Experiences After a Radical Cystectomy for Bladder Cancer: An Interpretative Phenomenological Analysis

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Thesis Declaration Form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Date: 13/06/2024

Overview

Medical and surgical advances have made it possible for more people to live longer with and beyond cancer, however, the long-term side effects from treatments that make prolonged life possible pose new challenges (Macmillan Cancer Support, 2013). This thesis explores patient experiences of bladder cancer and one of its treatments, the radical cystectomy (RC), which involves the removal of the bladder and often some surrounding areas.

Part 1 is a systematic review of 24 quantitative and qualitative studies, using narrative synthesis. The review aimed to understand how bladder cancer and its treatments impact body image and feelings of femininity/masculinity. Findings from the review of quantitative studies indicated a higher risk of poor body image among female patients, patients who have undergone an RC, patients with an ileal conduit, and patients with a more sedentary lifestyle. It was noted that quantitative studies on femininity/masculinity were absent from the literature. Findings from the review of qualitative studies generated three themes: "*A Lack of Space for the Sharing of Female Experiences", "Visual and Functional Changes From Treatment Undermining One's Sense of Femininity and Masculinity",* and *"Visual and Functional Changes From Treatment Undermining Body Image and Sense of Attractiveness"*.

Part 2 is a qualitative study of how changes resulting from an RC for bladder cancer are experienced by individuals, that uses Interpretative Phenomenological Analysis (IPA). Semi-structured interviews with six participants who had undergone an RC resulted in four superordinate themes: "*Ways of Coping", "Narratives Around One's Bladder, Stoma, and Body", "Relationships to Others",* and *"The Role of Information"*. Part 2 concludes with a discussion of the main findings, along with the limitations and implications of this research.

Part 3 is a critical appraisal of Part 2 which aims to demonstrate reflexivity undertaken during the research process. Influences on the research at various stages are explored, along with challenges and limitations that arose, and the impact of the research on my own views.

Impact Statement

This thesis contributes to the literature on bladder cancer by providing a voice to individuals to share their experiences of a radical cystectomy (RC). Findings from the empirical paper indicate the importance of empowering individuals to actively take ownership of their stoma management and the value of taking an accepting stance around changes that occur after an RC. Moreover, findings demonstrate the benefit of cognitively reappraising the procedure as a life-saving measure if patients struggle with adjustment. The empirical paper also recommends themes for psychological therapists to consider exploring when they support individuals who have undergone an RC, namely loss, existential fears, decisional regret and self-blame, and control. Also highlighted is the need for healthcare professionals to provide tailored, patient-centred information so that patients receive the right amount of information at the right time and in a format that works well for them. Findings also point to the value of normalising the long-term nature of adjustment after an RC, as well as the varied ways in which individuals respond to each stage of the process.

The systematic review illustrates a gap in the literature around feelings of femininity/masculinity after undergoing bladder cancer treatments. The systematic review also summarises risk factors for worsened body image after treatment. Recommendations emerge from the review calling for the development of a preventative self-help psychological intervention for bladder cancer patients at risk of developing poor body image. Additionally, the findings suggest that for patients who experience threats to their body image or sense of femininity/masculinity, psychological therapists should support them in deconstructing gender or appearance ideals that they might be affected by.

Finally, the planned dissemination of these findings aims to increase bladder cancer’s profile in research and among the public.

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Part 1: Literature Review

The Impact of Bladder Cancer and its Treatments on Femininity, Masculinity, and Body Image: A Systematic Review

Abstract

Aims: This review aimed to synthesise quantitative and qualitative research on the impact of bladder cancer and its treatments on feelings of femininity/masculinity and body image.

Method: A systematic review was conducted in October 2023 across three electronic databases (MEDLINE, PsycINFO, and Web of Science). Selected studies underwent quality assessment, followed by narrative synthesis, including thematic synthesis of the qualitative studies.

Results: Of the 5775 papers initially identified, 24 were included in this systematic review. Findings from quantitative studies indicated negative changes to body image after an RC for bladder cancer, with women facing a higher risk than men of such changes. An absence of quantitative literature on feelings of femininity/ masculinity was identified. From qualitative studies, three themes emerged: "*A Lack of Space for the Sharing of Female Experiences", "Visual and Functional Changes from Treatment Undermining One's Sense of Femininity and Masculinity",* and *"Visual and Functional Changes From Treatment Undermining Body Image and Sense of Attractiveness"*.

