

Goal achievement as a patient-generated outcome measure for stress urinary incontinence

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Abstract

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Objectives To explore women's goals and goal attainment for the conservative and surgical treatment of stress urinary incontinence (SUI), and to examine the feasibility of Goal Attainment Scaling (GAS) as an outcome measure in this population.

Background Despite the range of treatments for SUI, little is known about the outcomes patients consider important. Current instruments measure the impact of SUI on the ability to live a 'normal' life without addressing what normal looks like for the patient. Patient-generated measures that address what a patient aims to achieve may fill this gap.

Design A mixed-methods exploratory design combined semi-structured interviews with validated questionnaires and individualized rating of goal achievement.

Setting and participants Participants with SUI ($n = 18$) were interviewed in their homes prior to initiation of treatment and 3–6 months afterwards.

Main variables Participants reported individualized goals pre-treatment and rated goal attainment after surgical and conservative therapy. Quality of life impact and change were measured using short forms of the Incontinence Impact Questionnaire and Urinary Distress Inventory.

Results Women expressed a median of four highly individualized treatment-related goals but goal achievement following conservative treatment was poor. GAS was not feasible as an outcome measure; women readily identified personal goals but could not independently identify graded levels of attainment for each goal.

Conclusions Although further work is needed to examine the most feasible, valid, and reliable method of measuring goal achievement in research, asking patients with UI to identify pre-treatment goals may provide useful information to guide treatment-related decision making.

Introduction

Urinary incontinence (UI) is a prevalent condition that affects approximately 27% of women worldwide¹ with far-reaching physical, psychological, social, and economic implications. Incontinence has been found to reduce health-related quality of life to roughly the same degree as chronic conditions such as depression and Type I diabetes.² Personal consequences include restriction of physical and social activity, self-imposed social isolation,^{3,4} sexual dysfunction,⁵ and disruption to employment.⁶ UI is also a major factor contributing to nursing home admission and hospital readmission among older women with co-morbid conditions.^{7,8} With direct costs estimated at over 25 billion dollars per year in the USA (approximately 3500 dollars for each incontinent person)⁹ and 1.5 billion dollars per year in Canada,¹⁰ UI is associated with major individual, societal, and health-care costs.

Stress urinary incontinence (SUI) is the most common form of UI in women 60 years of age or younger and is a contributing factor for the majority of older women with incontinence.^{11,12} Physiological factors include anatomical defects in pelvic support structures and/or neuromuscular dysfunction affecting urethral pressure.¹³ Women with SUI experience leakage associated with increases in intra-abdominal pressure, such as with physical exertion, coughing, laughing, and/or sneezing. Treatment options range from conservative therapies, for example pelvic floor muscle exercise (PFME), bladder training, and urethral/vaginal devices, to surgery. Conservative therapies are generally considered to be the first treatment option because they are non-invasive and have few side effects;¹⁴ however most require a degree of lifestyle modification and must be maintained at home by the patient. Surgical options are among the most common of all female surgeries.¹⁵

Growing evidence supports the effectiveness of treatments for SUI.^{16–22} This evidence has been based predominantly upon biomedical outcome measures, despite generally poor

correlation between objective and subjective findings.^{23–29} Such inconsistencies have led experts in the field to suggest that a strictly biomedical focus represents an oversimplified view of success³⁰ and have contributed to recommendations for the inclusion of quality of life measures in all treatment trials.³¹ Interpreting the relevance of quality of life findings for patients, however, has remained challenging as current condition-specific measures do not ask patients to rate the importance of quality of life changes.³² To enhance interpretability, researchers reported that a change of at least five points in the UI-specific King's Health Questionnaire reflected clinically meaningful improvement, but emphasized that perceived side effects and treatment costs must also be considered.³³ A second group used a statistical approach to define three distinct clusters of scores on the Incontinence Impact Questionnaire (IIQ) representing 'good', 'moderate', and 'poor' quality of life outcomes.³⁴ They noted, however, that 15% of patients had 'good' scores prior to treatment and could have been refused treatment based on these scores, while six women in the 'poor' category after treatment were satisfied with the intervention.

