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Managing bowel disorders with rectal irrigation

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BACKGROUND: The management of faecal incontinence and constipation is not well understood. Symptoms canseriously impact on quality of life. Rectal irrigation has been piloted as a self-management method.

AIM: To explore patients' experiences of defecation disorders and rectal irrigation.

METHOD:A qualitative study using semi-structured interviews of 11 patients attending a colonic irrigationclinic was carried out. Framework analysis techniques were used.

RESULTS: Participants revealed a background of physical and psychosocial suffering. All had notable symptomburden, including pain and restrictions in physical and social activity. The bowel problem had a negative impact on theirself-esteem, confidence and social functioning. Colonic irrigation was considered a 'lifesaver' that relieved symptoms,improved quality of life and helped manage the bowel problem.

DISCUSSION: Colonic irrigation provided a successful self-management option for the participants and gave themcontrol over their disorder.

CONCLUSION: Colonic irrigation has a potential role in the treatment of chronic functional bowel disorders(CFBD)but further interventional evaluations are required.

Background

This article explores the experience of people with chronic constipation and faecal incontinence. These disorders haveproven to have a major impact on quality of life (Christensen et al, 2006). Both the disorder and the symptoms are difficult totreat and, for many, resistant to surgical and medical interventions (Crawshaw et al, 2004). Recently rectal irrigation hasbeen piloted as a self-management method (Christensen et al, 2006; Crawshaw et al, 2004; Gardiner et al, 2004). Little researchhas been conducted to understand the impact of such conditions or to evaluate rectal irrigation as a management tool.

This article starts to address that gap by exploring patients' experiences of defecation disorders (chronic constipationand faecal incontinence) and their experiences of rectal irrigation as a management option.

Literature review

The extent and management of the severe, chronic bowel disorders of faecal incontinence and constipation are not wellunderstood. This is partly because of the range and diversity of the way people present with symptoms and the underlying cause.Some literature focuses on people with defecation disturbance due to neurological disorders (Christensen et al, 2006; Coggraveet al, 2006), while other authors have recognised the distress due to idiopathic incontinence and slow transit constipation,trauma, obstetric injury and rectocele or pelvic-floor weakness (Gardiner et al, 2004). Within this literature it is possibleto recognise two distinct groups of patients: those with constipation and those who have incontinence. However, there is anoverlay between the disorders, whereby treatment of one might exacerbate symptoms of the other (Coggrave et al, 2006). Inaddition, defecation disorders appear difficult to treat, with some patients not responding to medical and surgicalinterventions (Crawshaw et al, 2004). The diversity and complexity of this population might explain the lack of evidence toguide the management of these patients.

Rectal irrigation is starting to be used as a management option, especially for those people who are not responding to, oreligible for, surgical or medical techniques. Initial results are positive but the results are confusing and difficult to applyto practice as samples and interventions vary between studies. Some have demonstrated more improvement in patients with faecalincontinence (Christensen et al, 2000), while others reported efficacy to be higher in those with constipation (Gosselink etal, 2005). In addition, there are methodological weaknesses in existing studies. Many are cross-sectional, retrospectiveevaluations of people who have been allocated rectal irrigation as a treatment option (Gosselink et al, 2005; Crawshaw et al,2004; Gardiner et al, 2004). There is only one randomised controlled trial which is limited to people with neurologicalproblems. The quality of the studies mean it is difficult to discern who will benefit from rectal irrigation and why, and whowill discontinue its useand why.

One issue on which all authors agree is the extent of the distress, anxiety and suffering that patients experience due tobowel problems of this nature. People experience symptoms that can seriously impact on quality of life (Christensen et al,2006; Gardiner et al, 2004). However, there is little research that explores the patient experience of living with a bowelproblem in any depth. The trials cited above used various measures to evaluate quality of life but these do little to shedlight on the reality of living with a bowel problem or rectal irrigation as a treatment.

A recent literature review found that there is an absence of rigorous evidence on the effectiveness and efficacy of rectalirrigation as a management option for constipation or faecal incontinence (Tod et al, 2007). This lack of evidence may explainthe low profile rectal irrigation has in the recent NICE guidelines on the management of faecal incontinence (NICE, 2007). Thisguidance suggests rectal irrigation should be considered as a specialised management option only if more mainstream treatmentsfail.

