

# A qualitative analysis of patients' reasons for choosing neobladder or ileal conduit after cystectomy for bladder cancer

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## Abstract

**Objective:** Choice of reconstruction following bladder removal is often between neobladder or ileal conduit diversion. Identifying patient concerns about this little understood choice should provide better understanding of factors important in making surgical decisions. The current study used a qualitative technique to identify patient concerns and values influencing patient choice of bladder reconstruction following radical cystectomy.

**Subjects and Methods:** Thirty-two patients (neobladder: 11 male, 6 female; ileal conduit: 9 male, 6 female) participated in semi-structured interviews conducted at a Hospital Clinical Research Unit, and their responses were analysed by content analysis.

**Results:** Many procedure and lifestyle factors were secondary to survival considerations. Most patients adapted to reconstruction. Patients chose neobladder because of perceptions of normality and less-restricted activities (including sex life), or chose ileal conduit because of perceived simplicity of this operation, or the fear of urinary incontinence, and extra 'work' for the patient involved in having a neobladder. Male and female reasons were consistent with one another, except that body image was a greater issue for females in choosing neobladder.

**Conclusion:** Pre-existing concerns influenced the choice that patients made between undergoing ileal conduit or neobladder reconstruction after removal of their bladder. These findings are a step towards developing a tool to aid joint decision making when planning exenterative and reconstructive surgery for bladder cancer.

## Keywords

Bladder cancer, bladder reconstruction, ileal conduit, neobladder, patient choice, qualitative analysis

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## Introduction

The incidence of bladder cancer is estimated at 10.1/100,000 males, and 2.5/100,000 females.<sup>1</sup> Muscle invasive bladder cancer represents about 30% of presenting bladder cancers.<sup>2</sup> Radical cystectomy is the most commonly performed treatment with curative intent, and its frequency has increased over the last 15 years.<sup>3</sup> Following cystectomy, there is an immediate need for reconstruction to provide drainage of urine. This is usually provided by means of either ileal conduit (IC) or orthotopic neobladder (NB), which account for

86% and 6%, respectively, of all such procedures in the UK.<sup>4</sup> Cutaneous continent urinary diversion (1.5%) and rectal NB (0.3%) are comparatively uncommon.<sup>4</sup>

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**Table 1.** Summary of interview questions employed for all participants.

1. What were the attributes or aspects of the neobladder*/stoma* that influenced you to choose that option, and which was the most important of these for you?
2. Which aspects of your life and lifestyle were most important to you in making your decision?
3. How do you feel your choice influences, and plays a part in, your life today, and are you satisfied with your decision, and why?

Although there is extensive research concerning quality of life (QoL) after radical cystectomy, employing a range of well-validated QoL assessment tools,<sup>5-8</sup> this does not demonstrate health-related (HR) QoL superiority of either NB or IC.<sup>6</sup> Most studies demonstrate good HRQoL in most patients, irrespective of the type of urinary diversion.<sup>9</sup> The key differences are not in overall levels of HRQoL, but rather in the precise aspects of QoL impacted; patients with IC tend to report poorer body-image satisfaction and less active lifestyles, whereas NB patients report increased concerns regarding urinary leakage.<sup>10</sup>

However, it has been stressed<sup>9</sup> that the decision-making process, when choosing IC or NB, needs to address patients' preoperative lifestyles<sup>11</sup>, which cannot easily be assessed using existing HRQoL measures. Rather than basing treatment decisions solely on reports of superior QoL following one type of diversion, the best treatment decisions are made when tailored to the needs and choices of individual patients.<sup>12,13</sup> To address these issues, it is suggested that qualitative research is an essential first step in developing a treatment decision aid for patients with bladder cancer,<sup>14</sup> since before such an aid can be developed, patient concerns and values regarding urinary diversion must be adequately understood. Thus, the aim of the present research was to use qualitative research methods to establish patient concerns and values associated with choosing either IC or NB.

## Method

### Participants

All participants had advanced bladder cancer, with a grade of G3 Pta and above, and all were classed as severe cases requiring radical surgery. Individuals who had undergone either IC or NB procedures approximately one year previously were recruited. No patients had undergone either cutaneous continent urinary diversion or rectal NB at this institution within the timeframe. Participants were randomly selected from a patient database, and were sent a letter inviting them to attend an interview. No form of payment was offered for participation, but participants were offered reimbursement of travel expenses to and from the hospital where the interview took place. Twenty males volunteered to participate in the interviews, of whom 11 had chosen NB ( $M_{age}=64$  years) and nine had chosen IC ( $M_{age}=67$  years). Twelve females volunteered, of whom six had chosen NB

( $M_{age}=62$  years) and six had chosen IC ( $M_{age}=66$  years). Ethical approval was obtained from the Ethics Committee within the University Psychology Department.