The available condition-specific quality of life assessment instruments appear to measure the impact of UI on the ability to live a 'normal' life without addressing what normal signifies for the individual concerned.³⁵ Patient-generated measures that address what a patient aims to achieve through treatment may be an effective way to fill this gap.³⁶ Elkadry *et al.*³⁷ investigated goals among 78 women undergoing UI surgery and found that goal achievement was strongly correlated with return to normal activities ($P < 0.0005$), lifestyle ($P < 0.0005$), and perceived control of urinary symptoms ($P < 0.001$). Other surgical patients with SUI ($n = 33$) reported that their major goals were return to normal activity and relief of bowel or bladder symptoms.³⁸

The purpose of our study was to add to the growing body of knowledge about patient-generated outcomes for UI treatment by

exploring goals and goal achievement among women who had recently opted for either conservative or surgical treatments. We also sought to investigate the feasibility of using a standardized method, Goal Attainment Scaling (GAS),³⁹ to measure goal achievement in this population. The overall aim of our study was to explore and enable a patient-centred approach within UI research, which acknowledges that we cannot know any patient sufficiently well to measure relevant treatment outcomes from a biomedical standpoint alone.^{40,41}

Design and method

We used a mixed-methods exploratory design to more fully understand patients' treatment goals before and after UI treatment. Personal, semi-structured interviews facilitated exploration of women's incontinence history and goals for conservative or surgical treatment before clinical intervention. In addition to narrative data, women completed validated quality of life questionnaires and set treatment-related goals. Follow-up interviews investigated goal achievement and quality of life after clinical interventions had occurred. The University of Calgary Conjoint Health Research Ethics Board approved the study.

Sample

This was a pilot study to explore individualized goals among women who had selected to undergo conservative or surgical treatment of their SUI. A sample of 20 (10 conservative and 10 surgical patients) was deemed appropriate for this preliminary study, which included narrative data to augment and inform quantitative findings.

Women undergoing assessment at the Pelvic Floor Clinic in Calgary, AB, Canada, were given an information sheet explaining the study. Patients were eligible to participate if they were 18 years of age or older, had been diagnosed with SUI or mixed UI with a predominant stress component, were scheduled to

undergo conservative or surgical treatment of SUI, and were able to provide informed written consent in English. All eligible patients were invited to take part. Recruitment continued until the proposed cohort of 10 surgical and 10 conservative candidates had joined the study.

Data collection

Interviews were held in women's homes and lasted approximately 1 h. Each was audio-recorded for transcription. Using a semi-structured topic guide, a researcher (JM) not involved with patient treatment asked women to describe their incontinence, how it had affected their lifestyle, and what they hoped to achieve through conservative or surgical treatment.

Participants were then asked to record their treatment-related goals. They were initially guided by written and verbal instructions that were consistent with GAS format, as described below. However, the first five participants expressed difficulty in quantifying their goals and identifying degrees of greater and lesser improvement according to the GAS rubric (see Findings section). Subsequent women were given simplified instructions to consider areas of their lives that had been impacted by UI and to assign at least one goal to each problem area. Following goal assignment, women completed two condition-specific quality of life questionnaires: the IIQ (IIQ-7) and the Urinary Distress Inventory (UDI-6).⁴²

Three months after surgery and 6 months after initiation of conservative treatment, the researcher contacted participants by telephone to explore progress and measure goal achievement. The longer follow-up for conservatively treated women reflected the extended time that can be required to recognize improvement from therapies such as PFME. Women were also asked whether they would choose to undergo the same treatment again and whether they would recommend the treatment to a friend or family member with similar symptoms. Post-treatment IIQ-7 and UDI-6 questionnaires were mailed for completion at home with a prepaid return envelope.

