Patient Preference and Adherence

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ORIGINAL RESEARCH

Managing neurogenic bowel dysfunction: what do patients prefer? A discrete choice experiment of patient preferences for transanal irrigation and standard bowel management

This article was published in the following Dove Press journal:
Patient Preference and Adherence
17 February 2016
Number of times this article has been viewed

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Background: Most patients with bowel dysfunction secondary to neurological illness are managed by a range of nonsurgical methods, including dietary changes, laxatives, and suppository use to transanal irrigation (TAI). The aim of the present study was to explore individuals' preferences regarding TAI devices and furthermore investigate willingness to pay (WTP) for attributes in devices in the UK.

Methods: A discrete choice experiment survey was conducted to evaluate the patients' perceived value of TAI devices. Attributes were selected based upon a literature review and input from clinicians. Interviews were conducted with three clinicians and the survey was developed and finalized with the input from both patients and professionals. The final attributes were "risk of urinary tract infections" (UTIs), "risk of fecal incontinence" (FI), "frequency of use", "time spent on toilet", "ease of use", "level of control/independence", and "cost". Participants were recruited by a patient panel of TAI device users in the UK. Data were analyzed using the conditional logit model whereby the coefficients obtained from the model provided an estimate of the (log) odds ratios (ORs) of preference for attributes. WTP was also estimated for each attribute.

Results: A total of 129 participants were included in the final analyses. Sixty two percent of the participants had suffered from three UTIs in the preceding year and 58% of patients reported currently experiencing FI using their current device. All attributes were significant predictors of choice. The most important attributes for participants were the "risk of FI", "frequency of use", and "risk of UTIs".

Conclusion: Participants with bowel dysfunction regarded "risk of FI", "frequency of use", and "avoiding UTIs" as the most important features of a TAI device. These preferences are valuable in informing decision makers and clinicians regarding different bowel management solutions as well as for development of future devices.

Keywords: neurogenic bowel dysfunction, UK, transanal irrigation, patient preference, discrete choice

Introduction

Damage to the central nervous system (either brain or spinal cord) can have a significant impact on the function of the bowel and the patients' ability to maintain fecal continence. Neurogenic bowel dysfunction (NBD) affects ~80% of spinal cord injury (SCI) patients to some degree[1] and is also prevalent among patients with other neurological conditions such as multiple sclerosis (MS) and spina bifida (SB).[2] Up to 30% of MS patients can experience fecal incontinence (FI).[3]

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Dovepress
http://dx.doi.org/10.2147/PPA.S96082

Bowel dysfunction can affect patients' psychological, physical, and social well-being because of constipation, FI, the extended time spent on defecation, and the social restrictions that bowel dysfunction imposes on the patient.[4,5] Liu et al[6] evaluated the health status of 128 participants with spinal cord injuries (SCIs) using the Short Form 12 (SF-36) and a NBD score. Almost 50% of participants had moderate to severe NBD (moderate score 10–13, and severe dysfunction score $\geq$14) and this was associated with poorer physical functioning. Coggrave et al[7] also showed that NBD had an impact on longer duration of care, more frequent episodes of FI, more frequent management, and more than one intervention was used including stimulant laxatives, osmotics, and bulk formers. Furthermore, 58% of the participants spent up to 30 minutes on each bowel care episode.[7]

Approaches to management of NBD include dietary changes, digital anal stimulation, laxatives and suppositories, manual evacuation, and transanal irrigation (TAI).[8,9] The majority of bowel management methods can be time consuming, which increases the burden for patients.[10]

TAI is designed to assist the evacuation of feces from the bowel by introducing water into the rectum via a manual pump. TAI devices are commercially available and can be offered as part of a bowel management program to patients. TAI has been shown to be a significantly efficient health technology for improving constipation, FI, and symptom-related quality of life in adult SCI patients when compared to conservative bowel management.[11] TAI has also been shown to improve bowel function in children SB.[12,13]

However, evidence suggests that as many as 40% of the patients who start TAI have discontinued within 3 years.[14,15] Adherence may be better understood by identifying the value that patients place on the features and benefits of TAI. This could also potentially guide patient selection and future development of TAI devices. Patient preference surveys can be used to assess the value of different features of a device. The discrete choice experiment (DCE) methodology has been widely used to elicit preferences for this purpose.[16] This method can capture benefits in terms of willingness to pay (WTP), which is an estimation of the maximum amount a user may be willing to pay out of pocket in order to receive the benefits of the device. DCEs identify the key characteristics of a product (referred to as "attributes") with different levels associated with each attribute. Levels describe the various aspects of each attribute, eg, a device could be easy to use, or require several steps and each of these would be a level of the attribute. Hypothetical choices are then presented to participants in pairs, which feature distinct levels of each attribute. Participants are asked to indicate their choice of preference, and regression models can be used to understand the influence of each of the study attributes on participants' choices.