Conclusion: This review's findings demonstrated the need to explore body image in psychological assessments and psychotherapeutic interventions provided for bladder cancer patients. Findings also indicated that research ought to focus specifically on understanding bladder cancer experiences of femininity/masculinity given the gap in the literature.

Introduction

In the United Kingdom (UK), more than 10,000 people receive a bladder cancer diagnosis each year. Positioned as the 11th most common cancer among people in the UK, bladder cancer has the ninth highest rate of cancer mortality, with estimates of 46.3% of affected individuals surviving for over 10 years (Cancer Research UK, n.d.). Bladder cancer affects mostly men (73% of cases) and those aged 75 years old and over (56% of cases) (Cancer Research UK, n.d). Common treatments for bladder cancer include a transurethral resection of a bladder tumour (TURBT), chemotherapy, radiotherapy, immunotherapy, and a radical cystectomy (RC) (Macmillan Cancer Support, 2022).

The Impact of Bladder Cancer on Quality of Life and Mental Health

Individuals with bladder cancer have worse health-related quality of life (HRQL) than the general population and individuals with other pelvic cancers (Catto et al., 2021). Literature yields contrasting findings on the predictors of poorer HRQL. Those recently diagnosed or living with disease recurrence or metastasis can demonstrate a poorer quality of life than those who have completed treatment (Chung et al., 2019). Conversely, other findings suggest that treatment and disease stage do not predict the extent of this. Instead, poorer HRQL is more likely to be reported by younger patients (due to financial concerns), individuals living with comorbidities, and male patients experiencing sexual dysfunction (Catto et al., 2021).

In comparison to other urological cancer patients awaiting treatment, those with bladder cancer who are due to undergo an RC demonstrate the highest anxiety, indicating the fears associated with the procedure itself and the changes that can occur afterwards (Pastore et al., 2017). An RC removes the entire bladder along with nearby lymph nodes, the prostate glands, and seminal vesicles or the womb, fallopian tubes, the ovaries and some of the vagina. Once the bladder is removed, either a urostomy/ileal conduit (an external bag that collects urine) or a neobladder (bladder reconstruction) is created to pass urine. Informational needs of bladder cancer patients vary, from requiring medical information (e.g. on treatments and side effects) to practical information (e.g. frequency of appointments). Unmet supportive care needs of patients are highest among those who had recently been diagnosed with bladder cancer, despite this group having the most contact with medical and nursing teams (Chung et al., 2019).

There is a high prevalence of depression (77.5%), anxiety (69.3%), and post-traumatic stress disorder (PTSD) (resulting from both the diagnosis of cancer and the treatment) (25.2%) among patients with a recent bladder or kidney cancer diagnosis. Patients perceived social support has been associated with all three of these mental health conditions (Yang et al., 2016). A worsened bladder cancer prognosis is associated with more severe depression and anxiety, which are often present from the point of diagnosis. Moreover, bladder cancer patients face a higher risk of suicide, particularly those who are male, single, older, and live with poorer stages of the disease. The relationship between mental health and bladder cancer prognosis appears to be bidirectional; mental health problems have the potential to increase the risk of complications after surgery, along with other outcomes related to survival (Pham et al., 2019). Additional predictors of psychological well-being in bladder cancer patients include length of disease, income, cancer-related uncertainty, perceptions of one’s functioning and health care, and perceptions of family and social support (Heyes & Bond, 2020; Jung et al., 2022; Zhang et al., 2020).

Femininity, Masculinity, and Body Image

Despite literature existing on the effects of bladder cancer on general mental health and quality of life, we have a poor understanding of how it impacts feelings of femininity and masculinity. This understanding is important as illness can threaten roles and behaviours that individuals subscribe to because of their socialised gender, for example, masculine ideals of independence and strength that can become undermined by physical weakness and vulnerability (Pudrovska, 2010). Additionally, feelings of femininity/masculinity are related to body image. Our social environments contain ideals on body appearance that are largely based on gender, therefore, body image is influenced through the comparisons made between these ideals and one's perception of one's own body (Calogero & Thompson, 2010).

We have somewhat of an understanding of how bladder cancer influences body image, however, studies mostly consist of quantitative designs that use outcome measures, which limits our understanding of body image to what is captured by these measures (Hedgepeth et al., 2010; Somani et al., 2009). These aspects of experience are relevant to the understanding of bladder cancer, as illness often changes the appearance and functioning of one's body, which can result in alterations to body image (Striegel-Moore et al., 2002). It is important to have a thorough understanding and be able to support individuals with poor body image to prevent associated problems such as eating disorders (McLean and Paxton, 2019; Rodgers et al., 2011), depression (Brausch and Gutierrez, 2009; Prusaczyk and Choma, 2018), and low self-esteem (Amaral and Ferreira, 2017).