Research instruments

Goal Attainment Scaling

Goal Attainment Scaling was developed as a technique to guide treatment decisions in clinical settings. Later, it became used as an individualized measure of goal achievement to reflect the variability in patient perception of successful treatment outcome.³⁹ Patients, generally in conjunction with their clinicians, record condition-specific problem areas and assign a precise and realistic goal to each problem.³⁹ Each goal or expected outcome is assigned a value of 0. Patients then identify levels of attainment that would be somewhat better (+1) and much better (+2) than expected, as well as levels that would be somewhat worse (-1) and much worse (-2) than expected. Scores are aggregated to enable evaluation across a range of goals. Researchers have found GAS to be a valid and responsive measure in varied clinical settings and patient populations,⁴³⁻⁴⁶ but the method has not been evaluated among women with UI.

We included an example of GAS format to guide participants. The example listed the condition-specific problem as, 'I can't go on car trips without stopping every half hour to urinate', and the goal as, 'I would like to be able to drive for an hour without stopping to urinate'. Greater and lesser levels of attainment reflected increasing and decreasing time intervals without urinating.

Quality of life measures: IIQ-7 and UDI-6

The IIQ-7 is a seven-item scale that asks about the impact of UI on specific areas of an individual's life, including emotional health, social activity, travel, physical activity, entertainment, and activities of daily living, using a four-point Likert scale (from 'not at all impacted' to 'greatly impacted').⁴² The IIQ-7 produces a single measure of incontinence impact (0-100), with a higher score corresponding with greater impact and lower perceived quality of life. The UDI-6 produces a single measure of distress (0-100) from responses to six questions that ask about the presence of specific urinary symptoms (Yes/No) and the degree of bother associated with those symptoms. Both instruments

have been independently validated and have been widely used in a variety of trials.⁴⁷⁻⁴⁹

Data analysis

Descriptive statistics were used to summarize participant characteristics, rating of symptoms, baseline quality of life measures, and goal achievement. Goal achievement was measured by women's responses to the statement, 'I feel I have accomplished this goal', using a five-point scale (from 'strongly disagree' to 'strongly agree'). An overall achievement score was produced for each participant by calculating the average of all goals they identified. Differences between pre- and post-treatment quality of life scores were tested using the one-tailed Wilcoxon signed-ranks test, and Spearman's rho was used to explore the relationship between quality of life and goal achievement. $P \leq 0.05$ was considered to be statistically significant. Analysis was conducted using SPSS 15.0 for Windows (SPSS Inc., Chicago, IL, USA).

Narrative data were analysed using qualitative content analysis. Transcribed interview data and responses to open-ended questions were coded to identify major thematic, substantive content, such as *description of UI* and *treatment-related decision making*. Two subsequent levels of coding identified subcategories that included *getting it done*, and *avoiding surgery*. Codes were derived directly from participants' utterances.

Findings

Eighteen women (10 conservative and eight surgical) participated in this study and completed follow-up questionnaires. Twenty women were recruited, however, one was not available for follow-up and another was later deemed ineligible when diagnosed with predominant urge incontinence. Participants were of Caucasian descent and ranged in age from 43 to 80 years (Table 1). Most ($n = 14$; 78%) had completed post-secondary education, were employed full or part-time ($n = 12$; 67%), and lived with a partner and/or dependents ($n = 13$; 72%). On average, women who opted for

Table 1 Participant characteristics

	Surgery group (<i>n</i> = 8), <i>n</i> (%)	Conservative group (<i>n</i> = 10), <i>n</i> (%)
Age, mean (SD)	51.9 (12.1)	58.6 (10.8)
Range	43–80	46–78
Caucasian	8 (100)	10 (100)
Post-secondary education	5 (63)	9 (90)
Living alone	3 (38)	2 (20)
Employed outside home	7 (88)	5 (50)
Menopausal	3 (38)	7 (70)
UI longer than 5 years	5 (63)	8 (80)
Prior treatment for UI	3 (38)	3 (30)

UI, urinary incontinence.

surgery were younger (mean = 51.9; SD = 12.1) than women in the conservative group (mean = 58.6; SD = 10.8) and more likely to be working full or part time outside the home. In addition, a greater proportion of women in the surgical (*n* = 4 or 50%) than conservative group (*n* = 4 or 40%) considered their stress urinary symptoms to be a big problem prior to treatment.

