

Patient and Carer self-reported incontinence evaluation. Providing guidance for management and intervention

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FUNDED BY THE NATIONAL CONTINENCE MANAGEMENT STRATEGY, 2002

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Background:

It is estimated that 850,000 Australians suffer from incontinence. The enormity of this figure demands that health care services are consistently able to meet the complex physical, psychological and social needs of those directly and indirectly affected by incontinence. An effective continence service needs to understand and meet the needs of its clients from both a clinical and a quality of life perspective. In order to be responsive to these needs, clinicians must be consultative, taking the time and effort to understand individual patient's specific concerns about the impact of continence problems on their physiological and mental health and on lifestyle in general. However, as recognised by Roe and May, a commitment to a consultative process and time to explore clients' experiences of incontinence and treatment and intervention expectations may not overcome the barrier of incontinence's "taboo status [which] restricts open discussion".¹ It is clear both from clinical practice and research that "people need encouragement to seek help, information on how to access services and to overcome their feelings of embarrassment".²

The difficulty of establishing and maintaining discussion between clients and service providers challenges continence services to overcome the disparity between what is clinically measurable and what is experienced by service users. Incontinence has been shown to have a significant impact on patients' quality of life, but what is clinically demonstrated may be distinct from what is perceived by patients to be the most troublesome aspect of their condition. Current clinical tools do not adequately address patient's perceptions of how incontinence impacts on their life and may not help in developing the best strategies to address these issues.

Initiating discussion regarding clients' experiences of incontinence, and their preferences and priorities for treatment and intervention, is often difficult. Clients' expectations of limited impact of treatment, fear of surgery, a belief that declining continence is an inevitable process of ageing or the consequence of childbirth and clients' discomfort with the psychosocial experiences of incontinence combine to make the access of clients' preferences and priorities fraught within the clinical area.³

⁴ The establishment of useful discussion between clinicians and service users is further exacerbated by the perception that incontinence (particularly urinary incontinence) is not an illness and as such is "not considered appropriate for discussion with a health professional".⁵

The outcome of these communication barriers may lead to a dissonance between clinical treatment and intervention and clients' own preferences. Individual clients' own preferences for treatment and intervention and the differing degree of

¹ Roe, B., and May, C. "Incontinence and sexuality: findings from a qualitative perspective" *Journal of Advanced Nursing*, 1999, 30(3), 573-579.

² Roe, B., and Wilson, K., "Health interventions and satisfaction with services: a comparative study of urinary incontinence sufferers living in two health authorities in England", *Journal of Clinical Nursing*, 2000, 9(5), 792-800.

³ Cohen, S.J., Robinson, D., et al, "Communication between older adults and their physicians about urinary incontinence", *The Journal of Gerontology*, 1999, 54A(1), M34-M37.

⁴ DuBeau, C.E., Levy, B., et al, "The Impact of Urge Urinary Incontinence on Quality of Life: Importance of Patient's Perspective and Explanatory Style", *The Journal of Urology*, 1998, 160(6-1), 2303-2304.

⁵ Shaw, C. "A review of the psychosocial predictors of help-seeking behaviour and impact on quality of life in people with urinary incontinence", *Journal of Clinical Nursing*, 2001, 10(1), 15-24.

‘bothersomeness’ experienced by clients with similar symptoms demand individual care plans.⁶ Whereas clinicians may (not surprisingly) measure outcome of treatment or intervention with regard to functional assessments, clients may still find that despite clinical improvement the negative impact of incontinence on their well-being and quality of life remains.^{7, 8}

Interpretation of clients’ subjective evaluation of their incontinence contributes to the difficulty of reconciling functional outcomes with clients’ satisfaction or otherwise with their treatment and intervention plans. The extent to which people view themselves as incontinent, despite seeking help for urinary leakage, or whether they view such leakage as problematic, vary considerably between clients. As Clayton and Smith et al note:

One person’s ‘damp’ might be another’s ‘quite wet’ and the degree of impact of urinary incontinence in social and emotional terms is not necessarily directly related to amount of leakage or impact in practical terms.⁹

Similarly, for some client groups, the level of self-management successfully achieved, duration of incontinence, and ability to avoid activities which may be associated with incontinence episodes (for example, toilet-seeking, restriction of fluids, avoidance of exercise and social activities¹⁰) will impact on their perceptions about the efficacy of proposed treatments and interventions.^{11, 12} Both research and clinical experience clearly illustrate the need to consider clients’ perceptions of their quality of life and the social and emotional burdens of incontinence in the evaluation of treatment and intervention strategies.¹³

For some clients a carer may also need to be involved in discussion; clinicians are required to access and respond to the impact of incontinence on both the client and the carer. Cognitively impaired clients may deny or not recognise their incontinence creating significant challenges to both professional and other carers.¹⁴ Thus, clinicians may be faced with developing continence care, treatment and intervention which encompasses conflicting expectations and needs.

Thus, a key question for service providers asks, “how can clinicians adequately engage clients (or their carers) in discussion of the psychosocial impact of their incontinence?” An equally important question is “how can clinicians be confident that treatments and interventions for incontinence are responsive to clients’ (and their

⁶ Peters, T.J., Donovan, J.L., et al, “The International Continence Society “Benign Prostatic Hyperplasia” Study: The Bothersomeness of Urinary Symptoms”, *The Journal of Urology*, 1997, 157(3), 885-889.

⁷ DuBeau, op. Cit.

⁸ Clayton, J., Smith, K., et al, “Collecting patients’ views and perceptions of continence services: the development of research instruments”, *Journal of Advanced Nursing*, 1998, 28(2), 353-361.

⁹ Clayton, et al, op cit, 357.

¹⁰ Davila, G.W., Neimark, M., “The Overactive Bladder: Prevalence and Effects on Quality of Life”, *Clinical Obstetrics and Gynecology*, 2002, 45(1), 173-181.

¹¹ Skoner, M.M., “Self-Management of Urinary Incontinence Among Women 31-50 Years of Age”, *Rehabilitation Nursing*, 1994, 19(6), 339-343.

¹² Shaw, C., Williams, K.S., Assassa, R., “Patients’ views of a nurse-led continence service”, *Journal of Clinical Nursing*, 2000, 9(4), 574-582.

¹³ Fultz, N.H., Herzog, A.R., “Self-Reported Social and Emotional Impact of Urinary Incontinence”, *Journal of the American Geriatrics Society*, 49(7), 892-899.

¹⁴ Thompson, D.L., Smith, D.A., “Continence Restoration in the Cognitively Impaired Adult”, *Geriatric Nursing*, 1998, 19(2), 87-90.

carers’) psychosocial priorities?” Or, as Clayton et al ask “How does a response ‘I can’t get to aerobics or “step” classes. I used to do it but it got too embarrassing’ become an accepted outcome measure...?”¹⁵ These questions form the basis of the current project.