### Interview sessions

All interviews took place in a quiet room in the Clinical Research Unit of the hospital, and were conducted by a researcher independent from the urology team. Participants were encouraged to answer as honestly as possible, and were reassured that any criticisms of their consultation or treatment experience were welcomed.

A semi-structured interview format was adopted to allow participants latitude in expressing issues that were important to them, and without forcing particular issues. The same semi-structured interview script was used for each participant, ensuring all were asked the same questions. The key issues that the script sought to elicit are displayed in Table 1. The responses were digitally recorded for subsequent analysis.

### Content analysis

The transcribed recordings were subjected to thematic content analysis, in line with previous recommendations<sup>15</sup> (Table 2). The current methodology has been widely employed in health contexts,<sup>16,17</sup> and it is accepted as appropriate for the purpose of examining interview responses.<sup>15</sup> Transcripts were examined to identify the 'key themes' within the data. To ensure the reliability of these themes, two researchers agreed upon all categories together at the same time. The individual 'units of information' contained within each transcript were then highlighted. A 'unit' was any piece of text that related to the identified themes, and that could be interpreted on its own to provide a meaningful and informative comment. Participants' comments containing more than one such 'unit of information', as in the case of long comments that made a number of points, were divided into several separate 'units'. From reading the unitised comments, the initial category headings were further refined, so that all of the 'units of information' could be categorised according to those themes. The 'units' were then coded according to the category headings. The coding of the individual 'units' into the categories was conducted separately by two researchers. The placement of all 'units' into the categories was agreed upon by the researchers.

**Table 2.** Stages in the content analysis.

1. Identification of key themes or 'big ideas' within the data, following reading and re-reading of each set of comments.
2. Identification and highlighting of 'units of information' (phrases and/or sentences) relevant to the research purposes.
3. Selection of category headings to sort and group these 'units of information'.
4. 'Units of information' are coded according to category headings, to enable the units to be placed within a category.
5. Negotiation between researchers to agree the category headings that most economically accommodate the 'units of information'.
6. Categories generated in the first phase of data analysis are reviewed and revised.

After Vaughn et al. (1996).<sup>15</sup>

**Table 3.** Percentage (number) of responses falling into each category for males and females after both operations, in terms of the attributes of the procedure that influenced their decision (in response to Question 1).

Operation	Sex	Normality	Upkeep or safety	Body image	Negative perceptions of the alternative
Neobladder	Male (53)	51% (27)	26% (14)	15% (8)	8% (4)
	Female (60)	30% (18)	23% (14)	45% (27)	5% (1)
Ileal conduit	Male (45)	47% (21)	40% (18)	0% (0)	13% (6)
	Female (39)	33% (13)	67% (26)	0% (0)	0% (0)

## Results

### *Question 1: Which attributes/aspects of the procedure itself influenced you to choose that option?*

The percentage (and number) of responses to Question 1 are displayed in Table 3. There were four themes that emerged from the responses made by this sample. The most important of these themes concerned normality, which indicated that patients felt that the operation allowed them to continue with their life without changing their behaviours. A second theme was in relation to the upkeep or safety of the procedure, which was related to the amount of work they felt the procedure would lead to, or the relative safety or likely complications of the operation. Body image also was a theme that emerged, as was the patients' negative perceptions of the alternative procedure.

When comparing the responses across the two types of procedure, it can be seen that NB was chosen due to its perceived ability to allow a more normal lifestyle (e.g. 'still urinating through your penis'; 'more natural than having a bag'; 'can continue as normal'), but IC was chosen more for its perceived safety relative to NB (e.g. 'I knew the construction would be a lot more work'; '...more complications'; 'I just took the view that the neobladder seemed like a lot of hard work'). Body-image issues were more important for females than they were for males (e.g. 'not having a contraption on your side'), with 45% of females' statements versus 15% of males' statements

mentioning this issue. There was slightly more importance given by females than by males to the upkeep and safety issues associated with IC, with 67% of females' statements versus 40% of males' statements mentioning this issue. Apart from those categories, the sexes were quite similar in their responses regarding the attributes of the procedure that attracted them.