At baseline, all women in the conservative group and most in the surgical group reported

Table 3 Goal domains

Goal-related domain	Number of goals per domain	
	Surgical (<i>n</i> = 8)	Conservative (<i>n</i> = 10)
Physical activity	13	13
Symptom	6	8
Emotional	4	6
Pads	1	5
Travel	5	1
Social	3	2
Sexual	0	2
Knowledge	0	2
Total	32	39

leakage associated with coughing, sneezing, or laughing (Table 2). The majority of women in both groups also reported leakage associated with a strong urge to void; however, more in the surgical group considered this to be a big problem.

Participant goals

Women reported between one and six goals that were categorized into eight domains (Table 3). The most frequently reported goals related to physical activity. Some were general, such as, 'to do normal physical activities'; however, most

Table 2 Participant rating of symptoms

	Baseline, <i>n</i> (%)		Post-treatment, <i>n</i> (%)	
	Surgical (<i>n</i> = 8)	Conservative (<i>n</i> = 10)	Surgical (<i>n</i> = 8)	Conservative (<i>n</i> = 9)*
Stress leakage				
No leakage	1 (13)	0 (0)	6 (75)	1 (11)
Leakage: no/small problem	3 (38)	6 (60)	0 (0)	6 (66)
Leakage: big problem	4 (50)	4 (40)	2 (25)	1 (11)
Urge leakage				
No leakage	2 (25)	2 (20)	4 (50)	3 (33)
Leakage: no/small problem	1 (13)	6 (60)	1 (13)	4 (44)
Leakage: big problem	5 (63)	2 (20)	3 (38)	2 (22)
Voiding overnight				
No leakage	3 (38)	5 (50)	2 (25)	2 (22)
Leakage: no/small problem	4 (50)	5 (50)	6 (75)	7 (78)
Leakage: big problem	1 (13)	0 (0)	0 (0)	0 (0)

One woman reported symptoms of stress leakage but did not rate how problematic the symptom was.

*Nine of 10 conservative patients returned post-treatment quality of life questionnaires.

were specific: 'To be able to jump while exercising without leaking'. Goals relating to urinary symptoms reflected a desire to reduce/eliminate urinary leakage, including not leaking when laughing, sneezing, coughing or with a full bladder.

Goals categorized as emotional were always expressed in conjunction with other desired endpoints that were physical, social, or sexual:

To not have the fear of leaking during sexual intercourse.

To be able to drink when thirsty when dancing without fear of embarrassment soon after.

To go dancing and have a social evening out without worrying about leaking.

Remaining domains were classified as pad reduction, social, sexual, travel, and knowledge. Most women wanted to eliminate the need for pads altogether: 'to be free of wearing a pad', and 'to do sports without wearing a pad'. Fewer ($n = 4$) expressed social goals. One wanted to return to volunteer work that she had given up because of her UI. She also expressed a desire to travel again, to 'go on a short bus trip, even one day'. Other travel-related goals implied that the incontinence had complicated, rather than pre-empted this part of their lives: 'To go on road trips without stopping every half hour', 'Not to have to worry between stops; to make the trip without leaking'. Two goals related to sexual activity and two knowledge-related goals were recorded. The latter involved a desire to learn more about pessaries and about causes of and solutions for UI.