It has become increasingly common for health care services to espouse the benefits of participatory care. This involves the development and implementation of a care model, which “engages the patient in deliberation about health issues and related values”, demands “[I]ncreased patient involvement in the medical encounter and greater patient control.”¹⁶ The project can be fruitfully viewed as part of the increasing trend to include health care consumers in their treatment decisions. Identified benefits from a consumer participation model of health care include:

- Improvements in health outcomes;
- Service users undertaking a more active role in their health management; and
- Improvements to health care services.¹⁷

In an effort to establish and maintain communication between clients and clinicians the Caulfield Continence Service (CCS) developed a tool to facilitate the provision of treatment and intervention which is responsive to clients’ own priorities. Importantly, the tool was required to enable clients to determine their own level of participation. As found in studies of participatory care with cancer patients, the level of participation and client decision-making needs to take account of individual needs and desires.¹⁸ The tool is not intended to replace the use of quality of life instruments, but rather to gain a snap-shot of clients’ needs and wishes for treatment and intervention outcomes. The tool was required to be sufficiently flexible to meet the following demands:

- To be useful for the diversity of clients attending CCS (geriatric, women of child-bearing age, inpatient, outpatient, residential care residents);
- To be useful for the range of clinical areas associated with CCS (nursing, physiotherapy and medicine); and
- To capture the needs of professional and other carers where appropriate.

¹⁵ Clayton, et al, op cit, 357.

¹⁶ Gotler, R.S., Flocke, S.A., et al, “Facilitating Participatory Decision-Making: What Happens in Real-World Community Practice?”, *Medical Care*, 2000, 38(12), 1200-1209.

¹⁷ Consumer Focus Collaboration, The evidence supporting consumer participation in health, National Resource Centre for Consumer Participation in Health, Melbourne, 2001.

¹⁸ Sainio, C., Eriksson, E, Lauri, S., “Patient Participation in Decision Making About Care: The Cancer Patient’s Point of View”, *Cancer Nursing*, 2001, 24(3), 172-179.

The Project:

CCS was established in 1996, is funded by DHS ,Victoria, and provides comprehensive assessment and management of incontinence (both bladder & bowel) in our region which covers three local council municipalities. This is done through outpatient specialist clinics, inpatient visits and a domiciliary service employing medical, continence nursing and continence physiotherapy staff. Patients may be self-referred or referred by GPs, Specialists, carers, community agencies (eg RDNS, ACAS, CCRC)and institutions (SRS/ Hostel/ public & private hospitals etc).

The majority of patients are able to attend the clinic while the more frail, elderly and their carers are visited in their place of residence.

CCS identified the need for the development of a simple, valid and reliable instrument for the clinical evaluation of patients' and carers' perceptions of the impact of incontinence on their lives and to help develop strategies to address these issues. This project developed a goal-oriented clinical tool for the collection of information relating to patients' and carers' perceptions of priority issues in terms of the impact of urinary incontinence on their quality of life. The tool is also used to assess the impact of the treatment strategies adopted in relation to patients' and carers' priorities.

Development of tool

The first draft of the tool (Tool A) together with a complementary checklist of life issues were developed through consultation with continence care health professionals, patients and their carers (see Appendix 1). Initially, two focus groups were held with a small number of service users and carers recruited through CCS (total participants 6). The focus group participants made recommendations regarding content and presentation of the tool; minor amendments to this were made after a meeting with representatives from nursing, medicine and physiotherapy (see Appendix 1). Employing previous research investigating patients' explanatory style of urinary incontinence¹⁹, focus group participants developed a list of issues to act as a prompt for self-completion of the original tool. In particular, the inclusion of this list was expected to widen the scope of issues for patients to include in discussion with their health carers – moving from the clinical measurements expected in a health consultation to acknowledgment and inclusion of the psychological and social impact of patients' condition.

Tool A was piloted by four clinicians (2 doctors, 1 nurse, and 1 physiotherapist) for 7 weeks within the clinic. Forty-nine patients and/or their carers were invited to complete the tool prior to their initial consultation with the continence care provider. It became evident to the clinicians that Tool A was unable to meet the aims of the project for the following reasons:

- A large percentage of outpatients were unable to successfully comprehend and complete the Tool (44%).
- None of the domiciliary population attempted to complete the Tool on their own.
- Only 25% of the domiciliary population were able to complete the Tool with considerable assistance from clinicians.

¹⁹ DuBeau, op Cit.

- Lack of consistency with the data obtained from the pilot due to the variety of ways in which the Tool was completed and lack of clarity regarding the impact of clinicians' involvement in the completion of the Tool.

Those patients able to complete the Tool in a way which was instructive to the development of treatment and management plans were generally younger and with a higher level of cognitive function than those unable to attempt the Tool or needing substantial assistance to complete. The clear limitations of the Tool for the domiciliary population suggested the format of Tool A was unsuitable for the frail elderly, and/or those with a level of cognitive impairment. Deficiencies of Tool A included problems identified with the format:

- Length: patients found the prospect of three pages daunting.
- Horizontal layout: the 'landscape' rather than 'portrait' layout was unfamiliar to patients.
- The use of a visual analogue scale for patients to rank their issues was not readily understood by the majority of the patient cohort and suggested the expectation that issues could not be ranked at similar or the same levels.

A further troubling factor of Tool A was the inclusion of the list of possible issues. Clinicians felt that patients were automatically choosing issues from the list rather than considering their individual situation. This was not wholly unexpected, as the list included common troubling issues for people faced with incontinence; nevertheless, the clinicians and research team lacked confidence that Tool A was facilitating access to the individual and personal information it had been designed to solicit.

Despite the perceived failures of the initial pilot the research team and clinicians wished to incorporate the positive attributes of Tool A in a modified form. These attributes included:

- For those patients who were able to complete Tool A clinicians' understanding of issues to be addressed in treatment and/or management was enhanced.
- Completion of Tool A enabled access to information regarding the psychological and social impact of incontinence that was otherwise difficult to obtain.
- Access to this information was achieved within a much shorter time-frame than would otherwise have been possible, enabling a speedier response to the issues.

In response to both the brief pilot of Tool A a further focus group was held which included representatives of CCS' clinical areas, patients and carers. Apparent deficiencies and positive characteristics of Tool A were discussed at length, and substantial modifications to the form were made (Appendix 2). In addition, changes to the protocol were developed. These changes were implemented to redress problems associated with independent completion prior to the consultation and a recognised need for greater clinician input.

Changes in the protocol included:

- Removal of the list of issues used as a prompt from the form.
- A separate sheet of issues commonly faced by people with incontinence sent to patients prior to their initial consultation for their consideration.

- Clinicians actively engaged in both soliciting responses and assisting with assigning rank and priority to issues on the form.

As a result the completion of the form became a vehicle to facilitate the discussion of personal and troubling issues throughout the completion of the form, rather than the completed form being used as the basis for initiating this discussion. This led to a substantial shift in focus for both the project and the form. The initial effort to quantify subjective patients' issues in a manner that could be ranked both for individual patients and for patient populations was relinquished and instead a focus to an open-ended individual goal-oriented form was established.

Pilot:

The second draft of the form (Appendix 2) was piloted for 15 weeks using the following protocol.

Prior to the first consultation patients were sent:

- A letter signalling a discussion of the psychosocial issues facing the patients and/or carers (Appendix 3).
- A blue coloured page listing issues commonly faced by patients and/or carers (Appendix 4).

At the first consultation (time 1):

- The amended form (Tool B) was completed in discussion with the clinician using established questions and prompts to elicit the required information (Appendix 5).
- Patients and carers were able to list up to 5 of their most bothersome problems.
- These problems were then rated for “priority”(severity) ie. “How much does this bother you?”.
- Then they were rated for “frequency” ie.“How often does this bother you?” as per rating scale.
- These rating scales were presented to the patient on large separate rating cards to minimise confusion (Appendix 6).