This small qualitative study aims to provide some insight into patients' experiences so that those caring for them mayhave an increased understanding of their situation and feelings. The study was conducted involving patients attending aninnovative pilot service - a nurse-led rectal irrigation clinic. It is not an established part of the service provided. Thisstudy is part of a mixed method evaluation to provide evidence to inform decisions about future service provision.

Method

This qualitative study used semi-structured interviews and framework analysis techniques.

Sampling and recruitment

The sampling frame comprised all the patients who had attended the nurse-led rectal irrigation clinic since it had opened.The method of irrigation used is given in Box 1. Approximately 200 patients had attended the clinic over a 30-month period.Patients were approached by letter from the nurse consultant who ran the clinic. Those interested in participating returned areply slip to the researchers. The nurse conducting the interview then contacted the patient to further explain the study andarrange a suitable time and location.

Box1: Rectal irrigation

A commonly used rectal irrigation procedure, and the one used in this study, is as follows:

Warm water at body temperature is instilled into the rectum (500ml-1L) with the patient sitting on the toilet or lying in the left lateral position. This will be done using an irrigation set consisting of a water bag, tubing and either a cone or rectal catheter. The volume of water stimulates the urge to defecate normally into the toilet. The frequency of performing the procedure and the volume of water used vary. People work out their own pattern of use over time as they become familiar with rectal irrigation and its impact on bowel evacuation.

Twenty-one patients were selected from the clinic attendees to provide a range of key characteristics. A total of 16patients responded. Three of these refused to be interviewed but did not give a reason. One person had a family crisis thatmeant they could not be interviewed and another could not be contacted. Eleven female patients participated in semi-structuredinterviews. This is partly explained by the fact clinic attendance was predominantly by women but did mean there was a genderbias in the sample. The key characteristics on which we collected date included age, gender (all were female), occupation(Table 1); type of bowel problem (Table 2); and those who had continued and not continued to use rectal irrigation, and theamount of time they had been attending the clinic (Table 3).

Table 1. Participant characteristics

Participant	Age	Marital status	Children	Occupation	Employ-ment status
1	53	Married	1	Hairdresser	SE
2	42	Co-habiting	3	Community support worker	E
3	59	Married	2	Nurse	R
4	65	Married	1	School dinner lady	R
5	54	Married	2 (1 died)	Civil servant	U (ill health)

6	30	Single	0	Psychologist	E
7	59	Married	2	Social worker	E
8	71	Married	1	Clerk	R
9	47	Married	2	Nurse manager	E
10	38	Widowed	0	Administrative assistant	E
11	56	Single	0	Scientist	R (early due to ill health)

E = Employed; SE = Self-employed; R = Retired; U = Unemployed

Table 2. Bowel problem

Participant	Nature of bowel problem (cause)	Duration of problem	Symptoms	Impact of problem
1	Incontinence (bad episiotomy repair)	Symptoms for 6 years	Leakage	Distress, stays in and avoids people, impaired quality of life
2	Constipation (rectocele)	37 years	Pain, discomfort, bloating, nausea, feeling ill	Can't go out, impaired sex life
3	Constipation (rectocele)	25 years	Pain, flatulence, bloating	Embarrassed, avoids going out
4	Constipation	20 years	Straining, bloating, loss of appetite, lack of sleep	Can't be far from a toilet, lack of sleep
5	Constipation	Long term, worse last 14 years	Discomfort, anxiety, straining	Anxiety, depression, sexual difficulties

6	Constipation (failed surgery)	12 years	Severe pain, depression, feeling ill	Sexual difficulties, social isolation, low self-esteem
7	Incontinence (failed surgery)	Since childhood, over 32 years	Leakage, smell, discomfort	Restricted activity, embarrassed, sexual problems
8	Constipation	Since childhood	Urgency, no control, bloating, depression	Impaired quality of life
9	Constipation (rectocele, failed surgery)	Since a teenager, at least 22 years	Back/leg pain, gastritis, nausea, headaches	Impaired social life, activity levels and sex life
10	Constipation	Since childhood	Pain, discomfort all day, bloating, flatulence, pain	Affects ability at work, impaired social life, sexual difficulties
11	Constipation (rectocele, failed surgery)	4 years	Pain, discomfort, soiling	Lower activity level, given up work