The relationships between bladder cancer and its treatments and body image and femininity/masculinity are important to establish because prior research demonstrates that both are linked to mental health and quality of life among patients with other types of cancer. Brunet et al. (2022) investigated how breast cancer patients understood their experiences to have impacted body image. They identified that losing a breast from a mastectomy, weight changes, and scarring all contributed to poorer body image, which in turn contributed to lower mood. Changes to body image, self-esteem, sexual function, and self-perception of masculinity in prostate cancer patients can cause psychological distress, however, patients' ability to reformulate their definitions of masculinity and find other ways to connect with it help to cope with this (Bowie et al., 2022). After being diagnosed and treated for testicular cancer, some men feel less masculine, with those who were single and child-free being at an increased risk, which the authors suggest could be due to the lack of support and the absence of stereotypical roles to protect and provide for offspring. Findings also indicate that self-esteem and sense of security in relationships are affected by threats to masculinity in men with testicular cancer (Dax et al., 2022).

After prostate cancer treatments, patients can experience a reduced sense of masculinity because of erectile and ejaculation dysfunction, decreased libido, and urinary incontinence (Andreasson et al., 2023). Three masculine gender scripts have been outlined that hinder adjustment to prostate cancer treatment: self-reliance, emotional control, and sexual potency, which are important to consider in psychological interventions because of the distress associated with threats to these scripts (Burns & Mahalik, 2007). Patients who undergo a partial or radical penectomy due to penile cancer can also experience a sense of threat to their masculinity (Da Conceicao et al., 2022).

Some women report a reduced sense of femininity after a mastectomy for breast cancer, attributing this change to maternal and beauty ideals being threatened (Mansoor & Abid, 2020). On the other hand, some women decline breast reconstructions following mastectomies for breast cancer, partly due to the rejection of dominant ideas of femininity (La et al., 2019). Findings from breast cancer research therefore indicate that a nuanced exploration is required when researching cancer patients' experiences of femininity/masculinity, as meanings differ for each person.

Aims

Given that findings from research on other cancers and their treatments indicate that body image and feelings of masculinity/ femininity are affected, it is important to establish whether the same experiences exist for bladder cancer patients. As the experiences of bladder cancer treatments, particularly a RC, are unique due to changes to urinary function and often the introduction of a new means to pass urine, it is important to understand these as distinct experiences, rather than making generalisations from research on other types of cancer and their treatments. Exploring experiences of an RC in more depth would provide an understanding of how to support bladder cancer patients more effectively through formal psychological therapy or informal psychological support from other healthcare professionals. This research has never been synthesised before; thus, it is hard to draw clear conclusions from the studies that do exist in the area. A systematic review can overcome this obstacle, as it is designed to identify studies and synthesise findings using a clear methodology. Therefore, a systematic review was conducted on the impact of bladder cancer and its treatments on femininity/masculinity and body image to understand this area better. To the author's knowledge, this was the first systematic review to answer this question for bladder cancer patients.

Methods

The review was registered on Prospero (PROSPERO CRD42023466322).

Search Strategy

The review searched across three electronic databases (MEDLINE, PsycINFO, and Web of Science) in October 2023. Appendix 1 contains a list of search terms used in each database for this review.

