



Swansea University
Prifysgol Abertawe



Cronfa - Swansea University Open Access Repository

This is an author produced version of a paper published in:
Journal of Clinical Urology

Cronfa URL for this paper:
<http://cronfa.swan.ac.uk/Record/cronfa48868>

Paper:

Reed, P. & Osborne, L. (2019). Factors related to patient choice of bladder reconstruction following radical cystectomy. *Journal of Clinical Urology*, 205141581983323
<http://dx.doi.org/10.1177/2051415819833231>

This item is brought to you by Swansea University. Any person downloading material is agreeing to abide by the terms of the repository licence. Copies of full text items may be used or reproduced in any format or medium, without prior permission for personal research or study, educational or non-commercial purposes only. The copyright for any work remains with the original author unless otherwise specified. The full-text must not be sold in any format or medium without the formal permission of the copyright holder.

Permission for multiple reproductions should be obtained from the original author.

Authors are personally responsible for adhering to copyright and publisher restrictions when uploading content to the repository.

<http://www.swansea.ac.uk/library/researchsupport/ris-support/>

**Factors related to patient choice of bladder reconstruction following
radical cystectomy**

Phil Reed¹ & Lisa A. Osborne²

¹*Swansea University*; ²*Abertawe Bro Morgannwg University Health Board.*

Correspondence address: Phil Reed,

Department of Psychology,

Swansea University,

Singleton Park,

Swansea, SA2 8PP, U.K.

e-mail: p.reed@swansea.ac.uk

Tel: 0044 (0)1792 602047

Fax: 0044 (0)1792 295679

Abstract

Objective: To identify patient values and concerns related to choice of bladder reconstruction following removal, in order to provide understanding of factors important in making surgical decisions.

Subjects and Methods: 62 patients treated for advanced bladder cancer (grade pT1 and above), and choosing either ileal conduit (IC) or orthotopic neobladder (NB) following cystectomy, each completed three questionnaires: EORTC QLQ-30; Bladder Reconstruction Satisfaction Questionnaire (BRSQ); and Life Values Inventory (LVI).

Results: Health status (EORTC) was not related to procedure-satisfaction. Older, and female, patients had IC. IC-patients rated ease of post-operative maintenance, and perceived ease-of-surgery, as more important; NB-patients rated returning-to-normality as more important (BRSQ). IC-patients had higher life-values (LVI) concerning environment, humility, and loyalty; while NB-patients had higher values concerning creativity, independence, and science.

Conclusion: Pre-existing concerns influence choices that patients make between IC and NB after removal of their bladder. Those wanting to minimise surgical difficulty and extra work following the reconstruction, and valuing living their life with regard to others, favour IC. Patients being younger, male, valuing the way they lived their life pre-operatively, and valuing science/technology, favour NB. These findings are a stepping-stone towards developing a tool to aid joint patient/consultant decision-making, when planning reconstructive surgery for bladder cancer.

Keywords: bladder cancer; bladder reconstruction; ileal conduit; neobladder; patient choice.

Introduction

The incidence of bladder cancer is about 10.1/100,000 males, and 2.5/100,000 females¹. Muscle-invasive cancer represents 30% of bladder cancers². After radical cystectomy, bladder reconstruction is usually provided by either ileal conduit (IC) or orthotopic neobladder (NB)³. No consistent health-related quality-of-life (HR-QoL) superiority is noted for IC or NB⁴⁻⁷ – there is good HR-QoL for most patients, irrespective of their type of urinary diversion^{5,8,9}.

Contemporary thinking suggests that the key issues to consider, when advising on reconstruction, are the precise aspects of QoL impacted by each procedure. Decision-making processes regarding whether patients should opt for IC or NB should take into account patient views about these aspects of their preoperative health status and lifestyle¹⁰. That is, rather than basing treatment decisions on reports of superior QoL, decisions are best when tailored to individual patients' needs and preoperative lifestyles and values^{9,11,12}.