The aim of the present study was to elicit the preferences of patients with NBD (related to SCI, MS, and SB) with regard to TAI as well as other standard approaches to bowel management.

Materials and methods

Identification of attributes

To determine which aspects of using TAI may be most important to people with NBD, information on currently available bowel management approaches was reviewed. This included studies regarding best practice of TAI in adults and the cost-effectiveness of using this approach compared with standard bowel management.[15,17] The information was used to develop a list of potential device attributes and levels which could be included in a DCE.

Seven key attributes were selected in order to ensure that the survey was not too long or burdensome for participants but was still able to capture information regarding different features of the device. The attributes reflected the different aspects of currently available treatments and the studies that showed the impact of devices on daily functioning. Selected attributes and levels identified by the study team, were explored by clinician and patient interviews (as described in the following section), and are shown in Table 1.

Development of DCE survey

The attributes and levels were combined into choice sets using a published orthogonal array (http://neilsloane.com/oadir/). An orthogonal fractional factorial design was used to identify the minimum specification of the DCE experimental design in order to fairly represent combinations of the attributes and levels. These combinations were paired using a fold-over design. Each choice question presented two TAI devices (device A or B) and participants were asked to indicate their choice of preference. In addition, participants were also presented with a third choice, which was designed to reflect a standard or conventional approach to bowel management, which did not include anal irrigation. The conventional approach relied upon the use of suppositories and laxatives, or antidiarrheal products; active monitoring of diet and fluid intake; use of incontinence pads on a daily basis; and some use of digital evacuation to empty the bowel. The third option remained constant in each choice question in the survey.

Table 1 Final attributes and levels

Attribute	Levels
Risk of urinary tract infection: People can experience bladder or urinary infections while using various approaches to bowel care. The infection can last for several days and may require a course of antibiotics.	• No infection • One infection in the following year • Two infections in the following year • Four infections in the following year
Risk of fecal incontinence: People can experience fecal incontinence which can result, for instance, in soiling of clothes from time to time. Some devices can minimize the likelihood of incontinence by enabling you to decide when to go to the toilet and empty your bowels. This would give you more control over your bowel movements.	• No episodes of fecal incontinence per month • One episode of fecal incontinence per month • Two episodes of fecal incontinence per month • Three episodes of fecal incontinence per month
Time spent in the toilet: Different approaches to bowel care vary in the time that you have to spend in the toilet in order to empty your bowel. This may be related, for instance, to the number of different steps required to use a device. This feature relates to the time that you spend in the toilet.	• You will spend up to 30 minutes • You will spend up to 1 hour • You will spend up to 1.5 hours • You will spend up to 2 hours
Ease of use: Devices to help your bowel care often rely on water being gently pumped into your bowel. Existing irrigation devices are manually operated, requiring several steps along with some hand movement and strength to operate the device. Some new irrigation devices are automatically operated, thereby reducing the number of steps involved and requires less hand movement and strength.	• You will use a manual pump (process requiring ~30 steps) • You will use an automatic pump (process requiring ~15 steps)
Frequency of use: Some approaches to bowel care can be undertaken every other day, some need to be done every day, and some people need to be on the toilet more than once a day. Different approaches can give you control of when you wish to empty your bowels. This can enable you to feel more in control and plan ahead in terms of when you need to use the toilet.	• Once every two days on average • Once every day on average • Twice a day on average • Three times a day on average
Level of control/independence: Devices for bowel emptying can require a lot of different steps to work properly. Different components or parts need to be operated in the correct sequence. Some people need help from others because the devices are complex to use. However, with simpler devices people may feel confident to use the device on their own.	• No help needed while emptying your bowels • You need less help than you did previously • You need as much help as you did previously • You need more help than you did previously
Out-of-pocket cost: Most people do not pay out of their own pocket for devices to assist with bowel care. However, we would like you to think about how much you would value different approaches to bowel care.	• £20 • £40 • £60 • £80

The survey included 17 pairs of choice sets (each also combined with the conventional approach). This included 16 choices from the statistical design plus an additional choice to permit an assessment of consistency. The consistency check involved device A, which was better than device B on every attribute. In addition, participants were asked to state whether they would choose their selected device over their current bowel care plan.