At discharge OR at the completion of the study period which was between 3-20 weeks into treatment (time 2):

- Tool B again completed in discussion with the clinician using the established questions and prompts.(Appendix 7)
- Then the form completed at the first consultation (time 1) was revisited by the patient and/or carer and the clinician to establish changes to previous rating of problems and any new issues.

- The patient/carer however was not able to see the ratings they had previously attributed to each problem.
(See Figure 1)

Completed tools were coded consistently throughout the pilot in a manner which:

- Maintained privacy and confidentiality of patients.
- Enabled comparison of data between patients.
- Enabled comparison of data between time 1 and time 2 to measure progress.

The tool was used twice with each new patient attending CCS during the pilot to enable clinicians to evaluate the impact of treatment and interventions on the priorities for care identified on the tool. Due to a change in the internal processes of admission within CCS Tool B was administered by clinicians from nursing (2) and physiotherapy (1). No medical practitioners participated in the pilot. The study had ethics committee approval from the Alfred HREC and LaTrobe university HEC.

The patients/carers recruited in this study had to fulfill the following criteria:

- Be unknown previously to the service
- Have urinary and/ or faecal incontinence and/or frequency/urgency
- Have sufficient cognitive function to be able to answer the questions involved in the completion of the tool or have a carer available to answer on their behalf
- Give their verbal consent

Over a period of fifteen weeks 50 patients / carers consented to completion of the tool at their initial visit. Consent was gained verbally from the patient or carer. 44 patients(88%) and 6 carers (12%) took part in the study. At discharge (completion of treatment) or at the end of the study period (interim group) they were asked to complete the tool again.

This time period varied from 3 weeks to 20 weeks (average 12 weeks).

Of these patients/carers 78 % (39)were female and 22% (11) male. The average age was 73.4 years with a range 31 – 91 years.

6 patients/carers did not complete the second tool for a variety of reasons. The most commonly identified reasons were lack of compliance, denial of the problem or refusal of further interventions.

Table 1: Study Population by Age

| Age (years) | N = 50 | Percentage (%) |
|--|--------|----------------|
| < 50 | 5 | 10 |
| 50-59 | 4 | 8 |
| 60-69 | 8 | 16 |
| 70-79 | 13 | 26 |
| 80-89 | 17 | 34 |
| 90-99 | 3 | 6 |
| Average age 73.4 years (range 31-91) | | |

Length of Treatment

Range 3-20 weeks Average 12 weeks

Number of Visits

Range 2-9 visits Average 4 visits

Evaluation of Participants:

Both patients and clinicians involved in completing the form participated in a formal evaluation of the piloted tool. Six patients, (five women, aged 20-80 and 1 man, aged 80-90) and three clinicians (one physiotherapist and two continence nurses) took part in individual interviews to assess the tool. An interview schedule (See Appendix 8) was used for both the patient and clinician interviews, asking questions regarding the usefulness, clarity, process of completion, and suggested changes to the form.

All the interviews were undertaken at the CCS; interviews took approximately 1 hour, allowing time for clarification and discussion. The evaluation data collected from both patients and clinicians is presented below. Five main categories of data are presented for each group:

- Clarity, accessibility and difficulties with the tool
- Priority and frequency ratings
- Impact on discussion between patients and clinicians
- Impact on treatment
- Suggested changes in tool

Patients:

Patients interviewed were largely positive about the form, not suggesting any major changes to the format or wording. They felt that the inclusion of the tool enhanced both their relationship with the relevant clinician and also their treatment.

Clarity, accessibility and difficulties with the tool

Overall, the patients interviewed found the form easy to understand, the questioning clear, and the completion of the form was not difficult.

One interviewee suggested having a separate form for bladder and bowel conditions, as she found the optional reading of the question awkward:

[[I]t's a bit loose, I feel ... I read it two or three times and I thought now hang on, what part of this questions am I answering.

At the same time, however, she described the form as 'a terribly simple form'. Other patients made similar comments, for example:

I think it's fairly simple.

It's short, sharp and to the point.

Easy, it was easy.

Yes, it was easy to understand.

I think it's very clear., How much clearer could it be? It's very straightforward and simple.

There was some discussion regarding when and how the form was filled out. Only one of the patients had remembered the blue sheet sent prior to their visit that lists common psychosocial issues facing people with incontinence. A need for some 'prompt' or similar was expressed:

Maybe it would help to have some things down there, just to prompt the person. Because I came away thinking did I, not having time to think beforehand, because some things don't always occur [to you] ... So, they could be listed. Maybe alphabetically, so that they are not in any particular order.

You're not always thinking clearly, whereas a few prompts, you know... if they're rattled off so that whatever is relevant hits the brain.

One patient suggested responding to the questions on their own would enable them to have more time to consider their responses:

I had to be prompted with the type of things that I should be looking at. The second time, I had to be prompted again. I think if you had the form and you went away and you sat down and you thought about it, I suppose you'd come up with things.

There was no clear consensus on when the form should be filled in however; other patients found the form a useful discussion prompt and found completing the tool with the clinician a useful exercise:

For starters I think it just has to be very basic ... I think it is pretty good... no problems. Doing it on the spot is a plus.

[I]t gives a starting point for [clinician's name] to work from, so I think it's a useful form.

Priority and frequency ratings

The interviewees recognised the problems inherent in reducing their issues to numbers, but also found it a useful undertaking. In particular, the repeat use of the tool provided a clear indication to them of the effectiveness of their treatment, and also acted to strengthen their commitment to comply with treatment and therapies. The tool seemed to encourage patients to share the responsibility for treatment; particularly important in the area of incontinence.

Well, I suppose you have to have these ratings, and they're always a bit dubious, but how else can you measure things?

I think this [the ratings] was quite good, and it addresses the fact that people, I think, can also not realise the manifestation of their continence problem for quite a while.

I thought it was very helpful and I think it was also good to help you get a grip on how much it is affecting your life.

Impact on discussion between patient and clinicians

One of the main objectives of the project was a tool that would facilitate discussion of incontinence between patients and clinicians. The patients interviewed found the tool a useful prompt and guide for discussion, acknowledging both the need to discuss the issues raised by their incontinence and the difficulty of this exchange:

You've got to talk about your own problems ... It forces you to look at what the problems are.

Possibly it helps you to clarify what the issues are, to yourself, in your own mind.

I found her very sympathetic and very understanding, she understood where I was coming from. It did open up, looking at the priority ratings, how much of a problem is it, and the frequency.

I actually thought it was very good, and I think providing the patient is comfortable with discussing things which are quite personal [the form facilitates discussion].

Impact on treatment

The patients interviewed strongly believed that the issues raised during the completion of the tool were addressed through the treatment plans developed by the relevant clinicians. There was a confidence that the treatment 'is trying to correct those problems'.

Again, this appeared to encourage a greater commitment to treatment, and also a shared responsibility for the resolution of the issues raised. Patients benefited from the discussion necessary to complete the form in terms of measuring their progress (if any) and felt reassured that clinicians had their particular issues written down for reference.

I think whatever information you get must be written down and you know, but following up [is important]. Well, this was followed up to see whether the problem did go down.

Completion of the tool, and the follow up, also seemed to clarify for the patients the time involved in obtaining benefits from treatment, for example exercise and bladder training:

The issues of priority and frequency were definitely reduced by the second visit. There are still issues that are there, things don't go away over night, but they're [improving].