Unfortunately, there is little information regarding patient views in this context. Studies have suggested patients choosing IC tend to report poorer body-image satisfaction, and less active lifestyles; whereas, those choosing NB report increased concerns with urinary leakage¹³. One qualitative study⁹ identified that procedure- and lifestyle-factors were secondary to survival considerations, and that most patients adapted to reconstruction. However, beyond this, patients tended to choose IC because of perceived simplicity of this operation, or the fear of urinary incontinence, and extra “work” for the patient involved in having NB; and chose NB because of perceptions of normality and less-restricted activities.

The present research used a quantitative approach to explore further patients' lifestyles, concerns, and values, associated with choosing either IC or NB. It is hoped that this information will provide medical professionals with a better understanding of the factors

important to patients in making their treatment decisions, which will help to ensure that the right guidance is given to patients regarding their decision.

Method

Participants

Sixty-two participants, who had been treated for advanced bladder cancer (grade pT1 and above), and had chosen either IC or NB procedures, responded to advertisements regarding the study. The advertisements were sent to patients identified by health organisations (Boards/Trusts), and participants came from multiple sites in the UK. All had their operation not less than one year previously, nor more than five years before. Thirty-eight participants chose IC (14 males, 24 females; mean age = 62 years), and 24 participants chose NB (18 males, 6 females; mean age = 52 years). No form of payment was offered for participation.

Materials

*European Organization for Research and Treatment Quality of Life Questionnaire (EORTC QLQ-30)*¹⁴ is a patient-completed 30-item questionnaire that assesses QoL outcomes relevant to cancer patients. Each item asks about a specific symptom or aspect of the patient's life, and is answered on a 4-point scale ('not at all', 'a little', 'quite a bit', 'very much'). There are a number of scales produced, and this study used the functioning scales: physical functioning; role functioning; emotional functioning; cognitive functioning; social functioning. Each scale produces a score between 0 (low) and 100 (high). The scale also gives a global health status (0 – 100).

*Life Values Inventory (LVI)*¹⁵ is a patient-completed 42-item questionnaire. Each item asks about whether a specific value guides behaviour on a 5-point scale ('almost never'

to ‘almost always’). It measures patient-held values across a number of domains: achievement; belonging; concern for the environment; concern for others; creativity; financial prosperity; health and activity; humility; independence; loyalty to family or group; privacy; responsibility; scientific understanding; and spirituality. Each scale produces a score between 3 (low) and 15 (high).

Bladder Reconstruction Satisfaction Questionnaire (BRSQ) was a new questionnaire developed for this study, and is a patient-completed, 11-item tool concerned with patient views on the aspects of the reconstruction that were most important to them. These questions were constructed with input from Consultant Urologists involved in the treatment and care of bladder cancer patients. One item asks about levels of satisfaction with bladder reconstruction on a 5-point scale (‘very satisfied’ to ‘very dissatisfied’). Another item asks about the aspects of participants’ lives prior to surgery that were important to them (body image; ability to return to normality; ease of passing urine; incontinence; sexual function; removing the cancer quickly; urine infections; maintenance of bladder; physical activity; and severity of surgery), rated on a 7-point scale (‘very unimportant’ to ‘very important’).

Results

--- Table 1 ---

All participants indicated that they had chosen their bladder reconstruction procedure. Table 1 presents the gender breakdown of these procedure choices. These data show that, while there was a relatively even split across the procedures for males, most females had chosen IC, $X^2(1) = 8.57, p < .001, \phi = .372$.

In terms of satisfaction with their bladder replacement (assessed by a question in the BRSQ), 28 participants indicated that they were ‘very satisfied’, 27 that they were ‘satisfied’,

4 'neither satisfied or dissatisfied', no participants indicated that they were 'dissatisfied' or 'very dissatisfied', and 3 participants did not answer this question.

The remaining analyses were conducted only on those participants who were 'very satisfied' or 'satisfied' ($N = 55$). The mean age of those participants who had chosen IC was 62.25 (± 8.82) years, and the mean age of those choosing NB was 51.64 (± 11.57), $t(53) = 3.86$, $p < .001$, $d = 1.01$. Table 2 shows these satisfaction data for each of the procedures, and reveals that more participants were 'very satisfied' with IC than with NB, $X^2(1) = 34.29$, $p < .001$, $\phi = .790$.