### *Question 2: Which aspects of your life/lifestyle were most important to you in making your decision?*

The responses to this question are shown in Table 4. There were five categories of response: unrestricted QoL, by which participants meant the ability to function as they had previously with confidence; survival; physical activities, which related to the ability to continue to live an active lifestyle, including participation in sport; body image; and the perceived extra work associated with NB.

The most important aspects for the patients who chose NB were: unrestricted QoL ('you can carry on as much as before'; '...didn't want to have accidents in public') and physical activities ('...the neobladder did not impose on this sailing'; 'activities and sports were an issue'). However, survival was also an important issue for this group ('not having cancer'; 'sex not that important compared to dying'). For the patients who selected IC, this latter category of survival was the most important. In terms of sex differences, there were few, with the exception of

**Table 4.** Percentage (number) of responses falling into each category for males and females after both operations, in terms of life/lifestyle attributes that influenced their decision (in response to Question 2).

Operation	Sex	Unrestricted QoL	Survival	Physical activities	Body image	Extra work with neo-bladder
Neobladder	Male (29)	41% (12)	35% (10)	21% (6)	3% (1)	0% (0)
	Female (30)	30% (9)	23% (7)	27% (8)	20% (6)	0% (0)
Ileal conduit	Male (31)	13% (4)	74% (23)	0% (0)	0% (0)	13% (4)
	Female (25)	24% (6)	76% (19)	0% (0)	0% (0)	10% (0)

**Table 5.** Percentage (number) of responses falling into each category for males and females after both operations, in terms of their satisfaction with their procedure – top panel, and how it has affected their life – bottom panel (in response to Question 3).

Operation	Sex	Mobility	Activities	Leakage	Restricts travel/work	Sexual problems/inhibitions
Neobladder	Male (27)	52% (14)	26% (7)	19% (5)	4% (1)	0% (0)
	Female (24)	42% (10)	25% (6)	33% (8)	0% (0)	0% (0)
Ileal conduit	Male (41)	20% (8)	17% (7)	27% (11)	10% (4)	27% (11)
	Female (37)	30% (11)	11% (4)	30% (11)	16% (6)	14% (5)

Operation	Sex	Satisfied	Adapting	Problems
Neobladder	Male (19)	89% (17)	11% (2)	0% (0)
	Female (19)	84% (16)	14% (3)	0% (0)
Ileal conduit	Male (22)	57% (12)	43% (10)	0% (0)
	Female (14)	21% (3)	72% (10)	7% (1)

body image, which was important for females choosing NB ('...the bag was less "natural" than a reconstruction').

### Question 3: How does your choice influence your life today, and are you satisfied with your decision?

Table 5 shows the patients' responses to the question about how their choice has influenced their life. This question was split into two sections for the purpose of analysis: (1) satisfaction with their choice – top panel of Table 5; and (2) current impact on everyday life – bottom panel of Table 5.

In terms of patient satisfaction (see top panel of Table 5), most patients were either satisfied with (e.g. 'I'm totally happy') or adapting to (e.g. '...on the right track'; 'I'm learning to deal with it') their choice. There was marginally more satisfaction with NB than with IC.

In terms of the impact on the patients' lives (see bottom panel of Table 5), five categories emerged. Two of these categories were positive: mobility, involving getting around; and the ability to participate in activities (e.g.

'...becoming more active'; '...can still go on holiday regularly'; 'I can do everything I want to do'). The remaining three categories were negative: leakage as a result of the procedure; restrictions to travel and work; and sexual problems or inhibitions (e.g. 'it does inhibit me'; 'we tried different positions, so it wouldn't show, but it is still there'). The responses concerning NB were more positive (around 70%) than negative, and this was the case for both males and females. The responses regarding IC were evenly split between positive and negative, and leakage for females, and sexual problems or inhibitions for males, were the most commonly mentioned negative consequences of the IC procedure.

## Discussion

Many participants placed the issues of both lifestyle and potential negative impacts of the procedures as secondary to survival. Many adapted to the changes induced by their procedure, so that even if they could not do the things they had done previously, their QoL was the same as before.

This is a common adaptational response to living with a long-term condition.<sup>16</sup> The majority of participants' responses indicated they were either satisfied or adapting to the changes brought about by their operation, although there was slightly greater satisfaction with NB. This finding is in line with previous studies that suggest that patients who undergo IC are more likely to be unhappy with their treatment compared with NB patients.<sup>5</sup>

The main reason why participants chose NB was that it was 'more natural' and 'normal' than IC, and allowed a more unrestricted QoL, which is consistent with findings from previous QoL studies.<sup>8</sup> The present findings also provide evidence consistent with the notion that patients choosing NB have a more active lifestyle.<sup>8</sup> This appears to be a main source of dissatisfaction for active individuals who have had IC. This finding could be related to those that suggest NB patients tend to be younger than IC patients,<sup>6</sup> which was also marginally the case for the current sample. In the NB group, participants identified body image as an important factor when making their decision. In contrast, neither body image nor self-confidence came up in the responses of the participants who had undergone IC.