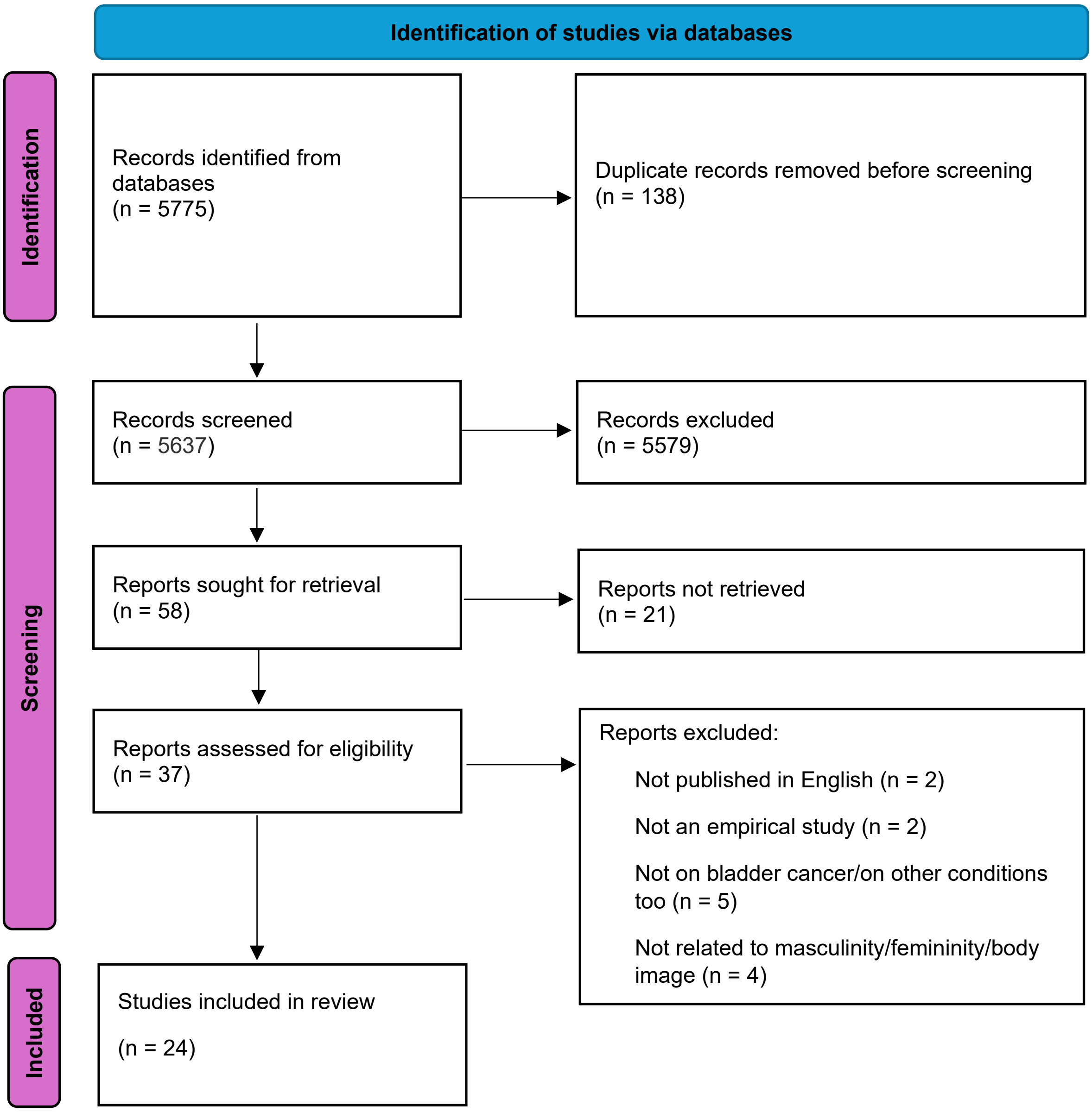
Studies on adults with non-metastatic bladder cancer were included in the review to ensure that the effects of cancer metastasis in other regions of the body were not being confounded with the effects of bladder cancer. Only English language publications were included due to a lack of translation resources, and there was no restriction on publication date as a large volume of papers was not expected to be obtained from the search. Both quantitative and qualitative empirical studies of all designs were included. Studies exploring a sense of masculinity, femininity, self-concept/self-image, and body image were included, and studies without mention of any one of these themes were excluded.

I screened titles and abstracts of all papers generated in the search, applying the inclusion and exclusion criteria. I then screened papers deemed relevant in the full-text screening using the same criteria.

The search strategy generated 5775 papers as possibly relevant to the review question. Endnote removed 79 duplicate papers, and then I removed a further 59 duplicate papers manually. 5637 papers were screened at the stage of title and abstract screening, and 58 papers were included at full-text screening, however, 21 papers could not be retrieved as they were abstracts for conference presentations. Papers were then excluded after full-text screening for the following reasons: not being published in English (n = 2), not being an empirical study (n = 2), not being on bladder cancer or being on additional conditions (n = 5), and not relating to masculinity/femininity/body image (n = 4). As a result, 24 papers were included in the systematic review. Figure 1 contains the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) Flowchart for the identification process.

Figure 1

PRISMA Flowchart



Quality Assessment

Papers deemed eligible after the full-text screening were assessed for quality by two reviewers using *QualSyst*, which provides checklists for both quantitative and qualitative studies (Kmet et al., 2004). All studies were rated above 55% (the recommended exclusion cut-off) by both reviewers in the quality assessment, and thus, none were excluded from this review. Appendix 2 contains the quality assessment ratings from each reviewer for all studies eligible after full-text screening.