--- Table 2 ---

In terms of QoL outcomes, as assessed by the EORTC QLQ-30, the participants with IC had a mean global health status of 59.83 \pm 1.91, and those with NB had a mean global health status of 66 \pm 9.50, $t(53) = 1.17$, $p = .245$, $d = .30$. This global health status score was not associated with satisfaction with the procedure measured by the BRSQ ('very satisfied', scored as 1; or 'satisfied', scored as 0), $r_b = -.127$, $p > .30$.

--- Figure 1 ---

The mean scores for the functioning scales of the EORTC QLQ-30 are shown in Figure 1. Inspection of these data reveals little difference between the two types of bladder replacement in terms of role, $t < 1$, $d = .02$, or social, $t < 1$, $d = .10$, functioning. There were greater scores for NB in terms of: physical, $t(53) = 3.20$, $p < .001$, $d = 1.25$; emotional, $t(53) = 3.37$, $p < .001$, $d = 0.90$; and cognitive, $t(53) = 4.08$, $p < .001$, $d = .52$, functioning. A logistic regression using these factors as predictors, and 'very satisfied' (1) and 'satisfied' (0) from the BRSQ as the outcome, revealed a significant predictive model, $-2LL = 31.93$, $X^2(5) = 42.93$, $p < .001$, but only physical functioning ($\beta = 10.51$, $p < .05$) was an independent predictor of satisfaction with reconstruction.

--- Figure 2 ---

Figure 2 shows the mean scores for the aspects of the participants' lives that they rated as important to them prior to surgery, according to the BRSQ. Inspection of these data shows that returning to normality, and removal of the cancer, were the most important aspects of the participants' lives prior to the surgery, irrespective of the type of procedure chosen. However, some aspects of life were rated as differentially important between those who opted for IC and NB. In particular, those opting for IC rated maintenance, $t(53) = 3.84, p < .001, d = 1.60$, and severity of surgery, $t(53) = 5.72, p < .001, d = 2.90$, as more important. In contrast, those opting for NB rated the ability to return to normality as more important than those opting for IC, $t(53) = 4.27, p < .001, d = .90$. All other comparisons between these groups of participants were not significant, all $ps > .10$. A logistic regression using these factors as predictors, and IC (0) and NB (1) as the outcome, revealed a significant predictive model, $-2LL = 87.93, X^2(5) = 59.58, p < .001$, with 'maintenance' ($\beta = -11.38, p < .001$), and 'severity of surgery' ($\beta = -19.11, p < .001$), predicting IC choice, and 'normality' predicting NB choice ($\beta = 13.22, p < .001$).

--- Table 3 ---

Table 3 shows the group means for each of the thirteen life values measured by the LVI. These data show that there were some significant differences between the values held by participants who chose IC, and those who chose NB. The IC group had higher values in terms of the environment, humility, and loyalty; while those choosing NB had higher values in creativity, independence, and science. These differences might be summarised as implying values focusing on others favour IC choice; and values focusing on the person (themselves), and science, favour NB choice.

Discussion

The findings from the present study provide insights into the factors involved in patients' decision-making processes, and should be viewed as part of a fundamental shift in research from typical HR-QoL studies regarding urinary diversion to a more patient-centred approach. It is among only a few pieces of research to focus on the specific lifestyles, values, views/perceptions, concerns, and opinions, of patients regarding their choice of urinary diversion, rather than focusing purely on how their choice has subsequently affected their overall QoL¹³. Prior to consideration of the implications of these findings, the retrospective nature of the study should be noted, and there is always the chance of post hoc justification in patient responses. Nevertheless, the results show strong similarity to those that emerged from a qualitative study on this topic⁹.

In the current study, females tended to have an IC, and males tended to have an NB; with older participants having IC, and younger participants having NB. The majority of participants indicated that they were satisfied with their operation^{5,8,9}, with a suggestion of greater satisfaction with IC. The difference between this finding, and that previously reported in the qualitative study⁹, where NB was favoured, is almost certainly produced by the different methods of asking the question in the two studies. The EORTC QLQ-30 scale suggested that any differences in satisfaction between the procedures, in the current study, might be related to physical functioning, which will be highly dependent on participant perceptions of what they desired in this regard.

