-	-	
Frequency psychosocial problems (range: 9-45)	-0.69	0.10	-0.88	-0.50	<0.001
>10 years (n = 640) R ² 0.119, Adjusted R ² 0.107 F	12.1 Sig. ANOVA <0	0.001			
Constant	98.12	4.64	88.97	107.27	<0.001
Gender					
Male ^a	-	-	-	-	-
Female	-3.36	1.13	-5.58	-1.15	0.003
Age	-0.18	0.05	-0.28	-0.07	0.001
Education					
Low ^a	-	-	-	-	-
Moderate	-1.71	-1.59	-4.85	-1.43	-0.284
High	-2.40	1.19	-4.74	-0.06	0.045
Aware of stoma					
No, acute situation	-6.16	1.59	-9.28	-3.03	<0.001
Unexpected or unlikely	-2.92	1.43	-5.73	-0.11	0.042
Yes, elective surgery ^a	-	-	-	-	-
Frequency psychosocial problems (range: 9–45)	-0.49	-0.49	0.13	-0.76	<0.001

Abbreviations: B, beta coefficient for total SSCQ score; CI, confidence interval; SE, standard error; SSCQ, satisfaction concerning stoma care questionnaire (SSCQ).

^aReference category.

The bold values indicate significant *p*-values

Functionalities	Useful (%)	No opinion (%)	Not useful (%)	N
Advice for stoma related problems	89.6	8.6	1.8	1238
Information on stoma care	84.7	12.4	2.9	1246
Information on stoma materials	84.7	12.8	2.5	1234
Information on instructions at discharge	84.4	12.2	2.5	1218
Information on lifestyle	82.0	15.4	2.5	1224
Direct contact with healthcare providers	75.7	19.9	4.4	1229
Preoperative information	75.5	21.1	4.5	1214
Contact details of healthcare providers	75.2	19.8	5.0	1223
Personalised information	71.2	23.3	4.5	1236
Information on stoma site selection	71.1	23.2	5.7	1206
Videos on stoma care	69.1	25.2	5.7	1228
Links to other websites	67.1	26.4	6.5	1203
Frequent asked questions	63.2	29.7	7.2	1214
Feedback	61.2	31.6	7.2	1206
Receiving daily information	45.9	39.8	14.3	1209
Contact with peer patients	42.6	43.3	14.1	1216
Sensor measuring stoma production	29.4	45.8	25.4	1213

TABLE 4	Assessment of functionalities
of a mobile	application.

concerning stoma care in the perioperative period. However, patient satisfaction was comparable across all time periods. Stoma care may not have improved over the years or recall bias may have disguised possible improvements. A third limitation might be the questioning of patients' willingness to use an app. A description of its potential functionalities was not provided, although it could be assumed that

TABLE 5 Association of patient characteristics and their willingness to use a mobile app.

	OR ^b	95% CI		p-value
Not willing to use an app				
Experience in mobile technology				
No	1.56	0.56	4.30	0.374
Some ^a	-	-	-	-
Moderate	0.59	-0.35	-0.99	-0.047
A lot	0.47	0.25	0.90	0.024
Excellent	0.47	0.25	0.87	0.017
Willing to use an app				
Experience in mobile technology				
No	0.58	0.21	1.64	0.302
Some ^a	-	-	-	-
Moderate	-1.39	-0.83	-2.31	-0.207
A lot	2.23	1.27	4.16	0.008
Excellent	3.12	1.62	6.02	0.002
SSCQ: Preoperative care and guidance	1.03	1.00	1.06	0.021
SCCQ: Postoperative care and guidance	0.96	0.94	0.98	<0.001
SCCQ: Contact with nurse	1.03	1.00	1.07	0.046
Time having a stoma				
<3 year ^a	1.59	1.18	2.14	0.003
>3 years	-	-	-	-
Frequency of psychosocial problems (range: 9–45)	1.03	1.00	1.05	0.035
Frequency of physical problems (range: 10–50)	1.03	1.00	1.07	0.037

Abbreviations: CI, confidence interval; OR, odds ratio; SSCQ, satisfaction concerning stoma care questionnaire (SSCQ). ^aReference category.

^bReference category=no opinion.

Bold indicates significance level at p-value <0.05.

the app would contain stoma-related information. Some patients will not have a concept of a mobile app, as it might be difficult to think in all potentials, while the remaining patients will have a different concept from each other. Therefore, the interpretation of these results requires caution because willingness is likely to be underestimated. Presenting a clear description of a well-designed app using visual images or videos will improve patients' willingness to use an app. Finally, it can be argued that the variance of the satisfaction analyses was low, only determining the outcome to a small extent (see Tables 3 and 5). However, the variance in patient satisfaction is usually less than 20% [25–27].

CONCLUSION

In this study, patients were only moderately satisfied with the stoma care they received, with shortcomings reported in the

provision of preoperative information, stoma site selection, information on stoma-related problems, and material and postoperative care. For many patients, especially those with high proficiency in using smartphones, an app is considered an important addition to regular stoma care or support groups. Digital literacy should be a focus point of health and patient organisations, counselling patients appropriately about the benefits and helping them to use the apps. Further qualitative research on how to best support patients in building such an e-health solution is needed to provide additional in-depth insights that could be used as a blueprint for the development of an app and how to disseminate this well. Subsequently, it is highly recommended that the app will be evaluated on its safety and effectiveness in clinical research, and compensates for digital literacy as much as possible, involving patient groups who are not proficient in using apps in the app development.

AUTHOR CONTRIBUTIONS

Sebastiaan L. van der Storm: Conceptualization; investigation; writing – original draft; methodology; visualization; formal analysis; data curation. Nikita Hensen: Writing – original draft; formal analysis; data curation. Marlies Schijven: Supervision; conceptualization; methodology; visualization.

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CONFLICT OF INTEREST STATEMENT

The authors have no disclosures or conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS APPROVAL STATEMENT

Ethical approval was waived by the local Ethics Committee of Amsterdam UMC.

PATIENT CONSENT STATEMENT

Members of patient associations were invited by mail to complete a web-based survey. Informed consent for the present survey was obtained from all those agreeing to complete a survey, with participants informed on the welcome page that the survey concerned stoma care and potential solution of a mobile app, that all responses were confidential and anonymous and that reporting would be on an aggregate level only. Consent was indicated when respondents clicking the 'Go to Survey' button from this page.

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SUPPORTING INFORMATION

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

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