Data Analysis

A narrative synthesis combined data from the studies due to the expected heterogeneity across their designs. Studies were grouped firstly by either qualitative or quantitative design. Then qualitative studies were sub-grouped by themes based on their focus, for example, masculinity, whilst quantitative studies were sub-grouped according to the measures they used. Synthesis of data from qualitative studies was based on thematic synthesis (Thomas & Harden, 2008) to generate descriptive codes and themes.

Results

Table 1 presents a summary of the 24 studies included in this systematic review.

Table 1

Summary of Studies Included in the Systematic Review

Author	Study location	Study design	Sample size	Demographics	Outcomes measure	Key findings
Aboumohamed et al. (2014)	US	Quantitative	182	Gender: 134 men, 48 women Median age = 71.5 Ethnicity: Not reported	BCI, BIS	No significant difference in health-related quality of life (HRQL) measured by BCI and BIS between surgical or diversion techniques of the RC. Better sexual function experienced over time in participants with an open RC.
Bahlburg et al. (2023)	Germany	Quantitative	842	Gender: 683 men, 159 women Median age = 68 Ethnicity: Not reported	EORTC QLQ-C30, EORTC QLQ-BLM30, QSC-R10	Significant improvements in quality of life one-year post-RC, although psychosocial distress is high one-year post-RC for several participants.
Ben Hassine et al. (2019)	Tunisia	Quantitative	40	Gender: 40 men, 0 women Average age = 68 Ethnicity: Not reported	Stoma Quality of Life Questionnaire, IIEF	Low quality of life scores for 77.5% participants. Sexual dysfunction experienced by all participants after a cystoprostatectomy.
Bjerre et al. (1995)	Denmark	Quantitative	67	Gender: 67 men, 0 women Median age: Ileal conduit group = 68.2, bladder substitution group = 64.8	Survey designed within study	HRQL after a cystectomy better among participants with bladder substitution than for those with an ileal conduit.

				Ethnicity: Not reported		
Bjerre et al. (1998)	Denmark	Quantitative	76	Gender: 76 men, 0 women Median age: Ileal conduit group = 68.7, bladder substitution group = 64.5 Ethnicity: Not reported	Survey designed within study	Increased need for sexual counselling after a cystectomy in the ileal conduit group than in the bladder substitution group. Older participants are more likely to become unable to orgasm and sexually inactive. Increased feelings of sexual unattractiveness among participants who experienced radiation or impotence treatment.
Clements et al. (2022)	US	Quantitative	411	Gender: 323 men, 88 women Average age: Continent diversion group = 62, Ileal conduit group = 72 Ethnicity: 381 White, 13 = Black, 8 = Asian	EORTC QLQ-C30, EORTC QLQ-BLM30, EORTC QLQ-CR38, Female Sexual Functioning Index, IIEF, Urinary Distress Inventory, Incontinence Impact Questionnaire, American Urological Association Symptom Score, MSKCC Bowel Function Questionnaire, Decisional Conflict Scale, Satisfaction with Life Scale, Fear of Recurrence Questionnaire, Mental Health Inventory, Functional Assessment of Chronic Illness Therapy	Most areas of HRQL improve by 24 months post-RC other than body image for those with an ileal conduit, and sexual function for those with a conduit or continent diversion
Gacci et al. (2013)	Italy	Quantitative	37	Gender: 0 men, 37 women	EORTC QLQ-C30, EORTC QLQ-BLM30, FACT-BL	Women who undergo a cutaneous urostomy display poorer HRQL due

				Mean age: At surgery = 67.3, at follow-up = 73.1 Ethnicity: Not reported		to deterioration of body image, compared to women who undergo a Bricker or Paduan ileal neobladder.
Hart et al. (1999)	US	Quantitative	224	Gender: 171 men, 53 women Mean age: Ileal conduit group = 76.2, cutaneous Kock pouch group = 70.6, urethral Kock pouch = 67.3 Ethnicity: Not reported	Profile of Mood States, Sexual History Form, Body Image Dissatisfaction Scale, Quality of Life Questionnaire	Longer term quality of life is good one-year post-RC, with no significant difference between type of urinary diversion, which is possibly due to choice over diversion rather than the actual type of diversion being the strongest predictor of quality of life.
Hart (1997)	US	Quantitative	224	Gender: 170 men, 54 women Mean age: 69.6 Ethnicity: 93.1% Caucasian, 6.9% ethnicity not specified	Profile of Mood States, Sexual History Form, Body Image Dissatisfaction Scale, Quality of Life Questionnaire, Dyadic Adjustment Scale	Appraisal of changes post-RC impacts psychological adjustment.
Hedgepeth et al. (2010)	US	Quantitative	336	Gender: 290 men, 55 women Mean age: 67.53 Ethnicity: 324 White, 21 “Non-White”	BCI, BIS	Body image is significantly impacted by an RC but improves with time.
Huang et al. (2015)	China	Quantitative	294	Gender: Mixed, split not reported Mean age: 63.8 Ethnicity: Not reported	BCI, BIS	Significantly better BIS scores are observed among the neobladder group than ileal conduit group at one-year post-RC, but longer term, no