Suggested changes in tool

Given the general acceptability of the tool for the patients interviewed, not surprisingly there were few changes suggested. Interestingly, and unexpectedly, it was suggested by 4 of the interviewees that the tool could be used to also discuss the level of commitment necessary for successful treatment. Acknowledging the time and patient commitment needed for much of the treatment, and coming to a realistic expectation regarding how much time patients are able or prepared to commit could be included on the form.

I can't see any problems, you've got all the questions here ... I suppose the only other thing is getting into a routine of doing the exercises.

Clinicians:

The three clinicians that participated in the pilot were also interviewed. Following an adapted interview schedule, their responses are presented within the same categories as the patients. While two of the clinicians were largely positive about the form, the continence nurse responsible for domiciliary visits found the form overwhelmingly inappropriate for her patients within the current protocol. While this is a disappointing outcome – the frail elderly who largely made up her patient cohort were also those the project team most wanted to access – the suggested changes to protocol for this group indicate some worth in re-piloting the tool for this group. A separate discussion on domiciliary visits is therefore included below.

Clarity, accessibility and difficulties with the tool (outpatients)

The developed protocol included the opportunity to prompt patients to respond; both the clinicians seeing patients at CCS found it necessary to use this prompt when

completing the tool. This was especially evident, not surprisingly, during the initial completion of the tool:

The majority of [my patients] did [understand the form] but again when you ask the question about what are the worst things they go off on a bit of a tangent and you'd have to bring them back.

A lot of the time you had to give examples ... I'd say probably 80% of them. You kind of had to push them in the direction of what their problems might be.

Despite efforts to reduce the reliance of the tool on patients' cognition, this remained relevant to the confidence clinicians had in the completed tool:

I think there is still a cognitive component to the whole thing unfortunately, definitely.

The only ones who struggled were the ones who perhaps had some cognitive problems. I guess it was quicker and easier with the younger patients; it got a bit harder as they got a bit older.

Both clinicians seeing patients at the CCS noted the difficulty that the frail elderly had with the form:

[W]hen we designed it I thought it was going to be really easy ... but it wasn't as easy as we thought ... For the frail elderly it was very difficult.

It has a role, and I think it's good, but I think it's not good with the frail elderly group. It's not identifying their issues well enough [...]

It's a difficult group. I don't know [what would work with them]. I think they find the scale confuses them, they can't break it down to how often or how much it bothers them, but they also can't tie the problems down and that's the hardest thing.

I think for a proportion of people it works really well, like people who do have the understanding, can understand what you're talking about. But I did find it difficult with the more frail elderly group that really had problems identifying what their complaint was.

Despite reservations the clinicians held regarding the extent of prompting, issues of cognition and lack of suitability for the frail elderly, they reported the form as acceptable and useful for the majority of their patients:

The majority was quite happy to answer the questions and go through it.

Priority and frequency ratings (outpatients)

The clinicians' insights revealed in discussion regarding the priority and frequency ratings largely confirmed those of the patients' observations. Improvements enabled patients access to evidence of improvement (where applicable) in ways that reassured them more than clinical measures.

They found the rating scale – once we had identified the problems – they then found the rating scale quite easy to use. They could work that quite easily.

I guess, often in progress, it's been more an informal gauge of how people are going.

Encouraging a realistic expectation of treatment was also a benefit of revisiting the form:

I think there was one lady in particular who was still rating her numbers quite high even though her incontinence had reduced a lot. So, then I guess you have to think does this patient have realistic expectations of the treatment. We sort of talked about what the form showed, and she was actually quite surprised that some of it had gone up, some of it had gone down.

Impact on discussion between patient and clinicians (outpatients)

The tool enabled greater clinician insight into the issues facing patients, and also facilitated the establishment of discussion regarding patients' psychosocial issues. This in turn led to clinicians more closely following up the psychosocial impact of treatment with the patients.

It certainly makes it easier to ask about, you know, do they worry about smell and those kinds of things which perhaps they don't offer and perhaps within the context of the clinical visit we don't get around to, that we tend to kind of skim over.

I guess for me it's made me, with every patient, visit that area of how it's affecting them more specifically. Not just in a social context, but also just psychologically I suppose. Because, as I said, it's very easy to go through the normal history and not really look so much at the impact unless they offer it.

[I]t does give them that permission to express their fears about, you know, odour, and being embarrassed.

Increased attention to the psychosocial issues related to their patients' incontinence was evident in discussion on the impact the tool had on treatment.

Impact on treatment

While broad treatment methods were not changed by the clinicians, modifications in response to the information gleaned from the tool and increased attention to patient needs have resulted.

I guess for those people who have specific fears like, you know, being able to find a toilet ... in a strange place, as part of their bladder training talking about strategies to overcome that particular issue. Like, giving them

permission to perhaps, that it's ok to go to the toilet before you go to one of these unknown places. That the rules, as such, can be bent.

Obviously odour, you pay much more attention to what pads they use, and how often they change them and those sorts of things.

While the clinicians said that they probably haven't changed their treatment substantially in response to the information, the interview data suggests that greater reflection on what is happening for their patients leads them to revisit treatment regimes to ascertain ongoing suitability:

There's been a couple of patients though who, sometimes the numbers have gone up, and I suppose that's made me really think, you know, what am I doing with that patient, am I doing everything that I should have been, have I missed things, or what's going on.

It did make me understand how much of a psychological problem ... fear and avoidance of going out and that type of thing affects continence. It didn't actually alter what I did, what we did for them, but it does make me have more of an awareness of how much the psychological affects [the patients].

While it was not within the scope of this project to measure the impact of this greater awareness and attention, it is likely that this translates into an improved care and experience of incontinence treatment for the patients. One of the clinicians described the use of the tool as a 'bit of a wake-up call':

Again, it hasn't really probably changed so much what I've done, just made me more aware, things aren't, in their eyes, what they want them to be. Whereas perhaps I thought they were doing better, perhaps physically, but not psychologically I guess.

The use of the tool as a regular measure of progress and for keeping treatment in line with patients' issues was suggested:

I think it would be good to use it halfway through treatment, say every six weeks. Just to revisit those issues that concerned them and make sure that I'm tackling them.

Suggested changes in tool (outpatients)

In addition to the above comment suggesting regular use of the tool, clinicians also raised other issues regarding the format and protocol developed. One important note for consideration is the terminology used in the key question:

*I still wonder sometimes whether the question we ask is the right question, or the right wording. Whether we need a different question, or a different wording, I'm still not 100% sure of that. I think what are the **worst** things, some people misinterpret.*

The suggestion to change this to ask the question framed around "bothersomeness" was raised; this is in keeping with the language often used by patients, clinicians and within the literature and may be less open to misinterpretation.

Clinicians also expressed concern regarding the level of prompting often necessary for the completion of the tool. It was noted that few of the patients had read the blue sheet sent out prior to their appointment; when shown the sheet patients tended to select something from the list leaving some doubt as to whether this accurately reflected the patient's individual issues:

Even though it was sent out to them, they didn't read it. And often when I showed them this they would just try and pick something to make it fit rather than using it to think of a specific problem.

A similar problem was found with the prompt list on the initial draft (see above). While it is not clear how this issue could be addressed, it is worth noting that both the blue sheet and the earlier prompt sheet list common issues related to incontinence; it is not unlikely that these would be applicable to the patients.