Background information regarding sociodemographics, experience of current device, medical history, and health-related quality of life (HRQL) assessed using EuroQoL-5D (EQ-5D-3L),[18] was collected. The EQ-5D-3L categorizes participants into health states based upon five domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) and provides an estimate of each person's health state utility (ranging from 1 which is full health through 0 which is dead). Participants also completed the St Mark's FI score which is a validated self-reported measure of the severity of FI.[19] Each domain has a score of 0–4 and the total score is a sum of all domain scores where 0 is perfect continence and 24 is totally incontinent. The Cleveland Clinic Constipation Scoring System was also completed by participants to evaluate the severity of constipation in the sample.[20] The total score is a sum of all domain scores from 0–4, with a maximum score of 30. Higher scores represent significant constipation.

An electronic version of the DCE survey in a format appropriate for administration via the web was developed. This was designed to be user-friendly. Prior to patient interviews and main online survey, all study documentation was approved by a US Institutional Review Board (Salus IRB) (REF OXO-0649-0016). Online consent was obtained from all participants before they completed the survey.

Expert interviews

Semi-structured telephone interviews with three clinical experts in the field of bowel management were undertaken.

The identified attributes and levels were discussed with the three clinical specialists (gastroenterologist and specialists in bowel care) in order to explore their views on their appropriateness.

Patient interviews

Telephone-based interviews with three individuals in UK suffering from NBD were conducted to explore their understanding of the survey questions. The individuals were asked to complete the survey and participate in a cognitive debrief exercise in which they could comment on the clarity of the questions, the response options, and ease of completion of the overall survey.

Overall, the participants found that the survey was easy to understand and complete and some minor inputs were implemented in the final DCE survey. Descriptions of the attributes were programmed into the online survey so that participants could refer back if needed. Some changes were made to the descriptions of each feature of the device to make them easier to understand.

Main study

Sample

Participants were recruited through a panel of patients in the UK who have used TAI products of one manufacturer (Coloplast; Humlebaek, Denmark) at some stage. Inclusion criteria included participants who: 1) had a diagnosis of SCI, MS, or SB; 2) had used a bowel management program for a minimum of 3 months; 3) had used a bowel management program previously or currently including a TAI device; 4) were aged between 18 and 85 years; 5) had access to the internet; and 6) were currently residing in the UK. Exclusion criteria included an acute illness or cognitive impairment that in the opinion of the interviewer would interfere with the study requirements. All potential participants were required to provide online consent before access to the DCE survey. Participants received a small compensation at the completion of the online survey.

Data analysis

Sociodemographic and medical information were analyzed as means, standard deviations (SDs), and frequencies or percentages. The EQ-5D-3L was scored using standard UK preference weights, whereby full health has a value of 1.0 and dead has a value of 0.

The choice data were analyzed using a conditional logit model to explore the impact of each attribute on participants' choices.[21] The conditional logit model evaluates choice responses after conditioning them on the attributes of the other alternatives available within the choice set. Hence, if, for example, "device option A" is preferred in the choice set 1, this preference is conditional on the attributes of "device option B". The coefficients obtained from the logit model provide an estimate of the (log) odds ratios (ORs) of preference for attributes. Within each attribute one level was set as a reference point and participants' strength of preference for achieving other levels of the attribute was estimated (Table 5). WTP was calculated by dividing the estimated coefficients for each attribute by the coefficient for out-of-pocket cost (so-called marginal rates of substitution).

Results

Participant characteristics

A total of 143 participants completed the study questionnaires, of which 14 participants were excluded due to failure on the consistency check. This resulted in a data set of 129 participants of which 48 were diagnosed with SCI, 69 with MS, and 12 with SB.