The participants indicated that, although the impacts on their lives and their pre-existing values were considerations, these concerns paled relative to that of survival, which is consistent with previous studies⁹. Beyond this key 'survival' issue, the main reasons why participants chose IC was the perception that it offered a quicker, less surgically-involved, and safer means to recovery after cancer treatment⁹. These participants also expressed more

concerns relating to the degree of work needed to maintain NB, relative to IC. These participants also tended to have what might be termed ‘outwardly-directed’ values, especially concerning others, their relationships with others, and the environment.

A key reason for choosing NB was that participants felt that it was more natural, and allowed a return to perceived normality, relative to IC^{9,13}. The present findings provide evidence consistent with the notion that patients choosing NB have a more active lifestyle¹³. These participants also tended to be concerned with what might be termed more ‘inwardly-directed’ values (e.g., creativity, independence), than those participants who favoured IC. Previous studies have indicated that those choosing NB identify body image as an important factor, when making their decision^{9,13}. Interestingly, the type of bladder reconstruction – partially ‘external’ for IC, and ‘internal’ for NB – on the whole, match the general values-orientation of participants who chose each of these procedures – ‘outwardly-directed’ for IC and ‘inwardly-directed’ for NB.

Although the degree of consistency with the few existing studies is encouraging, these suggestions should be treated with caution until they can be extended further, using a wider and larger sample of individuals. The current patients were volunteers, and this will have introduced a selection bias, which needs to be acknowledged, but is difficult to overcome in any study that seeks informed consent. Nevertheless, it is possible that the observations, above, regarding the patient characteristics associated with the choices, may have resulted from such selection bias. In the current sample, very few participants were not satisfied with their procedure, and the results might be different with a wider range of opinion in terms of outcome. The limited size of the sample also precluded any more sophisticated analyses of these data; for example, determining whether different values were associated with reconstruction choice for males and females. The current data were collected with only a limited range of measurement tools, and it may be that different results would be obtained

with a different battery of tools. In addition, the use of psychological scales may illustrate whether some personality factors, alluded to above, could be useful predictors of reconstruction choice. It should be noted that the questionnaires were completed post-surgery, so it cannot be concluded, definitively, that these measures predict reconstruction choice. There may have been some degree of post hoc justification, and/or differences in the pre- or post-operative counselling, that might have impacted outcomes, and a prospective study is needed to reach that particular conclusion. Once further studies have been conducted to generate a larger, more diverse, sample of patients, the findings could be combined to further develop, and test, a joint patient/consultant decision-aid tool to identify which type of urinary reconstruction may be best suited to the lifestyles, values, and concerns of patients.

In summary, it might be concluded that being older, being female, wanting to minimise the risks and difficulties of the surgical procedure, wanting to minimise extra work following the reconstruction, and valuing living your life with regard to others, favours IC. In contrast, being younger, being male, valuing the way you lived your life before the operation, wanting to do the things that you want to do, and valuing science and technology, favours NB.