The patients' suggestion for the tool to include a discussion of patient commitment and willingness to comply with treatment was discussed within the clinician interviews. Clinicians recognised this as an important part of the treatment plan and felt it was an area they gave attention to, although not in a formal or documented manner. They did however express a level of frustration at the resistance to changes in life style by the clients in addressing incontinence and doubted that this item included on the tool would make a substantial difference, for the more frail elderly housebound group. Often these clients were not especially bothered by the problem particularly if they had been referred by an outside source. This was a key area of difference between clinicians and patients in the evaluation.

Some don't want to change their life style at all. They're not prepared to give up their coffee, they're not prepared to drink more, they're not prepared to try holding on. And it just comes down to bothersomeness, how much does it actually bother them at the end of the day and so how motivated are they. And if they're not motivated then you're never going to solve the problem.

Data collected from the patient interviews suggest that the level of motivation could be made clearer to clinicians through the inclusion of an item addressing this on the tool. In addition motivation and compliance might increase in patients with a more detailed discussion and better understanding of their role within their treatment.

Domiciliary patients

As noted above, the efficacy of the tool with the outpatient population was not replicated for domiciliary patients. While this was predominantly due to frailty and cognition of the patients unable to attend CCS, patients motivation was a significant barrier to employment of the tool: the majority of these patients are referred by other services:

We attempted to use [the tool] on every new patient. There were a few that just had a blank and wouldn't respond at all [through] lack of interest. A lot of the clients that I see ... are very, very elderly. A lot of them are very demented as well. And, unfortunately, they don't necessarily realise that

they've got a problem. And, while some kind-hearted caring professional has referred them for help, it's not really what they want.

As in the previous discussion, patient motivation is central to the improvement of incontinence. Further exacerbating these visits is the disclosure of incontinence to others when patients and/or carers may have felt they were addressing the issue competently and in a manner which accorded them privacy:

You feel a bit like [the police] coming in! Somebody's told this nurse that you've got a problem, this problem that you've been trying to hide for the last 10 years and suddenly she knows about it and she's going to make me do all these things I don't want to do.

It's like a privacy thing, like, somebody's dobbed them in and they've felt that they might have been managing this quite discreetly for a long time. And you can see that they're actually quite upset by the fact that their cover has been blown.

The protocol developed for the pilot proved unworkable with this patient cohort. The location of the visits makes it more difficult to establish a clinical relationship, and the introduction of the tool on the first visit was inappropriate:

I think it's one, you're doing a home visit and I don't think they perceive that as being a clinical thing ... And that's a barrier. But it's also as I said that people you're actually seeing haven't referred themselves. So, they go along with it. I think they feel pressured into doing it and they don't feel like they've got a say, unfortunately.

I think you need to establish a bit of rapport before you start asking a lot of these questions that we're asking anyway. And, when you first go in they're very embarrassed anyway and perhaps it may not be appropriate to ask them to spill out their feelings about this problem on the first visit. It may be more appropriate to perhaps go back a second time and tackle it then.

While any improvement in incontinence will still depend largely upon the motivation of the patients, the clinician did see a potential use for the tool as an adjunct to the initial assessment on subsequent visits:

It might be better to go and do the assessment first and go back and try this. After they've actually met you and know where you're coming from and what they would actually be talking about [...] Certainly if they were willing to cooperate then I think it would be beneficial for everybody.

One way of establishing this motivation and a more collaborative approach to addressing incontinence for this patient cohort was the use of the tool in a care plan with an active role for the patient and/or carer:

I felt it would be good to try and incorporate this with some sort of a care plan that you actually left them with [...] just for very, very simple information, like drink 6 cups of fluid every day.

The clinician suggested that this might also be a way to both chart progress as well as motivate compliance:

And, going back to them perhaps [getting] those sheets of paper out, saying the last time I was here, this is what you thought were the problems, and this is how bad you thought it was, this is what was suggested then, have things changed? To see if there has been any change at all.

Analysis of the Tool:

The analysis was mainly descriptive in nature, conducted on the 95 completed questionnaires. Fifty of the questionnaires were completed by clients of the Caulfield Continence Clinic on admission to their treatment program, of these 29 (58%) completed a second form at an interim stage during their treatment and 15 (30%) completed a second form on completion of their treatment. Most of the clients (88%, n=44) were able to complete the forms with the clinician. In 6 (12%) of the cases, the spouse or carer completed the form with the clinician as the client had insufficient cognitive function.

The data collated in the database was recorded as client-based data, with each of the clients/carers recording up to seven problems that they had experienced leading up to and during the treatment period. The majority of clients (88%) recorded three or fewer problems with an average of 2.22 problems overall.

The client-based data (where each client was able to list up to seven problems) was transformed to problem-based data (where all of the problems were pooled into twelve categories – see table 2). This was to allow further analysis of the nature, severity and frequency of the problems. This transformation yielded a total of 117 problems identified when the questionnaire was completed, at either admission or at a time during or on completion of treatment. There were 108 problems listed on admission with 9 new problems added at the time of the second questionnaire.

Table 2: 12 Categories of Problems Identified

| Category | Patients Statement of problem |
|-----------------------------------|--|
| Embarrassment/Indignity | Eg: “Embarrassment” “Worry about public embarrassment” “Fear of embarrassment” “Being wet, smelly, embarrassed” “Loss of dignity” |
| Psychological | Eg “Effect on relationships” “Concerns about future and being a burden to others” “Anxious / nervous” “Depression” “The feeling of having no control” “Annoying” “Fear of accident in public” “Fear of going to unknown places” “Always thinking about the bladder” |
| Restrictions | Eg “Not being able to go away” “Depression - about loss of freedom” “Restricted social activities” “Unable to travel overseas” “Reduced participation in physical activity” “Not being able to go out without pads” “Restriction of outdoor activity” “Having to change pads” “Inconvenience of wearing pad and changing clothes” “Hating having to use public toilets” |
| Hygiene | Eg “Cleaning up after accidents” “Constant washing” “Feels uncomfortable when wet” “Inconvenience - of having to change/wash” “Having wet underwear” “Damp pants” “Excessive cleaning / wiping needed after bowel actions” |
| Nocturia/Sleep disturbance | Eg “Interrupted sleep” “Poor sleep” “Getting up to toilet at night” |
| Urinary | Eg “Loss of urine” “Feeling the bladder is not emptying” “Leakage when coughing” “Loss of control of bladder” “Not being able to hold on” “Not getting to toilet at nighttime” “Running to the toilet in the morning” “Having to rush to toilet and getting wet pants” |

| | |
|----------------------------|--|
| Location of toilets | Eg “Locating toilet in some places” “Have to know where toilets are” “Worrying about where the toilets are” “Having to find a toilet when out” “Anxiety about being able to find toilet in time” |
| Odour | Eg “Worry about odour” “Smell of urine” “Urine smell in house” “Urine smell in bedroom” |
| Urinary frequency | Eg “Going to the toilet often” “Going to the toilet all the time” “Exhausting going to toilet frequently” |
| Laundry | Eg “Laundering” “Washing bed linen” “Washing underwear” |
| Bowel | Eg “Bowels not regular” “Bowel accidents” |
| Cost | Eg “Cost of pads” “Expensive” |

The most commonly identified problem on admission was embarrassment which accounted for 15.9% of the problems raised. (See table 3) This was followed by psychological issues (14%) and restrictions (11.2%). The identification and rating of priorities was as per figure 1. The average priority rating of each of the problems listed was in the ‘moderate’(2) to ‘large’ (3) problem range with laundry being the exception in the ‘small’ (1) to ‘moderate’ (2) problem range.