Goal achievement

Goal achievement was somewhat higher among women in the surgery group (Table 4) (median 3.8) than the conservative therapy group (median 2.0). Five women (63%) who had undergone surgery reported that they had met some or all of their goals at follow-up, compared with four women (40%) who had initiated conservative treatment. Six women (60%) in the latter group indicated that they had not met any of their goals. Despite these figures the majority

Table 4 Goal achievement

	Surgical ($n = 8$)	Conservative ($n = 10$)
Number of goals identified per woman, median (range)	4 (1–6)	4 (1–6)
Average goal achievement score, median (range)	3.8 (1–5)	2.0 (1–5)
Goals achieved,* n (%)		
No goals achieved	3 (38)	6 (60)
Some goals achieved	1 (13)	2 (20)
All goals achieved	4 (50)	2 (20)

*A goal was considered achieved if the woman indicated 'agree' or 'strongly agree' that the goal was met.

of surgical ($n = 6$; 75%) and conservative patients ($n = 7$; 70%) reported that they would choose to undergo the same treatment again in similar circumstances. Most ($n = 6$ and 7 respectively) would also recommend their treatment to friends and family members.

GAS feasibility

The first five participants were asked to record treatment goals using GAS format, guided by written instructions and verbal reinforcement. Following a brief discussion about the personal impact of their SUI, each of these women was able to identify their treatment-related goals. However, goals were rarely precise in terms of expected degree of improvement, and none was able to conceptualize or record lesser and greater levels of goal attainment. All goals were therefore recorded as single-level items and participants rated their goal achievement at follow-up by responding to the question, 'I feel I have accomplished this goal' using a five-point scale (strongly disagree to strongly agree).

Quality of life

Women reported small-to-moderate quality of life impact, as measured by IIQ-7. Median pre-treatment quality of life impact was 38.1 (IQR 20.2) for the surgical group and 28.2 (IQR 23.2) for the conservative group (lower scores = lesser impact). Pre-treatment urinary distress

	Surgical (<i>n</i> = 8)		Conservative (<i>n</i> = 10)	
	Median (range)	<i>P</i> -value*	Median (range)	<i>P</i> -value*
IIQ Score				
Baseline	38.1 (0.0 to 52.4)	0.19	28.2 (9.5 to 76.2)	0.43
Post-treatment	4.8 (0.0 to 76.2)		19.0 (9.5 to 71.4)	
Change	-16.7 (-52.4 to 38.1)		-9.5 (-28.6 to 52.4)	
UDI Score				
Baseline	30.6 (0.0 to 66.7)	0.05	30.6 (11.1 to 66.7)	0.22
Post-treatment	17.8 (5.6 to 55.6)		27.8 (0.0 to 61.1)	
Change	-11.1 (-33.3 to 26.7)		-5.6 (-33.3 to 33.3)	

*Wilcoxon signed-ranks test, exact one-tailed *P*-value.

Table 5 IIQ-7 and UDI-6 Scores

scores (UDI-6) were comparable at 30.6 (IQR 43.1) among surgical patients and 30.6 (IQR 22.2) among conservative patients.

Among surgical patients (*n* = 8), there was no statistically significant difference between pre- and post-treatment quality of life impact scores (Table 5). Four women reported a decrease in quality of life impact (IIQ-7), one reported an increase, and three indicated no change. There was, however, a significant difference in distress (UDI-6) (*P* = 0.05), as seven of eight surgical patients reported less urinary distress after treatment. Among nine conservative patients who completed post-treatment quality of life questionnaires, changes were mixed. Six months after the initiation of treatment, five patients reported less quality of life impact while four reported increased impact. The majority reported less urinary distress.

To conduct a preliminary exploration of the relationships between quality of life and goal achievement, and urinary distress and goal achievement, we correlated change in IIQ-7 scores and UDI-6 scores with perceived levels of goal attainment at follow-up. The former relationship approached significance (*r* = -0.46; *P* = 0.07); however, there was less correlation between urinary distress and goal achievement (*r* = -0.39; *P* = 0.12) in this small sample.