						significant difference can be observed.
Imbimbo et al. (2015)	Italy	Quantitative	174	Gender: 159 men, 15 women Median age: 66 Ethnicity: Not reported	QLQ-C30, QLQ-BLM30, IONB-PRO	Post-RC HRQL is impacted by age, urinary incontinence, follow-up time and comorbidities.
Karvinen et al. (2007)	Canada	Quantitative	525	Gender: 392 men, 133 women Mean age: 70.2 Ethnicity: Caucasian = 515, Native/Metis = 7, Asian 0= 3	Leisure Score Index from the Godin Leisure Time Exercise Questionnaire, FACT-BL, Fatigue Symptom Inventory	Quality of life and exercise are positively correlated in bladder cancer survivors.
Poch et al. (2014)	US	Quantitative	113	Gender: 88 men, 25 women Mean age: 68.78 Ethnicity: White = 110, Black = 3	BCI, BIS	Urinary and bowel functioning recover by six months post-RC. Sexual function is mostly greatly impacted post-RC but recovers by 24 months. No significant changes to body image other than at four to 10 months post-RC.
Shim et al. (2014)	South Korea	Quantitative	42	Gender: 32 men, 10 women Mean age: 67.4 Ethnicity: Not reported	BIS, study-specific questionnaire on urinary function	Patients with an orthotopic ileal neobladder displayed better body image than those with an ileal conduit.
Volz et al. (2022)	Germany	Quantitative	382	Gender: 290 men, 92 women Mean age: 68.7 Ethnicity: Not reported	EORTC QLQ-C30, FACT-BL, QLQ-BLM30	No significant long-term differences in general and bladder-cancer specific HRQL.

Zou et al. (2022)	China	Quantitative	170	Gender: 126 men, 44 women Age: Not reported Ethnicity: Not reported	30-item questionnaire was used to evaluate the KAP (knowledge, attitude, practice), WHOQOL-100	Heider balance appears to reduce complication rates and increase KAP and quality of life.
Fitch et al. (2010)	Canada	Qualitative	22	Gender: 13 men, 9 women Average age: 68 Ethnicity: Not reported	Qualitative Description	Changes in body image, bodily function and sexual relationships can be challenging post-RC.
Gupta et al. (2021)	US	Qualitative	22	Gender: 0 men, 22 women Median age: Pre-operative group = 69, post-operative group = 67.5 Ethnicity: 20 = white, 2 = ethnicity not specified	Qualitative Description	Changes to body image, psychological distress and sexual function are experienced post-RC. Sexual health counselling and education provisions are inadequate.
Kandemir & Oskay (2017)	Turkey	Qualitative	20	Gender: 10 men, 10 women Mean age: 58.75 Ethnicity: Not reported	Content Analysis	Urostomy negatively impacts sexual function, and patients experience a lack of support from healthcare professionals.
Mohamed et al. (2014)	US	Qualitative	30	Gender: 22 men, 8 women Mean age: 67 Ethnicity: White = 30	Content Analysis	Informational and psychological unmet needs exist at diagnosis; medical and instrumental needs exist post-RC.

Osborne et al. (2016)	UK	Qualitative	32	Gender: 20 men, 12 women Mean age: 64.75 Ethnicity: Not reported	Content Analysis	Restrictiveness of activities and urinary incontinence were among reasons behind patients' choices between ileal conduit or neobladder post-RC. Body image played a greater role in the choice for female patients.
Villa et al. (2018)	Italy	Qualitative	11	Gender: 9 men, 2 women Mean age: 69 Ethnicity: Not reported	Interpretative Phenomenological Analysis	Themes of the impact of surgery, body image, daily activities and socialising, stoma and sexuality, education on managing stoma, support from family and friends after undergoing a urostomy.
Yi et al. (2022)	South Korea	Qualitative	9	Gender: 7 men, 2 women Mean age: 67.89 Ethnicity: Not reported	Thematic Analysis	Themes of "*confusion with bodily changes*," "*loss of daily life as it was before radical cystectomy*," "*feeling grateful for life*" after an RC.