Table 3 : Summary of problems and priority rating on admission

| Problem | N | % of Total N | Mean Priority Rating | Minimum Priority Rating | Maximum Priority Rating |
|------------------------------|------------|---------------------|-----------------------------|--------------------------------|--------------------------------|
| Embarassment / indignity | 17 | 15.9% | 2.53 | 1 | 4 |
| Psychological | 15 | 14.0% | 2.47 | 1 | 4 |
| Restrictions | 12 | 11.2% | 2.83 | 1 | 4 |
| Hygiene | 11 | 10.3% | 2.55 | 1 | 4 |
| Nocturia / sleep disturbance | 11 | 10.3% | 2.18 | 1 | 4 |
| Urinary | 10 | 9.3% | 2.50 | 2 | 4 |
| Location of toilets | 8 | 7.5% | 2.25 | 1 | 4 |
| Odour | 7 | 6.5% | 2.14 | 1 | 4 |
| Cost | 5 | 4.7% | 2.20 | 1 | 3 |
| Urinary frequency | 5 | 4.7% | 2.60 | 2 | 4 |
| Laundry | 4 | 3.7% | 1.50 | 1 | 2 |
| Bowel | 2 | 1.9% | 3.00 | 3 | 3 |
| Total | 108 | 100.0% | 2.43 | 1 | 4 |

The twelve categories from table 3 were then regrouped into two major categories (see table 4).

Table 4: Breakdown into Clinical and Psychosocial Grouping

| Clinical | Psychosocial |
|-----------------------------|---------------------|
| Nocturia /sleep disturbance | Embarrassment |
| Urinary | Restrictions |
| Urinary frequency | Hygiene |
| Bowel | Location of toilets |
| | Odour |
| | Cost |
| | Laundry |

Most of the problems identified by the clients were of a psychosocial nature (74.1%). The mean priority-rating was similar whether the problems were clinical (2.43) or psychosocial (2.40) ie the ‘moderate’ (2) to ‘large’ (3) problem range.(see table 5)

Table 5 : Summary of general nature of problems and priority rating on admission

| General Problem | N | % of Total N | Mean Priority Rating | Minimum Priority Rating | Maximum Priority Rating |
|-----------------|------------|---------------|----------------------|-------------------------|-------------------------|
| Clinical | 28 | 25.9% | 2.43 | 1 | 4 |
| Psychosocial | 80 | 74.1% | 2.40 | 1 | 4 |
| Total | 108 | 100.0% | 2.41 | 1 | 4 |

The frequency a problem was occurring (see figure 1) was then identified for the problems.

Problem frequency-ratings were generally in the range ‘sometimes’ (2) to ‘fairly often’ (3) with three problems: cost, nocturia/sleep disturbance and odour being considered in the ‘fairly often’ (3) to ‘very often’ (4) range. (see table 6).

Table 6: Summary of problems and frequency on admission

| Problem | N | % of Total N | Mean Frequency Rating | Minimum Frequency Rating | Maximum Frequency Rating |
|------------------------------|------------|---------------|-----------------------|--------------------------|--------------------------|
| Embarassment / indignity | 17 | 15.7% | 2.76 | 2 | 4 |
| Psychological | 15 | 13.9% | 2.73 | 1 | 4 |
| Restrictions | 13 | 12.0% | 2.77 | 1 | 4 |
| Hygiene | 11 | 10.2% | 2.91 | 2 | 4 |
| Nocturia / sleep disturbance | 11 | 10.2% | 3.27 | 2 | 4 |
| Urinary | 10 | 9.3% | 2.60 | 2 | 4 |
| Location of toilets | 8 | 7.4% | 2.38 | 1 | 4 |
| Odour | 7 | 6.5% | 3.29 | 2 | 4 |
| Cost | 5 | 4.6% | 3.40 | 2 | 4 |
| Urinary frequency | 5 | 4.6% | 3.00 | 2 | 4 |
| Laundry | 4 | 3.7% | 3.00 | 3 | 3 |
| Bowel | 2 | 1.9% | 2.50 | 2 | 3 |
| Total | 108 | 100.0% | 2.86 | 1 | 4 |

The mean frequency-ratings given to the clinical and psychosocial problems were similar in magnitude at 2.93 and 2.84 respectively, both around the ‘fairly often’ (3) rating. (See table 7).

Table 7: Summary of general nature of problems and mean frequency rating on admission

| General Problem | N | % of Total N | Mean Frequency Rating | Minimum | Maximum |
|-----------------|------------|---------------|-----------------------|----------|----------|
| Clinical | 28 | 25.9% | 2.93 | 2 | 4 |
| Psychosocial | 80 | 74.1% | 2.84 | 1 | 4 |
| Total | 108 | 100.0% | 2.86 | 1 | 4 |

Follow-up data for interim and completed treatment groups

The problem priority-data and frequency-data did not satisfy the assumptions for parametric analysis, therefore non parametric analyses were performed to see if any differences existed between the problems identified by those that completed the treatment and those that completed the second questionnaire at an interim stage during their treatment. A comparison of the two groups on their admission questionnaire using a Mann-Whitney U test revealed no significant difference on either the priority ($p > .05$) or frequency ($p > .05$) of the problems identified.

Comparison of the two groups on the second questionnaire using the same test however revealed a significant difference on the priority-rating ($p < .001$) but not on the frequency-rating ($p > .05$). Based on these findings it was decided to analyse the interim treatment group and the completed treatment group separately. It is of note, that those who completed treatment before doing the second questionnaire rated both the problem severity and frequency lower than those who completed the second questionnaire at an interim stage of their treatment.

There were 85 problems identified by the 29 individuals who had not completed their treatment when the second questionnaire was done.

The problems most often identified on the second questionnaire by these individuals, were embarrassment/indignity and psychological issues (see table 8) although the mean priority-rating given to these concerns was lower (around the 'moderate' problem rating) than those given to odour, nocturia/sleep disturbance, cost and restrictions (mean priority-ratings 2.25 to 2.33).

Table 8: Summary of problems and priority rating on interim group

| Problem | N | % of Total N | Mean Priority Rating | Minimum Priority Rating | Maximum Priority Rating |
|------------------------------|-----------|---------------------|-----------------------------|--------------------------------|--------------------------------|
| Embarassment / indignity | 16 | 18.8% | 2.00 | 0 | 4 |
| Psychological | 14 | 16.5% | 1.86 | 0 | 4 |
| Restrictions | 12 | 14.1% | 2.25 | 1 | 4 |
| Location of toilets | 9 | 10.6% | 1.67 | 0 | 4 |
| Nocturia / sleep disturbance | 7 | 8.2% | 2.29 | 1 | 4 |
| Urinary | 7 | 8.2% | 1.43 | 1 | 2 |
| Hygiene | 6 | 7.1% | 1.83 | 0 | 4 |
| Odour | 6 | 7.1% | 2.33 | 1 | 4 |
| Cost | 4 | 4.7% | 2.25 | 0 | 3 |
| Urinary frequency | 2 | 2.4% | 1.50 | 1 | 2 |
| Laundry | 1 | 1.2% | 0.00 | 0 | 0 |
| Bowel | 1 | 1.2% | 0.00 | 0 | 0 |
| Total | 85 | 100.0% | 1.92 | 0 | 4 |

Psychosocial issues accounted for most (80.0%) of the problems identified by those clients who completed the second questionnaire prior to finishing their treatment. (See table 9). The average priority-rating for psychosocial issues was 1.97, marginally higher than the mean priority-rating for the clinical problems (1.71) however both were around the ‘moderate’ problem rating.