Narrative findings

Analysis of narrative data suggested that participants had generally experienced a gradual worsening of their bladder symptoms prior to

seeking treatment, but had made lifestyle changes to reduce the personal impact of their UI. Factors that impacted therapeutic choices differed between conservative and surgical patients.

Gradual worsening

Women described a gradual worsening of their symptoms over intervals that varied from 4 to 27 years. One noted, 'I can't remember when I didn't have it' and another described the onset as, 'A long, long, long time ago...twenty plus years'. A participant who had been incontinent for 10 years had mentioned the condition to her doctor every time she received a physical examination 'for the record, so to speak, if it keeps getting worse'. Several recalled one incident that increased their awareness of the UI, such as leakage while performing in a play and while chasing after her children in a park.

Impact on lifestyle

Participants described varying degrees of UI impact. Drinking less before going out and calculating how long they would be away from a bathroom had allowed some women to carry on as usual. The majority, however, had given up certain activities, including jumping on a trampoline, running with their grandchildren, dancing, playing volleyball, and attending exercise class. One woman commented, 'So eventually, over the years, I'm probably not doing as much as I would like to and what I would want to'. An older woman who had undergone two prior surgeries for her incontinence had given up even

short-distance travelling as well as most of her volunteer work: 'I really don't feel I can go anywhere. That's why I stay home, where I can control it'.

Despite the changes that participants had made to manage their UI, the condition remained 'an annoyance' and a 'pain in the butt' rather than a major problem for most: 'I don't think of it as stay at home and not go anywhere because of it. If I want to go somewhere, I go'. This included two women who had opted for surgery, one of whom had been changing her clothes twice a day. The other emphasized that without pads, 'it would be a huge problem'. As a conservative patient summarized, 'I've just learned to deal with it, so I don't think of it as a problem. It's just life, kind of thing'. Another who wore a pad to exercise class despite concerns that it was noticeable said, 'This has been an accommodation that I'm willing to make anyways'.

This perceived lack of impact may have contributed to the fact that only two women, a conservative and a surgical patient, reported that they had sought help because their symptoms had worsened. Three in the conservative group commented that they had taken a proactive approach to 'do something for myself' and prevent the condition from worsening. One participant remarked, 'It's not the actuality of the loss; it's the wondering about it that gets you worried'.

Factors impacting treatment-related decision making

There was a prevailing attitude among women in the conservative group that non-invasive treatment should be their first option, but that surgery was a possibility in the future. One remarked, 'I really thought I should try this first because it's relatively easy and non-invasive'. Another, who was committed to doing something for herself said, 'It's easy to say fix me. I say let me see what I can do to help myself'. Three women seemed less convinced about their choices to undergo conservative therapy. One commented, 'we'll see how it works', while the others remarked that having a pessary and

maintaining PFME might be 'too intrusive' or 'too much work'. One had noted positive changes from her PFMEs.

Only two women who had opted for conservative therapy rejected the possibility of surgery in the future, one due to prior adverse effects from anaesthetic. Three who had opted for surgery emphasized that they wanted to 'go for the gusto', to 'just get it done', and to 'fix the darn problem'. The time required to maintain conservative therapies, including visits to a physiotherapist, was a perceived barrier.

Facilitators and barriers to goal achievement

Few women identified factors that had facilitated their goal achievement. One had found that using a tampon had been useful, and another said the PFMEs had helped and were 'better than counting sheep at night'. Likewise, women appeared to have difficulty identifying specific barriers to goal achievement. Factors discussed included lack of time, things getting in the way, and self-discipline. Another commented specifically that post-operative urgency had negatively impacted her goal achievement.