Table 3. Experience of rectal irrigation (RI)

Participant	Time since first CIC appoint-ment	Compli-ance with RI	Frequency of RI	Time of RI	Impact of RI
1	4 years	No, 3 visits to CIC	N/A	N/A	Did not work - leakage
2	2-3 months	Yes	Alternate days	Evenings	Feels better on the whole, in control, not bunged up, no longer needs surgery

3	12-18 months	Yes	Daily	Morning	Less pain and bloating, weight loss
4	12 months	Yes	Nearly every day	Morning	Feels better, no bowel strain
5	9 months	Yes	Alternate days	Morning	Feels a lot better, some normal bowel movements
6	6 months	Yes	Alternate days	Morning	Improved confidence, can go out and on holiday
7	11 months	Yes	Daily	Morning	Routine restricted, some leakage but better with rectal irrigation
8	14 months	Yes	3 times a week plus occasional lactulose	Morning	Improved quality of life, more varied diet, can go on holiday
9	4 months	Yes	Daily plus occasional sodium picosulfate	Morning	No nausea, no headaches, no pain, in control
10	6 months	Yes	5-7 times a week	Workdays in the evenings Weekends in the morning.	More energy, no longer needs surgery, no pain during sex
11	Not known	Yes	Couple of times a day	Morning plus one or two other times	A lifesaver, can go on holiday, no longer needs surgery, a weight lifted from shoulders

Data collection

All participants chose to be interviewed in their own homes. They were interviewed by nurses with appropriate researchtraining (JD, VG) who were experienced in colorectal care. In order to reduce bias, the nurse conducting the interview had notbeen involved in the individual participants' care.

Before the interview started the study was explained again and informed consent was obtained.

The interviews, which lasted approximately 30 minutes, were conducted between May and July 2006. All interviews weretape-recorded and field notes were taken during them. A schedule was used to guide the interview, and this was generated usingwhat little knowledge was available from the literature and from the clinical experience of the nurse consultant and nursespecialist.

Data analysis

Tapes and field notes were transcribed and made anonymous. The transcripts were then entered onto *qsr*NVIVO for data storage and management. Framework analysis techniques were used to analyse the data. A provisionalthematic framework was developed by the interviewers and another researcher (AT) after they had familiarised themselves withthe data. The data was then coded by two of the researchers (JD, AT) and comparisons were made between participants and themes.The thematic framework was then revised in the light of the analysis (Table 4).

Table 4. Themes evident during interviews

Theme	Sub-theme
Living with a bowel problem	Nature of the bowel problem • What the problem is Length of time with the problem Cause of the bowel problem • Symptoms • Impact • Coping
Previous management of the bowel problem	• Management by the NHS • Self-management
Expectations of rectal irrigation	
Experience of rectal irrigation	Irrigation • Compliance • Patterns of use • Ease of use • Impact Irrigation clinic • Staff • Information-giving

Results

The data provided unique insight into patients' experiences and revealed the extent and nature of the suffering anddistress related to the bowel problem. This experience is presented using the thematic framework in Table 4.

Living with a bowel problem

Nature and cause of the defecation problem

The majority (nine) of those interviewed experienced constipation rather than faecal incontinence (Table 2). Fourparticipants (three with constipation and one with incontinence)reported that their symptoms and underlying problem hadworsened as a result of failed corrective bowel surgery.

The participants all had long histories of bowel problems, some starting in childhood. Only two had reported problems forsix years or less.

'I always remember it being a problem going to the toilet and I think it has been like that all my adult life.'(Participant 10)

The causes were varied and complex. For example, one woman's symptoms started six years previously while on holiday abroadbut the cause of her incontinence was due to a poor episiotomy repair years earlier and exacerbated by failed corrective bowelsurgery.

'He[colorectal surgeon] *said it was negligence by whoever stitched me up after [having] one of my children. He said they had stitched the outsideup and left the inside and it was horrendous?. I was on loperamide and anything that could possibly stop bowel movement but itdidn't work?.he tried to repair it but said it was really damaged. The repair didn't really work.' (Participant 1)*

Four participants with constipation said their problem was due to or exacerbated by a rectocele. These women had allexperienced bowel problems prior to the rectocele developing.