Table 9: Summary of general nature of problems and priority rating for interim group

| General Problem | N | % of Total N | Mean Priority Rating | Minimum Priority Rating | Maximum Priority Rating |
|------------------------|-----------|---------------------|-----------------------------|--------------------------------|--------------------------------|
| Clinical | 17 | 20.0% | 1.71 | 0 | 4 |
| Psychosocial | 68 | 80.0% | 1.97 | 0 | 4 |
| Total | 85 | 100.0% | 1.92 | 0 | 4 |

The problems with the highest mean frequency ratings for those clients who completed the second questionnaire prior to completing their treatment were nocturia/sleep disturbance, odour, restrictions and cost all being in the ‘sometimes’ to ‘fairly often’ range. (See table 10).

Table 10: Summary of problems and mean frequency rating for interim group

| Problem | N | % of Total N | Mean Priority Rating | Minimum Priority Rating | Maximum Priority Rating |
|------------------------------|-----------|---------------------|-----------------------------|--------------------------------|--------------------------------|
| Embarassment / indignity | 16 | 18.8% | 2.00 | 0 | 4 |
| Psychological | 14 | 16.5% | 2.07 | 0 | 4 |
| Restrictions | 12 | 14.1% | 2.33 | 1 | 4 |
| Location of toilets | 9 | 10.6% | 2.00 | 0 | 4 |
| Nocturia / sleep disturbance | 7 | 8.2% | 3.00 | 2 | 4 |
| Urinary | 7 | 8.2% | 1.57 | 1 | 2 |
| Hygiene | 6 | 7.1% | 1.83 | 0 | 4 |
| Odour | 6 | 7.1% | 2.33 | 2 | 3 |
| Cost | 4 | 4.7% | 2.25 | 0 | 4 |
| Urinary frequency | 2 | 2.4% | 2.00 | 2 | 2 |
| Laundry | 1 | 1.2% | 0.00 | 0 | 0 |
| Bowel | 1 | 1.2% | 1.00 | 1 | 1 |
| Total | 85 | 100.0% | 2.09 | 0 | 4 |

There was little difference between the mean frequency-ratings for the clinical and psychological issues with the clinical issues having a slightly higher mean frequency-rating but both were in the ‘sometimes’ to ‘fairly often’ range. (See table 11).

Table 11: Summary of general nature of problems and mean frequency rating for interim group

| General Problem | N | % of Total N | Mean Frequency Rating | Minimum Frequency Rating | Maximum Frequency Rating |
|------------------------|-----------|---------------------|------------------------------|---------------------------------|---------------------------------|
| Clinical | 17 | 20.0% | 2.18 | 1 | 4 |
| Psychosocial | 68 | 80.0% | 2.07 | 0 | 4 |
| Total | 85 | 100.0% | 2.09 | 0 | 4 |

There were only 27 problems identified by the 15 individuals who completed their treatment prior to doing the follow-up questionnaire. Many of these problems identified initially were resolved during the treatment period as indicated by the zeros recorded in minimum values of the priority ratings. (See table 12).

Table 12: Summary of problems and priority rating for treatment group

| Problem | N | % of Total N | Mean Priority Rating | Minimum Priority Rating | Maximum Priority Rating |
|------------------------------|-----------|---------------------|-----------------------------|--------------------------------|--------------------------------|
| Hygiene | 4 | 14.8% | 1.25 | 1 | 2 |
| Restrictions | 3 | 11.1% | 1.67 | 0 | 4 |
| Nocturia / sleep disturbance | 3 | 11.1% | 0.67 | 0 | 2 |
| Urinary | 3 | 11.1% | 1.00 | 1 | 1 |
| Urinary frequency | 3 | 11.1% | 2.67 | 2 | 4 |
| Laundry | 3 | 11.1% | 0.67 | 0 | 1 |
| Odour | 2 | 7.4% | 0.00 | 0 | 0 |
| Embarassment / indignity | 2 | 7.4% | 0.50 | 0 | 1 |
| Psychological | 2 | 7.4% | 0.50 | 0 | 1 |
| Cost | 1 | 3.7% | 1.00 | 1 | 1 |
| Bowel | 1 | 3.7% | 1.00 | 1 | 1 |
| Total | 27 | 100.0% | 1.07 | 0 | 4 |

Most of the problems identified were of a psychosocial nature (63.0%) but these were generally given a lower priority rating, indicated by the lower average of these values which is in the ‘not a problem’ to ‘small problem’ range compared with the clinical problems, the mean priority-rating for which is in the ‘small’ to ‘moderate’ problem range. (See table 13).

Table 13: Summary of general nature of problems and priority rating for treatment group

| General Problem | N | % of Total N | Mean Priority Rating | Minimum Priority Rating | Maximum Priority Rating |
|------------------------|-----------|---------------------|-----------------------------|--------------------------------|--------------------------------|
| Clinical | 10 | 37.0% | 1.40 | 0 | 4 |
| Psychosocial | 17 | 63.0% | 0.88 | 0 | 4 |
| Total | 27 | 100.0% | 1.07 | 0 | 4 |

Cost and urinary frequency stood out as the most highly frequency-rated problems in the ‘fairly often’ to ‘very often’ range. The numbers here are quite small though and it is difficult to draw any conclusions from this data. (see table 14)

Table 14: Summary of problems and frequency for treatment group

| Problem | N | % of Total N | Mean Frequency Rating | Minimum Frequency Rating | Maximum Frequency Rating |
|------------------------------|-----------|---------------------|------------------------------|---------------------------------|---------------------------------|
| Hygiene | 4 | 14.8% | 1.50 | 1 | 2 |
| Laundry | 3 | 11.1% | 1.00 | 0 | 2 |
| Nocturia / sleep disturbance | 3 | 11.1% | 2.00 | 1 | 4 |
| Restrictions | 3 | 11.1% | 2.33 | 1 | 3 |
| Urinary | 3 | 11.1% | 1.33 | 1 | 2 |
| Urinary frequency | 3 | 11.1% | 3.00 | 3 | 3 |
| Embarrassment / indignity | 2 | 7.4% | 0.50 | 0 | 1 |
| Psychological | 2 | 7.4% | 1.00 | 0 | 2 |
| Odour | 2 | 7.4% | 0.00 | 0 | 0 |
| Bowel | 1 | 3.7% | 2.00 | 2 | 2 |
| Cost | 1 | 3.7% | 4.00 | 4 | 4 |
| Total | 27 | 100.0% | 1.63 | 0 | 4 |

The mean frequency-rating for the psychosocial problems was generally lower, in the ‘almost never’ to ‘sometimes’ range, than the clinical problems which rated in the ‘sometimes’ to ‘fairly often’ range. (see table 15)

Table 15: Summary of general nature of problems and mean frequency rating on treatment group

| General Problem | N | % of Total N | Mean Frequency Rating | Minimum Frequency Rating | Maximum Frequency Rating |
|------------------------|-----------|---------------------|------------------------------|---------------------------------|---------------------------------|
| Clinical | 10 | 37.0% | 2.10 | 1 | 4 |
| Psychosocial | 17 | 63.0% | 1.35 | 0 | 4 |
| Total | 27 | 100.0% | 1.63 | 0 | 4 |

Interim group (58% of the subjects n=29)

In the 78 reported problems by those who did not complete their treatment prior to responding to the second questionnaire 38 of the problems were given a reduced priority rating, 32 remained the same and 8 of the priorities increased. (see table 16) The frequency ratings for the problems identified by this group reduced in 43 reported incidences, didn't change in 30 incidences and increased in 5 incidences

A significant improvement was observed over the test period in the group that did not complete their treatment prior to filling out the second questionnaire on both the problem priorities and frequency rating based on the Wilcoxon Signed Ranks Test. The average reduction in priority-rating was from 2.50 to 1.92 ($p < .001$). The average reduction in frequency-rating was 2.87 to 2.09. ($p < .001$).