References

1. Ferlay, J.S.H., Bray, F., Forman, D., et al. (2008). *GLOBOCAN 2008 v1.2, Cancer incidence and mortality worldwide: IARC CancerBase No. 10 2010*. International Agency for Research on Cancer: Lyon, France.
2. Vaidya, A., Soloway, M.S., Hawke, C., et al. (2001). De novo muscle invasive bladder cancer: is there a change in trend? *J. Urol.*, *165*(1), 47-50.
3. British Association of Urological Surgeons Section of Oncology (2015). Analyses of cystectomies performed between January 1st and December 31st, 2014. Retrieved from: http://www.baus.org.uk/_userfiles/pages/files/Publications/Audit/Cystectomyfinalanalysis2014.pdf
4. Dutta, S.C., Chang, S.S., Coffey, C.S., Smith, J.A., Jack, G. & Cookson, M.S. (2002). Health related quality of life assessment after radical cystectomy: Comparison of ileal conduit with continent orthotopic neobladder. *The Journal of Urology*, *168*(1), 164-167.
5. Geharz, E.W., Mansson, A., Hunt, S., Skinner, E.C., & Mansson, W. (2005). Quality of life after cystectomy and urinary diversion: an evidence based analysis. *Journal of Urology*, *174*(5), 1729-1736.
6. Hart, S., Skinner, E.C., Meyerowitz, B.E., Boyd, S., Lieskovsky, G., & Skinner, D.G. (1999). Quality of life after radical cystectomy for bladder cancer in patients with an ileal conduit, or cutaneous or urethral kock pouch. *The Journal of Urology*, *162*(1), 77-81.
7. Hobisch, A., Tosun, K., Kinzl, J., et al. (2001). Life after cystectomy and orthotopic neobladder versus ileal conduit urinary diversion. *Semin Urol Oncol*, *19*, 18– 23.
8. Somani, B., Gimlin, D., Fayers, P., & N'Dow, J. (2009). Quality of life and body image for bladder cancer patients undergoing radical cystectomy and urinary diversion – A prospective cohort study with a systematic review of literature. *Urology*, *74*, 1138-1143.

9. Osborne, L. A., Dixon, C., Edwards, D. J., Begum, R., Younis, A., Lucas, M., & Reed, P. (2016). A qualitative analysis of patients' reasons for choosing neobladder or ileal conduit after cystectomy for bladder cancer. *Journal of Clinical Urology*, 9(5), 340-345.
10. Evans, B., Montie, J.E., & Gilbert, S.M. (2010). Incontinent or continent urinary diversion: how to make the right choice. *Current Opinion in Urology*, 20(5), 421-5
11. Gerharz, E.W. (2007). Is there any evidence that one continent diversion is any better than any other or than ileal conduit? *Current Opinion in Urology*, 17, 402-407.
12. Patel, H.R.H., Mirsadraee, S., & Emberton. M. (2003). The patient's dilemma: Prostate Cancer Treatment Choices. *Journal of Urology*, 169(3), 828-833.
13. Kikuchi, E., Horiguchi, Y., Nakashima, J., Ohigashi, T., Oya, M., Nakagawa, A., & Murai., M. (2006). Assessment of long-term quality of life: FACT-BL questionnaire in patients with an ileal conduit, continent reservoir, or orthotopic neobladder. *Japanese Journal of Clinical Oncology*, 36, 712-716.
14. N.K Aaronson, S Ahmedzai, B Bergman, *et al.* The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J. Natl. Cancer Inst.*, 85 (1993), pp. 365-376
15. Crace, R. K., & Brown, D. (1996). Life values inventory. *Minneapolis, MN: National Computer Systems.*

Acknowledgements

Many thanks are due to Mr. Malcolm Lucas and Professor Simon Emery for their help and suggestions regarding this research, and to all of the participants who very kindly gave their time and consideration to this project. Thanks are also due to Bethan Jones and Nicola Purdy, from Swansea University, for their assistance and support in solving some of the administrative issues that emerged during this work. Finally, a grateful thank you to Tenovus Cancer Care for providing the funding for this research, in the form of an iGrant, and to Jess Hall, from Tenovus, for her ongoing support and help during the research programme.

Table 1: Numbers of males and females undergoing Neobladder and Ileal Conduit procedures.

	Neobladder	Ileal Conduit
Male	18	14
Female	6	24

Table 2: Numbers of participants satisfied with Neobladder and Ileal Conduit procedures.

	Neobladder	Ileal Conduit
Very Satisfied	1	27
Satisfied	22	5

Table 3: Mean for life values for the two groups of participants as measured by the Life Values Inventory.