'I have had problems since being five years old, always had it, being shoved from pillar to post because nobody knows whatto do with me. Last time I saw the consultant she said it sounds as though I have a rectocele so then it went on from there.'(Participant 2)

Symptoms

The data revealed a background of physical and psychosocial suffering for participants. The bowel problem had resulted ina significant symptom burden for all participants - most notably regarding pain (Table 2).

'I had a huge amount of epigastric pain. It seemed to produce a gastritis symptom. The only other thing I could do wasvirtually fast. Travel was a real worry. I often went to work feeling very ill, nauseous and with headaches.' (Participant9)

Other gastric symptoms included headache, bloating, flatulence and discomfort. Distressing bowel problems includedstraining, urgency, soiling and leakage. Symptoms were compounded by difficulty sleeping and loss of appetite.

'I had no sensation[of]*wanting to go to the toilet - I would soil myself and it was awful.' (Participant 11)*

'I don't sleep muchso I get up a lot during the night.' (Participant 4)

Impact and coping

Participants described feelings of desperation due to the defecation problem. The years of trying to deal with the problemhad a psychological impact.

'Sometimes you really get desperate.' (Participant 1)

'I was at the end of my tether and just wanted to go to the toilet normally? I don't know what normal is anymore.'(Participant 2)

For some, profound depression was experienced, with associated feelings of lack of control and loss of self-esteem.

'I think it has really affected my self-image in the past because constipation is not a pretty thing to talk about. Therehave been times in the past when I have had quite intrusive thoughts in my head? When you are trying to maintain a self-imageof a young professional working person, constipation doesn't sit with that and how you fit it into your life.' (Participant5)

People reported that the bowel problem and potential embarrassment from leakage and smell had a massive impact onpsychosocial aspects of life. This was worst for those who had no control over their bowel at all.

'I would get the gut ache and then what would happen is I would have to go straight away, which can be difficult if you areout and about. You have the embarrassment of trying to find a toilet and I would be near to tears when I couldn't find atoilet.' (Participant 3)

'I didn't go swimming or walking and I enjoy both of these. This was because of my own fears of accident andembarrassment.' (Participant 7)

People restricted their physical and social activity by, for example, avoiding going to friends' homes, and reducing theirwork or giving it up altogether. This had an immense impact on normal functioning with family and friends and at work.

The bowel problem was described as a constant pressure in life before starting rectal irrigation:

'[It] *just wears me down, like a constant niggle. I just long to be normal and go to the toilet like other people. I found it areal drain.' (Participant 5)*

Coping with it was made more challenging by their feelings of isolation. This was attributed to not knowing anyone elsewith a similar problem and the difficulty of talking to people due to embarrassment. Even those with supportive partners foundit difficult to explain their problem. They felt guilty and self-conscious about the impact the bowel disorder had on manyaspects of their relationship, including sexual intercourse.

'Sexuality was very difficult when you have to be conscious about your bowel being kept under control.' (Participant9)

'When I started this new relationship sex was so painful and made me feel uncomfortable.' (Participant 10)

Previous management of the bowel problem

Self-management

The main self-management techniques were heavy reliance on laxatives and digitating to help evacuate the bowel. Both ofthese methods led to unwanted and unpleasant side-effects.

'It depressed me because I used to have to build myself up to taking the pills and I used to hate it.' (Participant 7)

'I would have to digitate and it was really, really painful. I hated having to go to the toilet.' (Participant 3)

The large amounts of laxatives, taken for prolonged periods, compounded the underlying problem - this was bitterlyregretted by participants. Attempts to self-manage sometimes failed, and only highlighted the extent of their problem. Oneexample was when a participant went to a private nutritionist for help.

'At one time when I was going to the nutritionist she told me not to take any laxatives and by the ninth week I stillhadn't been[to the toilet].' *(Participant 2)*

Management by the NHS

In between attempts at self-management, the participants had attempted to seek help from the NHS. While they were gratefulfor whatever they received, all had struggled to get constructive help. They encountered a lack of interest, experience andknowledge of defecation disorders among GPs.

'[I] *went to*[the] *GP and tried to get anywhere for help but it was just like a closed door? he just said that it was a rare case and hedidn't know the reason.' (Participant 1)*

'I have repeatedly gone back to the doctors over the years and I haven't really been taken seriously? It just feels likethey don't understand the emotional side of it.' (Participant 6)

Perhaps as a result of this, participants ended up being passed around between doctors and services. Cancelledappointments and lack of time during appointments further compromised their attempts to get help. These issues compounded thefact that participants felt the extent of their problem was not appreciated. The desperation some people had felt wasexacerbated by failed surgical attempts to solve the bowel problem.