Table 2 presents the sociodemographic profile of the sample. The mean overall duration of having a condition was 18.7 years. By condition, the participants suffering from SB had an average of 44 years (range: 20–66 years) for this lifelong condition, whereas those suffering from SCI and MS reported having their condition for an average of 15 (range: 1–48) and 17 (range: 1–44) years (data not shown), respectively. Eighty-three percent of the participants had not used an anal irrigation system for bowel management prior to the current one, but laxatives/suppositories had been used by 68% of the sample. "Insufficient effect", "bowel incontinence", and "emptying bowel takes too long" were the three main reasons for discontinuing previous bowel management approach. HRQL (as assessed by the EQ-5D index score) for the total data set was 0.37 (SD =0.32), but for the participants with SB it was 0.52 (data not shown). This study also reports data from the St Mark's Fecal Incontinence measure and Cleveland Clinic Constipation Scoring System, and these data indicate a moderate level of problems on both of these scales. Table 3 presents the clinical history/bowel care approach of the data set. All except two participants had a bowel care plan, which was discussed with a health care professional. The majority of participants currently used various methods, such as TAI, laxatives/suppositories, FI pads, abdominal massage, etc, to empty their bowel.

Participants were asked to describe their current TAI device in relation to the attributes of the DCE (Table 4). Sixty two percent of the participants had experienced a urinary tract infection (UTI) in the previous year and on average they had just over three UTIs requiring antibiotics in the previous year. Fifty eight percent of the participants reported experiencing FI using their current device. However, 33% of those had not

Table 2 Sociodemographic profile of the sample

Sociodemographic characteristics	N=129
Sex, female	72 (56%)
Average annual income of household (£), n (%)*	
<20,000	51 (40%)
21,000–30,000	31 (24%)
31,000–40,000	15 (12%)
41,000–50,000	8 (6%)
51,000–and higher	10 (8%)
Prefer not to answer	14 (11%)
Duration of condition in years (mean)	18.7 (14.0)
Number of bowel movements or attempts the previous day, n (%)	
None	46 (36%)
1–3 times	71 (55%)
4–6 times	11 (9%)
7 or more times	1 (<1%)
Was the number of times typical, n (%) (yes)	109 (84%)
Previous approach to bowel care, n (%)	
Same as current	12 (9%)
Previously used anal irrigation device	10 (8%)
Previously used approach that did not include an anal irrigation device	107 (83%)
Previous approach to go to toilet (more than one response could be selected) [a], n (%)	
Peristeen (Coloplast) – device	8 (7%)
B Braun Irrimatic – device	0 (0%)
MBH Qufora – device	0 (0%)
MBH Qufora Mini – device	1 (1%)
Practomed GmbH – Reprop Clyster – device	0 (0%)
Pads	15 (13%)
Diet plan	14 (12%)
Laxatives/suppositories	80 (68%)
Digital stimulation	27 (23%)
Manual digital evacuation	39 (33%)
Anal plug	2 (2%)
Physical exercise/muscular training	9 (8%)
Abdominal massage	22 (19%)
Smaller enemas with active ingredients (not anal irrigation)	34 (29%)
Other	10 (9%)
Length of time using previous approach [a], n (%)	
<1 year	12 (10%)
1–2 years	12 (10%)
2–3 years	16 (14%)
4 years or more	77 (66%)
Reason for discontinuing your previous approach (more than one response could be selected) [a], n (%)	
Insufficient effect	82 (70%)
Emptying bowel takes too long	39 (33%)
Bowel incontinence	49 (42%)
Dependence on carer	7 (6%)
Given up due to lack of support training	1 (1%)
Did not have a carer available to help	0 (0%)
Device was too complex to use	1 (1%)
Did not want to use anal irrigation device	3 (3%)
Other	20 (17%)
EQ-5D-3L score [b]	
Mean (SD)	0.37 (0.32)
St Marks Overall Score	
Mean (SD)	12.1 (4.9)
Cleveland Overall Score	
Mean (SD)	12.9 (4.3)

Notes: [a] Among patients whose previous approach differed from current approach; [b] Using UK weights; *not all data is shown.
Abbreviations: EQ-5D-3L, EuroQoL-5D-3L; SD, standard deviation.