Life Value	Neobladder	Ileal Conduit	t(53)
<i>Belonging</i>	8.91 (3.20)	9.79 (2.04)	1.28
<i>Environment</i>	9.37 (2.22)	12.21 (2.05)	4.99***
<i>Others</i>	13.25 (1.29)	13.23 (2.27)	< 1
<i>Creativity</i>	12.21 (1.44)	9.94 (2.53)	3.94***
<i>Finance</i>	8.39 (0.63)	7.97 (1.74)	1.11
<i>Health</i>	10.22 (1.86)	8.87 (1.92)	2.09
<i>Humility</i>	9.04 (1.65)	11.42 (1.96)	4.06***
<i>Independence</i>	11.21 (1.02)	9.72 (2.89)	2.38**
<i>Loyalty</i>	10.62 (1.24)	12.59 (1.61)	4.99***
<i>Privacy</i>	10.51 (2.56)	11.49 (2.06)	1.69
<i>Responsibility</i>	14.25 (0.71)	13.59 (1.78)	1.72
<i>Science</i>	12.50 (1.28)	10.41 (1.86)	4.75***
<i>Spirituality</i>	7.56 (3.75)	5.89 (4.11)	1.58

** $p < .01$; *** $p < .001$

Figure 1: Mean functioning scores for the EORTC QLQ-30 for the groups choosing NB and IC.

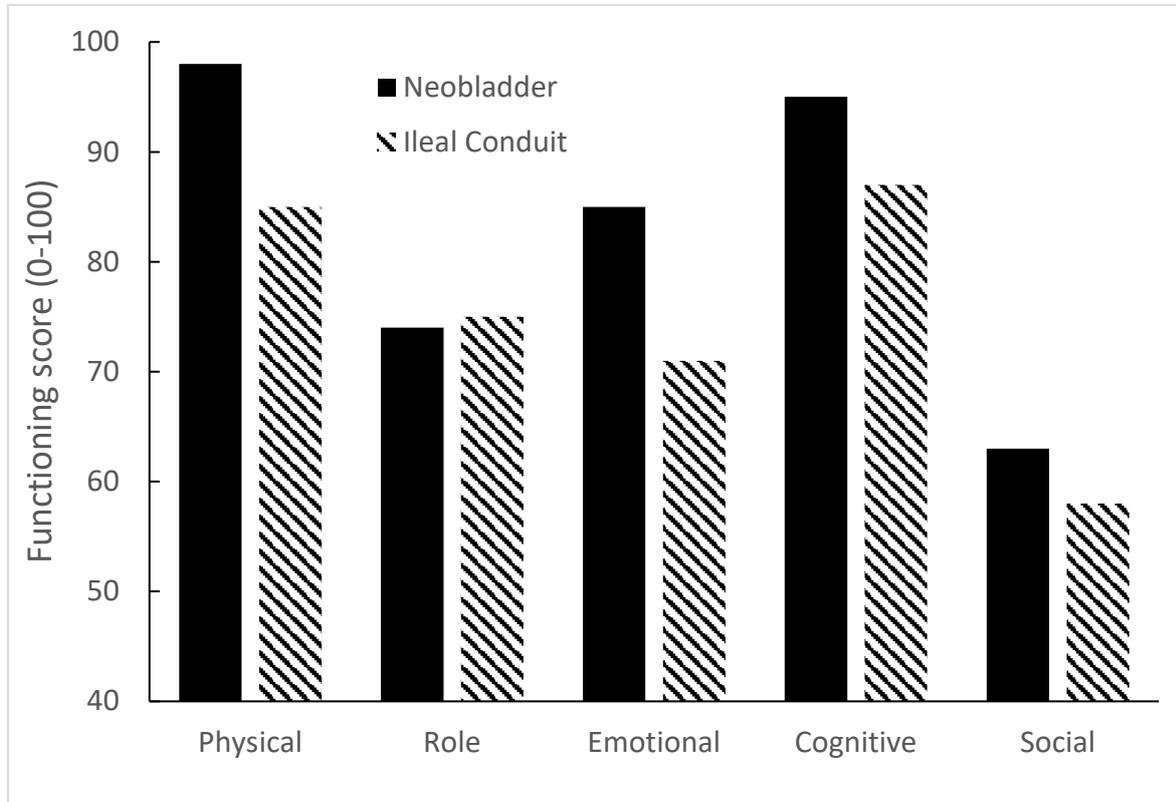


Figure 2: Mean life aspects identified as important prior to surgery according to the Satisfaction with Bladder Reconstruction questionnaire.