A reason for choosing IC was the perception that it offered a quicker and safer means to achieve normal functioning for that patient after cancer treatment. These participants expressed more concerns relating to survival than the NB group, which could possibly be explained by a greater perception of danger in the IC group. Additionally, the IC group thought that the NB procedure appeared to require more work. In fact, the present study found that the main problem for patients who underwent NB was leakage and accidents. These findings are consistent with those from previous studies that show NB patients have more leakage concerns.<sup>8</sup>

The majority of negative impacts of IC were related to effects on their sex<sup>7</sup> and work lives. While these may have been issues contributing to a somewhat lower satisfaction level following their procedure, for the IC group, it was also the case that the participants had adapted to, or come to terms with, these impacts. Many of the IC participants stated that although the impacts on their sex life were a consideration, this was not a major contributor to their initial decision, and it paled as an issue relative to that of survival.

The responses given by males and females about the two procedures were quite similar to one another. Any differences that did exist tended to be in the areas of body image, making females more likely to choose NB than males, and the perceived ease of use and safety, making females more likely to choose IC than males.

It should be noted that the qualitative approach employed allows the strength of feeling of the participants about particular issues to be assessed, but the results should not be taken as indicating population

frequencies of these views. The sample size, although adequate for the present qualitative analysis, was still small in relation to the size of this population, and the participants were self-selecting (i.e. those who volunteered to attend for interview). Additionally, this study was retrospective, and participants did have to rely on memory for some events. While remembering events from a year previous could be difficult for some patients, this period was not felt to be excessively long, given the salience of these events for the patients. Moreover, conducting the interview at this time point afforded patients time to recover from a radical procedure. This would not be as intrusive and stressful as conducting an interview soon after their procedure, thus not overburdening patients more than necessary (which may introduce its own problems). Although cutaneous continent urinary diversion is a valid reconstructive option, as is the rectal NB, very few of these procedures have been performed at the hospital involved in this study, and hence there were no patients available to be interviewed for this study. However, interviewing patients who have undergone such procedures could be beneficial for evaluation in future research studies.

In addition to aspects of the surgical procedure and lifestyle that influenced choice, patients may have been influenced by members of the surgical and hospital team. This was not the main focus of the current investigation, and this influence is difficult to assess. However, as part of the introduction to the interview, patients were asked with whom they consulted and discussed their options. The responses were recorded, and of these, 28.5% mentioned their consultant, 20.6% mentioned a nurse, 20.6% mentioned their spouse and family, 11.1% mentioned the Internet, 9.5% mentioned friends, 6.3% mentioned literature and 3.2% mentioned previous patients. Most patients mentioned more than one of these in their responses. It is difficult to know the strength of the influence of each of these avenues, but it is clear that there was a wide variety of potential influences on patient choice.

The findings from the present study provide insights into factors influencing patients' decision-making processes, and should be viewed as part of a fundamental shift in research from typical HRQoL studies regarding urinary diversion to more patient-centred approaches. It is one of the first pieces of research to focus on the views, concerns and opinions of patients regarding their choice of urinary diversion, rather than focusing purely on how their choice has subsequently affected their overall QoL. Once further studies, similar to the present research, have been conducted to generate a larger, more diverse sample of patients, the findings can be combined to develop a decision-aid tool to identify which form of urinary reconstruction may be best suited to the values and concerns of patients.

## Conclusions

Patients' values and concerns influence the surgical decisions that are made when selecting an appropriate bladder reconstruction. These findings are a step towards developing a tool that will aid joint decision making when planning exenterative and reconstructive surgery for bladder cancer.

## Conflicting interests

The authors declare that there is no conflict of interest.

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## Ethical approval

Ethical approval was granted by the Department of psychology Ethics Committee, Swansea University. UK.

## Informed consent

Written informed consent to participate in the study was obtained from all participants.

## Guarantor

PR.

## Contributorship

LAO designed the study, analysed the data and wrote the initial manuscript. CD, DJE and RB conducted the interviews and contributed to the write-up. AY designed the study, conducted the interviews and contributed to the write-up. ML designed the study and contributed to the write-up. PR designed the study, analysed the data and wrote the initial manuscript.

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