Table 3 Clinical profile of the sample

Bowel care approaches	N=129
Current approach to bowel care, n (%)	
Have a formal bowel care plan as discussed with a health care professional or have received training in use of an anal irrigation device	127 (98%)
Do not have a specific bowel care plan recommended by a health care professional and have not received any training in the use of an anal irrigation device	2 (2%)
Current approach to go to toilet (more than one response could be selected), n (%)	
Peristeen (Coloplast) – device	126 (98%)
B Braun Irrimatic – device	0 (0%)
MBH Qufora – device	1 (1%)
MBH Qufora Mini – device	1 (1%)
Practomed GmbH – Reprop Clyster – device	0 (0%)
Pads	17 (13%)
Diet plan	14 (11%)
Laxatives/suppositories	41 (32%)
Digital stimulation	18 (14%)
Manual digital evacuation	19 (15%)
Anal plug	5 (4%)
Physical exercise/muscular training	8 (6%)
Abdominal massage	28 (22%)
Smaller enemas with active ingredients (not anal irrigation)	7 (5%)
Other	2 (2%)
Length of time using current approach, n (%)	
<1 year	27 (21%)
1–2 years	21 (16%)
2–3 years	27 (21%)
4 years or over	54 (42%)
Position most frequently used to empty bowel, n (%)	
From wheelchair	1 (1%)
On toilet	121 (94%)
On bed	1 (1%)
On commode	9 (7%)
Other	3 (2%)

experienced any FI during the previous month and 43% had experienced one or two episodes of FI during the previous month. The majority (89%) of the participants used a manually operated device. Most participants emptied their bowel on the toilet (Table 3), 59% used the toilet once every 2 days, and 71% did not require help when going to the toilet. The majority (90%) of the participants did not pay out of pocket for the bowel care and those that had an out-of-pocket cost paid an average of £19 per month.

DCE findings

All attributes were significant predictors of choice (Table 5) except two levels of "level of control/independence" ("less help than previously" and "as much help as previously"). This means that all of the significant attributes and levels were independent and important drivers of people's choice. The most highly valued attributes were risk of FI (OR =5.18) and frequency of use (OR =4.69). The OR means that all other attributes being equal, participants in the survey were five times more likely to prefer a device that was associated with no episodes of FI compared with a device that was likely to cause three episodes of FI per month. Participants preferred a device that led to going to the toilet once in every 2 days rather than three times a day (OR =4.69). Participants also preferred a device that avoided the risk of UTIs completely, than a device that led to four UTIs in the following year (OR =3.43). Participants preferred to minimize the amount of time they spent on the toilet. Compared to spending 2 hours on the toilet, participants strongly preferred reducing this to 30 minutes (OR =2.66). The attribute "ease of use" was designed to understand patients' preference for an automatic pump compared with a manual pump. The results showed that overall people preferred a manual pump than an automatic pump or no pump (OR =0.88 and 0.30 respectively). Out-of-pocket cost was also a significant attribute, which meant that participants were trading improvements in device attributes against increases in cost.

Participants were willing to pay £164.50 and £123.20 per month for a device that could eliminate the risk of FI episodes

Table 4 Features of current appliances, all patients and by condition

Features of current appliances	N=129
Urinary tract infection in the last 12 months, n (%) (yes)	80 (62%)
Number of urinary tract infections requiring antibiotics in the last 12 months [a] mean (SD)	3.1 (3.1)
Any fecal incontinence on current treatment, n (%) yes	75 (58%)
Episodes of fecal incontinence in last month [b], n (%)	
None	25 (33%)
1–2 episodes	32 (43%)
3–4 episodes	12 (16%)
5–6 episodes	4 (5%)
Episodes most days	2 (3%)
Time on toilet, n (%)	
Less than 30 minutes	48 (37%)
30 minutes to 1 hour	58 (45%)
1 hour to 1.5 hours	14 (11%)
1.5 to 2 hours	6 (5%)
Longer than 2 hours	3 (2%)
Pump requirements on current device, n (%)	
Manually operated	115 (89%)
Automatically operated	8 (6%)
No device used	6 (5%)
Frequency of going to toilet, n (%)	
Normally once every two days	76 (59%)
Normally once every day	40 (31%)
Normally twice a day	6 (5%)
Normally more than twice a day	7 (5%)
Assistance needed with current approach, n (%)	
No help needed	92 (71%)
Sometimes need help	20 (16%)
Always need help	17 (13%)
Assistance received from [c], n (%)	
Carer, eg, spouse, family member, or friend	33 (89%)
Health care provider, eg, nurse	4 (11%)
Do you currently pay for your bowel care, n (%)	
Currently pay for a device	4 (3%)
Currently pay for laxatives, suppositories, or antidiarrheal medication	9 (7%)
Currently pay nothing	116 (90%)
Out-of-pocket cost per month (£) [d], mean (SD)	19.31 (39.39)