Note. The following abbreviations are used to denote outcome measures: BCI (Bladder Cancer Index), BIS (Body Image Scale), (EORTC QLQ BLM30) European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire – Muscle Invasive Bladder Cancer, EORTC QLQ C30 (European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire – Core), EORTC QLQ-CR38 (European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire – Colorectal Cancer), FACT-BL (Functional Assessment of Cancer Therapy – Bladder), FSFI (Female

Sexual Functioning Index), IIEF (International Index of Erectile Function), IONB-PRO (Ileal Orthotopic Neobladder – Patient Report Outcome), QSC R10 (Questionnaire on Stress in Cancer Patients), WHOQOL-100 (WHO Quality of Life-100).

Quantitative Studies

A total of 17 eligible quantitative studies were identified from the screening process. None of the identified quantitative studies reported directly on masculinity or femininity, so the following results reflect reports of body image. Five of the eligible studies reported on body image using the Body Image Scale (BIS) (Hopwood et al., 2001); Five studies used the Quality of Life Questionnaire for Muscle Invasive Bladder Cancer (QLQ-BLM30) (Danna et al., 2016); Two studies used the Body Image Dissatisfaction Scale (Berscheid et al., 1973); Two studies used questionnaires developed by the researchers as part of the study; One study used the FACT-Bl (Functional Assessment of Cancer Therapy – Bladder) (FACIT, n.d.); One study used the Stoma Quality of Life Scale (Baxter et al., 2006); Finally, one study used the World Health Organization Quality of Life assessment (WHOQOL-100) (Skevington, 1999).

Studies Using the BIS

Hedgepeth et al. (2010) found that neobladder and urostomy patients have worse body image after an RC compared to cystoscopy patients who do not undergo an RC, however, this improves over a long-term period ($p = 0.02$). Aboumohamed et al. (2014) reported no significant difference in body image between patients who underwent robotic-assisted and open RC ($p = 1.0$). Poch et al. (2014) found that after a robot-assisted (RC) the only significant change to patient body image was at four to 10 months post-RC ($p = 0.02$). Huang et al. (2015) reported that at one-year post-RC, ileal conduit patients displayed worse body image compared to neobladder patients ($p = 0.003$), although this difference was not significant at follow-ups beyond one year ($p = 0.11$). Shim et al. (2014) found that patients with an ileal neobladder had better body image than patients with ileal conduit post-RC ($p < 0.001$).

Studies Using the QLQ-BLM30

Bahlburg et al. (2023) found that scores on the body image domain of the QLQ-BLM30 worsened significantly between the end of an inpatient rehabilitation admission post-RC, and six months post-RC in both groups (ileal conduit and neobladder patients) ($p < 0.001$). They reported that body image improved significantly for those with neobladder at 12 months post-RC, and non-significantly for those with an ileal conduit.

Clements et al. (2022) reported stability of scores on the body image domain of the QLQ-BLM30 among participants with a continent diversion after an RC, however, participants with an ileal conduit after an RC showed persistent worsening of body image scores from three months post-RC. Women who undergo a cutaneous ureterostomy (CUS) display worse body image scores on the QLQ-BLM30 than those who undergo a Bricker or Paduan ileal neobladder, however, these differences were not statistically significant (Gacci et al., 2013).

Conversely, Volz et al. (2022) found that for patients who had undergone an RC with urinary diversion, there was no significant difference between body image scores on the QLQ-BLM30 of neobladder and conduit patients. Worsened body image (measured by QLQ-BLM30) in patients who undergo an RC with an Orthotopic Ileal Neobladder can be predicted by age (>65 years), absence of urinary incontinence, and peripheral vascular disease (Imbimbo et al., 2015).

Studies Using the Body Image Dissatisfaction Scale

Female patients who have undergone an RC for bladder cancer report worse body image, measured using the Body Image Dissatisfaction Scale, and lower sexual desire than male patients ($p < 0.001$) (Hart et al.,1999). Another study using the Body Image Dissatisfaction Scale explored the impact of negative appraisals made by bladder cancer patients who have undergone an RC on emotional distress (Hart, 1997). The study identified that 31.2% of participants expressed dissatisfaction with at least one of four areas of body image, and 21% expressed dissatisfaction with just one area.