Finally, all the participants failed to obtain individualised information and help to manage their bowel disorder.

Expectations of rectal irrigation

A range of expectations of rectal irrigation was reported among the participants. For some it was a relief that somethingwas finally available to them.

'I was pleased because it was another avenue I could investigate.' (Participant 5)

One woman had previously paid for colonic irrigation at a private clinic, although this had not been a frequent treatment.She had only paid for colonic irrigation when desperate and when she could afford it.

'I used to pay for it? She used a machine and[it] *cost me £40 each time? I had seen it and then I read it in a magazine so I thought I would go? Yes, I was thatdesperate so I went privately.' (Participant 4)*

Some participants had been horrified by the idea of rectal irrigation. This was explained by lack of knowledge andimpressions gained from the media.

'I was really freaked out by the idea. I just thought there was no way I could fit this into my life and you were justasking too much from me. I really, really remember sitting there thinking I can't do this, but I have done it.' (Participant6)

Some patients hoped that a surgical solution would be available and would have rectified the problem for good. If theywere otherwise fit and healthy they thought surgery would have been successful. Rectal irrigation was therefore not theirpreferred mode of treatment and they were initially disappointed by the idea of it. Their expectations were therefore low.

'I was a bit upset at first because I felt if I needed surgery I am a fit, healthy woman?I was very sceptical aboutirrigation as I didn't think it would help my problems.' (Participant 3)

Experience of rectal irrigation

Compliance

Only one of the participants did not continue with irrigation. This was because of leakage between irrigation.

'I didn't particularly like it but when you are desperate you will try anything.' (Participant 1)

All the other participants continued to use rectal irrigation to successfully manage their bowel disorder.

Patterns of use

Nine out of 10 patients conducted the procedure in the morning because of comfort and convenience. Having an empty bowelgave them more confidence during the day when they would be going to work and carrying out their normal activities.

'I do it in the morning when I wake up, then I have a shower and then I get on with my day. If I leave it till the eveningI am uncomfortable. It is not out of the way. It is part of my routine. It has been absolutely wonderful for me.' (Participant3)

Frequency of use varied from three times a week to twice a day but in most instances people used rectal irrigation once aday. Finding a suitable time was a matter of people working out a pattern that suited them and their lives.

'At the beginning I did it every day and now sometimes I do it every day or I might miss a day, probably doing it fivetimes a week.' (Participant 10)

Ease of use

Patients reported taking between 20 and 60 minutes to perform rectal irrigation. In general, they found the procedureeasier than expected.

'I feel a lot better, it is so simple and I feel I could do it for the rest of my life.' (Participant 4)

Some had experienced problems initially and had to adjust the way they conducted the irrigation until they found a waythat suited them. Many of the initial problems, however, related to fitting the irrigation into the daily routine.

'I suppose I'm a little bit easier at home now because at first it was fitting it in around the family. Once I got itfitted in I was okay.' (Participant 5)

The ability to integrate rectal irrigation into their lives was illustrated by those participants who had been successfulin going on holiday.

'I go on holiday but I haven't been on long haul flights - I have just come back fromSpainand I just take the stuff with me. It is wonderful that there is this sort of thing to help me with the problem.'(Participant 11)

Only one participant dwelt on the negative aspect of being reliant on a daily procedure.

'I want to be better and just be free when thinking what I am going to do in the day? I just want to not be consumed bythinking this is a routine that takes over.' (Participant 7)

Her negativity was explained by her bitter disappointment that previous bowel surgery had failed. Although she found theroutine restrictive and burdensome, she continued to perform irrigation and found that it did help.

Impact

Many participants considered rectal irrigation a 'lifesaver' that relieved symptoms and allowed them to turn their livesaround.