Post-treatment comments

When women were asked to comment on the treatment they had undergone, two of the seven who had tried pessaries were positive: 'I feel completely normal'; 'huge difference'. The majority reported difficulty finding the appropriate fit and/or one that would stay in, and one woman who had been scheduled for surgery after an unsuccessful pessary trial reported that next time she would skip conservative treatment. Experiences were also mixed among those who had initiated PFMEs ($n = 6$). Three were maintaining the exercises to varied degrees but three others had difficulty remembering to do them. One woman who had undergone surgery had also initiated pelvic exercises. Comments from surgical patients were varied. A woman with *de novo* post-void dribble said she would rather deal with that than with her pre-operative leakage. Another reported an on-going weak and intermittent stream that was 'disconcerting' but stated she would choose the treatment again

as it 'solves the problem'. Three reported their surgeries had failed, one of whom was particularly distressed because she had undergone previous surgeries for UI.

Discussion

The purpose of this study was to explore treatment-related goals and goal attainment among women who had chosen to undergo surgical or conservative treatment of SUI and to examine the feasibility of GAS as a patient-generated outcome measure in this population. Our findings support the growing body of knowledge about patient-generated goals for treatment of UI. Similar to earlier studies of surgical intervention for pelvic floor dysfunction^{37,38} participants recorded one to six goals that related predominantly to improvement of symptoms and return to usual physical activity, and had no difficulty verbalizing what they were aiming to achieve. Goals ranged in specificity and were highly individualized; however, three women in the surgical group and six women in the conservative group reported they had not achieved any of their goals at their respective 3 and 6-month follow-up interviews.

The small sample ($n = 18$) in our study requires that findings be interpreted with caution. Results have therefore been presented primarily as frequencies. Statistical inferences, most notably the association between goal achievement and quality of life change, must be re-examined in future studies with larger sample sizes. The generalizability of findings has been further impacted by sample homogeneity: women were of Caucasian descent and most (78%) had post-secondary education. Differences between conservative and surgical patients in this convenience sample may also have impacted the findings. Women in the conservative group were older and less likely to be working full or part time, and fewer considered their stress and urge symptoms to be a big problem (Table 2). These characteristics support recent findings that correlates of reduced quality of life among 655 female surgical patients with SUI included younger age, increased number of

daily leakage episodes, and more symptom bother.⁵⁰

This study was, to our knowledge, the first to explore patients' goals for the conservative as well as surgical treatment of SUI. Participants in both groups were clear about what they hoped to achieve prior to treatment and their goals appeared to be clinically realistic; although one surgical patient spoke about wanting her problem 'fixed', most hoped to return to some of the activities that they had given up and to do so without living in fear of leakage. This desire to normalize lifestyle while coping with a health-related condition has been a consistent theme among individuals with UI and others who live with chronic disease. In earlier studies, women undergoing surgery for UI aimed primarily to return to their normal lifestyles and activities.^{37,38} When another cohort of patients ($n = 100$) with stress, urge, or mixed UI was asked about treatment goals, 43% aimed for sufficient improvement that UI no longer impacted daily lifestyle, while only 17% expected to be cured.⁵¹ Patients with rheumatoid arthritis^{52,53} and diabetes⁵⁴ have been equally consistent in their desire to live as normally as possible by integrating self-care into their daily lives.

Although participant's goals to return to their usual activities appeared realistic, only four (50%) in the surgical group and two (20%) in the conservative group thought that all their goals had been met at follow-up. Of greater concern, three surgical patients (38%) and six conservative patients (60%) reported that none of their goals had been met. The lack of goal achievement by surgical patients was likely explained by their reports that surgeries had failed (one woman had had three prior surgeries for UI) and by narrative reports of troublesome post-operative urgency and intermittent stream. The disappointing results among conservative patients merit additional reflection. Although several women experienced difficulty obtaining an appropriately fitting pessary, narrative data suggest that competing demands were a greater barrier to goal attainment. Consistent with findings to date,^{55,56} women reported particular difficulty adhering to PFMEs.