Table 16: Changes in Priority and Frequency Ratings (Interim Group)

N = 78

| | | |
|-----------------------------------|-------------------|-----------------------------------|
| Decreased priority rating | No change | Increased priority rating |
| 38 (48.7%) | 32 (41%) | 8 (10.3%) |
| Decreased frequency rating | No change | Increased frequency rating |
| 43 (55.1%) | 30 (38.5%) | 5 (6.4%) |

Treatment completed (30% of subjects N=15)

Of the 25 problems identified from those who had completed their treatment, 16 were given a reduced priority, 9 of the priorities didn't change and none were given an increased priority. (see table 17). The average reduction in priority-rating was from 2.24 to 1.07.

The frequency of the 25 problems identified by those who completed their treatment reduced in 16 incidences, didn't change in 9 incidences and increased in 1 instance. The average reduction in frequency was 2.80 to 1.63.

Those who completed their treatment before doing the second questionnaire also showed a significant improvement in both the priority -ratings of their problems and the frequency-ratings of their problems according to the Wilcoxon Signed Ranks Test. The average reduction in priority-rating was from 2.24 to 1.07. ($p < .001$). The average reduction in frequency-rating was 2.8 to 1.63. ($p < .01$).

Table 17: Changes in Priority and Frequency Ratings (completion Group)

N= 25

| Decreased priority rating | No change | Increased priority rating |
|-----------------------------------|------------------|-----------------------------------|
| 16 (64%) | 9 (36%) | 0 (0%) |
| Decreased frequency rating | No change | Increased frequency rating |
| 15 (60%) | 9 (36%) | 1 (4%) |

Discussion

The nature of the Self-Reported Incontinence Evaluation Tool (SRIET), the small sample and the way in which the data were recorded make it difficult to determine how efficacious the tool is for the detection of change in the nature, severity and frequency of an individual patient's incontinence problems, however these preliminary indications are promising.

The time frame of the study only allowed for the tool to be administered twice to each patient and 58% of these patients had to complete the second questionnaire even before they had completed their treatment. For these patients the tool was only able to provide an indication of the change that had occurred at an interim stage of their treatment. Interestingly the priority ratings for the problems identified by these individuals was significantly higher ($p < .001$) than for the 30% of participants in the study who had completed their treatment despite there being no significant difference ($p > .05$) between the two groups on admission.

This data suggests that it is important for patients to complete the full treatment regime to gain the greatest benefits. It is not clear however whether this improvement is entirely due to clinical intervention or whether some improvement might have been expected anyway. Individual time series data would be helpful in further elucidating this point.

Because of the difference between the two treatment groups the follow up data provided by the second application of the tool was split for further analysis. A total of 112 problems were identified in the second round of data collection, the bulk of these (85) in the larger interim treatment group (those who did not complete their treatment prior to administration of the follow up evaluation). Discrepancies in data relate to invalid or missing data based on procedures formed.

The range of possible comparisons between the results of the two follow up groups is limited by the small size of the group who completed their treatment prior to administration of the follow up questionnaire.

It was possible however to compare the follow up data of each of the groups with the admission data. These comparisons revealed that the priority ratings and frequency ratings for the problems identified by both groups on the follow up questionnaire were significantly lower than those identified by the same individuals on admission.

The interim group reduced the priority ratings for 48.7% of the problems they identified, 41.0% remained the same whilst 10.3% increased. The frequency ratings for the same group were reduced in 55.1% of problems identified, remained the same in 38.5% of problems and increased in 6.4% of problems.(See table 16)

Those who completed their second evaluation tool after completing their treatment reduced the priority rating for the problems they identified in 64.0% of cases, 36% remained the same and none of the problem priority ratings increased. The frequency ratings for the same group were reduced in 60.0% of problems identified, 36.0% remained the same and 4.0% increased.(see table 17)

Although the analysis is based on the problems identified by the patients involved in the study and the priority and frequency ratings associated with these problems it does provide compelling evidence to suggest that the Self-Reported Incontinence Evaluation tool can be a useful instrument for helping to identify problems faced by people with incontinence and the degree to which they impact on the persons quality of life. It appears also to be useful for the evaluation of the efficacy of treatment and strategies employed to address the problems identified.

The tool, as developed, appears to have limited applicability for use by frail patients. Its value as a tool to assist clinicians working with carers in such situations would warrant further investigations, as carers in such circumstances are the ones struggling to manage the incontinent patient.

It was apparent that some form of prompting was seen to be important in assisting the patient to become focussed on the questions. Whether this in itself creates a bias was not able to be evaluated in this pilot study.

The challenge for clinicians in establishing a care plan, is to attempt to ensure they understand the patient/carer's real needs and priorities. All established quality of life questionnaires (QoL) use preset questions and therefore can easily miss the most pressing or important issues facing the patient/carer. This tool attempts to address this shortcoming by being patient/carer directed.

This pilot study did not attempt to establish its test-retest validity, inter-rater reliability nor its applicability in different groups (eg sex, different types of incontinence, different age groups).

It also provides a potential mechanism to be used as an outcome measure as it allows direct comparison of the same issues at the end of treatment. With further refinement and validation of the tool it should be possible to compare/ evaluate its usefulness as a practical outcome measure by comparing results to other "gold standards" such as bladder diaries and QoL questionnaires.

Recommendations:

1. Future studies using the form should record time-series data for larger numbers of patients before and after treatment. This would enable the reliability of the instrument and its efficacy for detecting change in the problems associated with an individual patient's incontinence to be determined.
2. The usefulness of the tool should be compared against other objective and subjective outcome measures.
3. Further study should be undertaken to assess the usefulness of the tool with carers.
4. Explore the value of adding a specific question to gauge patient/carer interest and motivation in being compliant with intervention strategies.
5. Explore various methods of "prompting" patients/carers before their first visit/assessment to enable them to be better prepared to list and rate their issues of concern.
6. Explore alternative phrasing of the key question to assess whether this elicits the patient/carer's responses more easily/readily.
7. Explore the value of this tool to guide management during the treatment phase.
8. Test-retest validation and inter-rater reliability should be established in different groups.

Conclusion:

The importance of patient/carer participation in defining their key issues has been central to the development of the "Self-Reporting Incontinence Evaluation Tool" (SRIET).

Despite this being a pilot study, the SRIET has demonstrated its potential usefulness, not only as an outcome measure, but more importantly as a measurable tool to assist clinicians to prioritise their management strategies. As such it is our conclusion that further more widespread testing of this tool on different settings and patient types be undertaken.

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Acknowledgement

This project was a collaborative project between Caulfield General Medical Centre and LaTrobe University and was funded by a grant from the National Continence Management Strategy.

This project would like to acknowledge the contribution from Ben Chodziesner "representing the Carer's Association of Victoria".