'For me there is no looking back? I had not emptied my bowels properly for a long, long time so doing this is great and ithas been a lifesaver for me.' (Participant 3)

'From that day on (which is three years ago) that has been my lifesaver, totally? Now it is part of my life and I don'teven think about it because without it things were impossible.' (Participant 10)

'From that day on I have never looked back, it is the most wonderful thing. Honestly, now it is part of my life and I don'teven think about it because without it things were impossible.' (Participant 11)

Importantly, participants claimed they were once again in control of their bowel function and, therefore, in control oftheir lives. The procedure gave people more confidence to resume physical and social activities that were previously denied tothem and, as a result, their quality of life was vastly improved (Table 3).

'It has been so effective and given me a sense of control. That has been the fundamental thing for me. I can go out, I cango for meals, I can go away, now I can plan when I can do it. I feel so confident.' (Participant 6)

Two participants had even started to have occasional normal bowel movements.

'The funny thing is I went to the toilet this morning normally and this is happening a lot more.' (Participant 5)

Close relationships, including sexual ones, had also improved.

Irrigation clinic

The participants all reported their experience of the clinic as being a positive one. Two aspects of care emerged from thedata as particularly important: staff and information.

All the participants emphasised how crucial the care of the clinic staff was to the success of irrigation. Whether theyfound rectal irrigation acceptable or not, all had benefited from being assessed by, listened to and advised by experienced andspecialist staff.

'She*[nurse consultant] *was very nice and seemed concerned. She had plenty of time to talk to you.' (Participant 1)

Knowing that a specialist service existed for people like themselves and being listened to for the first time in years hadhelped to relieve the anxiety and isolation participants had previously experienced.

'I think it is always nice to talk to somebody who knows and to listen to how your body works. Also knowing that otherpeople suffer from it and I am not alone.' (Participant 10)

The information people received was a vital aspect of care. To attend a specialist clinic and get relevant, targetedinformation as well as having time to discuss problems was a welcome relief.

'I didn't feel that I was being fobbed off. This really helped me and she drew a diagram for me to help me along. I cameaway feeling that I had achieved something and feeling like the information and care that was given was very, very good andhelpful? All the literature I received I understood it. There was no high technical jargon in it. I had no problems readingit.' (Participant 3)

People required, requested and received information on lifestyle issues related to their bowel problem, not just aboutirrigation.

Discussion

This study provides new insight into how people with chronic constipation and faecal incontinence can experience extremesymptoms and poor quality of life for years without effective treatment. The experiences of these participants illustrate thisdistress and the multidimensional impact on the lives of those with incontinence or constipation. Their stories revealed hiddenhistories of suffering and attempts to self-manage, which raises a question about the true extent of the population sufferingwith defecation disorders.

Rectal irrigation provided a successful self-management option for all but two of the participants: for one, it had notresolved symptoms, and the other found the routine burdensome but recognised that it was helpful in alleviating the problem.One startling indication is that rectal irrigation gave people control over their illness and lives. People who had hardly leftthe house for years were now able to socialise, go on holiday and start new relationships, including sexual ones.

Rectal irrigation did require compliance and discipline. It did take time for people to get used to the technique andintegrate the procedure into daily life. Specialist staff who are knowledgeable and who listen to patients' problems and livesand can put their minds at rest may well be key to the success of rectal irrigation. With the participants in our study theyprovided ongoing support while people were readjusting.

Results highlighted the fact that participants had been frustrated in their attempts to get information relevant to thembefore attending the irrigation clinic. The success of irrigation might be due not only to the procedure, but also to thetherapeutic and informative input from specialist nursing staff. Any future evaluation of rectal irrigation would have tofactor in this influence.

The study was limited by the sample size and the fact it comprised women only. It does, however, show insight into theexperiences of people who were referred to the irrigation clinic. For many, this last chance to manage a distressing,debilitating condition with physical, psychological and social implications had ended up being a 'lifesaver'.

Implications for practice

The experience of the participants illustrates the true nature and extent of suffering due to chronic constipation andfaecal incontinence. Reflection of this experience can help nurses understand patients' perspectives in their care.

This study indicates that rectal irrigation was well received by all but one of the participants and provided an effectiveway for them to manage their bowel. However, rigorous randomised controlled trials are required before rectal irrigation isadopted as routine practice. There are many unanswered questions including issues such as which patients are best suited torectal irrigation and what specialist nurse support and care is required to promote acceptability and success of rectalirrigation.

Conclusion

Rectal irrigation has a potential role in the management of chronic constipation and faecal incontinence, related symptomsand impact. Further interventional evaluations are required to establish an evidence base for its use.

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