Notes: [a] Among patients who had urinary tract infection; [b] among patients who had any fecal incontinence; [c] among patients who were receiving assistance; [d] among patients who were paying for their bowel care.
Abbreviation: SD, standard deviation.

and avoid all UTIs, respectively. Participants were willing to pay £154.60 for a device that could reduce the frequency of use to once every 2 days. Participants also placed significant value on reducing time spent on the toilet. To reduce the time spent each day from 2 hours to 30 minutes, participants were willing to pay £97.90 per month. Some other device features were valued slightly less highly. For example, participants placed less value (compared to other attributes) on a device that would allow them to be fully independent for bowel management.

An interaction model was explored to see whether preferences varied by condition (SCI, MS, or SB) whereby the reference case was the SCI group. The results showed that there were only differences in patient groups in the attributes "level of control/independence" and "cost" (results are not shown). The SCI group placed significantly more value than the MS group on devices that required "less help than previously" ($P<0.05$). The MS group were more willing to accept higher out-of-pocket cost compared with the SCI group ($P<0.03$). The results showed that all three patient groups placed similar value on the other attributes when choosing devices.

Discussion

The key original message emerging from this study is that it reflects user's perceived value and their WTP for TAI

Table 5 Results of conditional logit model, including odds ratios for preference of attribute levels

Parameter	Level	All (N=129)		
		OR (SE)	95% CI	WTP (£)
Risk of urinary tract infection				
	0 infection	3.430 (0.107)*	2.77–4.23	123.20
	1 infection in the following year	2.089 (0.117)*	1.66–2.62	73.70
	2 infections in the following year	1.502 (0.103)*	1.22–1.83	40.70
	4 infections in the following year (reference)	–	–	–
Risk of fecal incontinence				
	No episodes per month	5.182 (0.111)*	4.17–6.43	164.50
	One episode per month	2.861 (0.112)*	2.29–3.56	105.10
	Two episodes per month	1.588 (0.100)*	1.30–1.93	46.30
	Three episodes per month (reference)	–	–	–
Time spent on toilet				
	Up to 30 minutes	2.661 (0.107)*	2.15–3.28	97.90
	Up to 1 hour	1.890 (0.122)*	1.48–2.40	63.70
	Up to 1.5 hours	1.211 (0.092)*	1.01–1.45	19.10
	Up to 2 hours (reference)	–	–	–
Ease of use (how you will pump water into your bowel)				
	Use an automatic pump (requiring ~15 steps)	0.878 (0.066)*	0.77–0.99	−13.00
	No pump	0.295 (0.183)*	0.20–0.42	−122.00
	Use a manual pump (requiring ~30 steps/reference)	–	–	–
Frequency of use				
	Once every two days	4.691 (0.107)*	3.80–5.78	154.60
	Once every day	3.410 (0.120)*	2.69–4.31	122.70
	Twice a day	1.639 (0.100)*	1.34–1.99	49.40
	Three times a day (reference)	–	–	–
Level of control/independence				
	No help needed while emptying bowels	1.998 (0.092)*	1.66–2.39	69.20
	Less help than previously	1.174 (0.118)	0.93–1.48	16.10
	As much help as previously	1.203 (0.096)	0.99–1.45	18.50
	More help than previously (reference)	–	–	–
Out-of-pocket cost	Per £20 decrease	1.230 (0.034)*	1.15–1.31	–

Note: *Significant at $P<0.05$.
Abbreviations: CI, confidence intervals; OR, odds ratio; SE, standard error; WTP, willingness to pay; –, Not applicable.

devices. The study used the methodology of a DCE in a group of UK-based patients with neurological disease and secondary bowel dysfunction. The survey explored the importance that users place on seven selected features of a bowel care plan/device.