Pelvic floor exercises should ideally be performed 3 days/week to build strength and twice per week to maintain strength.⁵⁷ Given that persistence with conservative therapy in general is critical to positive outcome, it is possible that the lower levels of goal attainment reflected a lack of symptomatic improvement. It is also possible that a longer follow-up interval would have resulted in additional goal attainment. Participants had been incontinent for at least 4 years, some as long as 10–20 years, and had made numerous lifestyle adjustments. As coping strategies such as voiding frequently, staying close to bathrooms, and adjusting physical activity develop insidiously over time, it may take longer to change behavioural patterns and/or to develop the confidence to resume prior activities without reliance on pads. Despite the disappointing level of goal achievement among conservatively treated patients, the majority ($n = 7$) would choose the same therapy in similar circumstances and would recommend it to family and friends. Most of these women believed that non-invasive therapy should be the first line of action and seemed content with their choices and the option to move on to surgery as necessary.

The overall domains represented by participants' goals were similar to those found within existing quality of life measures such as IIQ-7,⁴² CONTILIFE[®],⁵⁸ and I-QOL.⁵⁹ Domains that have not been previously reported were pad reduction and knowledge enhancement. While pad reduction may arguably be associated with self-image, it has been presented as a stand-alone category because of its singular importance to respective participants.

What differentiates patient-generated measures of goal attainment from existing quality of life tools is that the former comprise only the domains of relevance to the individual patient. Although the association between goal achievement and quality of life change approached significance ($P = 0.07$), the opportunity to reflect upon one's goals appears to tap into areas of personal importance that would otherwise be missed. The individualized nature of women's goals suggests that population-normed, 'one size

fits all' quality of life scales may miss outcomes of relevance to the target population: women coping with SUI. They may also direct responses, as suggested by a study of 200 adults whose open responses to interview-based questions differed substantially from those elicited by prompt cards.⁶⁰

As the support for patient-generated outcomes increases, the need to select measures that are feasible and valid persists. We examined GAS as a validated means to capture individualized outcomes, but found it was not feasible in a sample of women with stress UI. This was predominantly due to the nature of participants' goals (Table 3), which were rarely quantifiable. For example, goals related to physical activity included 'to do normal physical activity', 'to start biking again', and 'to go on hikes again'. A social/emotional goal was 'to go dancing and have a social evening without worrying about leaking'. As many goals involved the return to activities the women had given up, the re-uptake itself was what mattered and excessive quantification ran the risk of impacting the goal identification process such that they were no longer patient-generated. As with other standardized patient-generated measures such as the Patient-Specific Functional Scale⁶¹ and Canadian Occupational Therapy Measure,⁶² the inherent emphasis on functional and/or behavioural outcomes may limit the feasibility of GAS among individuals with UI.

In addition, the purpose of the GAS may itself be problematic in relation to outcome assessment. GAS was originally developed as a clinical support tool designed to guide practitioners towards interventions that were relevant for patients.⁶³ Within a patient-centred care philosophy, this makes sense. GAS clinical procedures, however, require a trained practitioner to help patients identify both their preferred areas for improvement and appropriate levels of positive and negative attainment. Our study found that women could not successfully identify these appropriate levels of attainment without levels of guidance that would be considered inappropriate in a research setting. This may indicate that GAS, despite numerous attempts, is not

easily transferable from a clinical purpose to a research one, and further methodological research should be focused on examining the validity of this method.

Conclusion

As a research outcome, goal achievement offers a means to measure treatment success from the patient perspective that might otherwise go unrecognized. Women undergoing conservative and surgical therapy for SUI were readily able to identify personal goals. Although further work is needed to examine the most feasible, valid, and reliable means to measure goal achievement as a research outcome in this population, asking patients to identify their pre-treatment goals can provide useful clinical information to help guide treatment-related decision making. As many women did not attain their pre-treatment goals, this information should be supported by a clear understanding of the context within which conservative therapies, in particular, are to be initiated and maintained in order to ensure that decision making is truly informed.

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