The majority of the participants had experienced FI and were currently on a bowel care plan, which included a TAI device. Most of the participants were able to empty their bowel on the toilet and did not require any assistance. The sample reported poor HRQL as reflected by low EQ-5D scores. Pinder et al[22] conducted a DCE in which they explored preferences of people who use intermittent self-catheterization (ISC) devices in the UK, France, and the Netherlands. People using ISC reported EQ-5D scores between 0.40 and 0.56 in each country which were marginally higher than the current sample. Participants reported moderately severe scores regarding their experience of incontinence and constipation in Pinder et al.[22]

The seven attributes explored were “risk of UTI”, “risk of FI”, “time spent on toilet”, “ease of use”, “frequency of use”, “level of control/independence”, and “cost”. All attributes were significant predictors of choice except some degrees of “level of control/independence”, demonstrating the relevance of the chosen items to the patient group when considering a new device. TAI therapy, by its nature, requires active patient involvement, in terms of self-administration of the therapy for an intimate function. The relative low priority of independence may reflect that the majority of the sample was independent (only 29% were dependent on a carer to manage their bowel). This is similar to other cohorts with a similar patient population where complete assistance was required by 22.8%.[7]

Avoiding the risk of FI was the most important attribute for participants. This is consistent with the observation that the prevalence of FI significantly impacts HRQL.[9] SCI has a significant impact on bowel function and these changes result in a high risk of FI and constipation.[10,23] It is thought that up to 30% of patients with MS can develop regular FI.[3] The other most important attributes for participants were the "frequency of use" and "risk of UTIs". The majority of the sample (62%) reported that they had experienced a UTI in the last 12 months. Taken together, these observations reflect the importance of using patient-related outcomes and defining therapy on a case-by-case basis employing those metrics of patient preference which can transform health care.[24]

Frequency of use was a very important attribute of choice. Participants preferred a bowel frequency of once every 2 days rather than the traditionally used metric of a daily bowel action.[10,23] More than 40% of participants reported a bowel frequency of once a day or more often, and almost two-thirds spent more than 30 minutes on each attempted bowel action. As such, it is not surprising that patients prioritize minimizing the number of bowel movements they have.

Cost was also an important driver of choice for participants. This was an interesting observation given that in the UK, treatment via health care service is free at the point of delivery to patients. Given that people were trading other attributes against cost, it is possible to estimate WTP for significant attributes and levels. The ensuing results indicated how important attributes were in terms of WTP, and also gave an indication of the amounts that participants were willing to pay every month for a device with improved functionality on different attributes. In particular, the results of this study showed that a cost of up to £165 per month was deemed acceptable for a treatment that would eliminate the risk of FI.

There were some important limitations to remember when interpreting this study. Participants were recruited from a panel that included people who had used Coloplast products at some stage, which could result in possible bias in their experience of TAI devices. However, participants did report using a wide range of devices and bowel care plans, and the frequency of use of medications and devices was similar to that in other studies.[23] The current study also relied on people completing the survey online, which excluded some users who did not have access to the internet. However, all efforts were made to recruit a representative sample across the UK, including consideration of social stratum. In addition, it should also be noted that the sample size is relatively limited. While the aggregate results are largely clear, the sample is too small for reliably exploring differences between the three neurological diseases. As such, these analyses, which have explored differences between SCI, MS, and SB patients, should be treated as exploratory only. It is also worth commenting that the vast majority of the sample does not currently pay for their TAI devices and associated bowel care. Therefore, this may bias the estimates of WTP because the participants do not have experience of making such purchases. There are, however, examples in the literature where participants in DCE surveys are asked to make choices based upon hypothetical treatments for which they do not currently pay.[25]

Conclusion

This study assessed users' preferences regarding TAI devices. "Risk of FI" and "frequency of use" were the most important attributes of devices. The DCE method allows clinicians to identify important features of devices and understand the relative importance of attributes in terms of WTP. Such data are also important in helping care management decisions in an increasingly hard-pressed and complex financial environment of health care funding.

Acknowledgments

This study was supported by research funding from Coloplast A/S to ICON plc. However, no restrictions were placed on the design of the study, the choice of included data sources, the presentation of results, or the content of the final manuscript. Frederikke Bruun Andersen and Zenia M Størling contributed with data interpretation and critical scientific review of the manuscript.

Disclosure

AE has participated on advisory boards for Coloplast, Hollister, and Wellspect, all of whom are developing or have developed TAI devices. BN, AJL, and RB have conducted this study on behalf of Coloplast. The authors report no other conflicts of interest in this work.

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