Studies Using a Self-Developed Survey

A study comparing HRQOL between male bladder cancer patients who have undergone a bladder substitution versus those who have undergone an ileal conduit was conducted by Bjerre et al. (1995). This study developed its own quality of life questionnaire, containing a domain assessing body image, which identified that bladder substitution patients displayed post-operative body image scores closer to their pre-operative scores than the ileal conduit patients, however, this difference was not significant ($p = 0.26$). A later study by Bjerre et al. (1998), using the same quality of life questionnaire, looked at sexual well-being problems in male patients following an RC. The findings revealed that 23% of ileal conduit patients reported being less sexually active due to feeling less sexually attractive than before the operation, and 19% of bladder substitution patients reported the same.

Studies Using the WHOQOL-100

Zou et al. (2022) evaluated the impact of a Heider Balance intervention (aiming to shift attitudes and behaviours in response to identified cognitive dissonance around urostomy care) on quality of life among male and female bladder cancer patients who had undergone a urinary diversion. At six months post-hospital discharge, those who had received the Heider Balance intervention displayed significantly better body image than the control group ($p = 0.006$).

Studies Using the FACT-BI

A positive association between exercise and body image has been identified (Karvinen et al., 2007). Male and female participants who had survived bladder cancer and met exercise guidelines demonstrated significantly better body image ($p < 0.001$), assessed using the FACT-BI compared to participants who were completely sedentary.

Studies Using the Stoma Quality of Life Scale

Investigating quality of life after a total cystoprostatectomy (removal of bladder and prostate gland) in male bladder cancer patients, Ben Hassine et al. (2019) found that the urostomy bag always limited the choice of clothes for 52.5% of participants. Findings also indicated that the stoma made 70.0% of participants always feel sexually unattractive, and 60.0% always embarrassed about their bodies. 40.0% reported that they always found the urostomy bag challenging to conceal.

Summary of Quantitative Studies

Overall, the findings from the quantitative studies included in this review suggest that a significant proportion of patients experience negative changes to their body image after an RC for bladder cancer and that women are at a higher risk than men of such changes. Regardless of whether patients have a neobladder or ileal conduit after their RC, body image is worse for both groups compared to those who do not have an RC. Improvements to body image occur longer-term, suggesting some adjustment to changes from the procedure. Findings indicate that there does not appear to be a difference in body image between patients who undergo a robotic-assisted or open RC, and for those who undergo a robotic-assisted RC, worsened body image does not persist beyond 10 months. Results on the body image differences between patients with an ileal conduit versus a neobladder generally indicate that patients with an ileal conduit have poorer body image, be that due to feeling less sexually attractive, limited in choice of clothes, and a sense of embarrassment over one's body. Exercise is associated with improved body image, and worsened body image is predicted by age, urinary incontinence, and peripheral vascular disease.

Qualitative Studies

Seven qualitative studies were considered eligible for this review after full-text screening. Through the process of thematic synthesis of the selected studies that I conducted, initial coding and descriptive qualitative themes were generated. This resulted in three analytical themes emerging: "*A Lack of Space for the Sharing of Female Experiences", "Visual and Functional Changes From Treatment Undermining One's Sense of Femininity and Masculinity",* and *"Visual and Functional Changes From Treatment Undermining Body Image and Sense of Attractiveness"*.

Theme One: A Lack of Space for the Sharing of Female Experiences

Bladder cancer is less common in women than in men, and this appeared to influence patient experiences of peer support spaces: "Some participants described the experience of being a female BCa patient as isolating and had utilised social media or online resources to connect with other female patients." (Gupta et al., 2021). For women with bladder cancer who had attended peer support groups, there was a sense that these spaces prioritised the discussion of men's experiences, with the suggestion that women did not feel comfortable sharing their perspective on the discussed issues, such as sexual function, in mixed-gender spaces: "One participant conveyed frustration with existing BCa support groups that exclusively discussed men's sexual health." (Gupta et al., 2021). This was reinforced by the report that:

“I think a small group of just women, women would be more focused on specific women’s issues ... I’m sorry, but it’s different. And no matter what, even though it’s a girl issue what will come up will be the Viagra dosage...So whenever you talk about sexual function for men they’re already fully engaged in the whole conversation. For women, it’s more like, well, we’re not really getting there. “No, the doctor hasn’t given many pumps. He hasn’t given me that medical dosage of Viagra”” (Gupta et al., 2021).

This indicated that conversations about female sexuality and femininity that are altered by bladder cancer and its treatments have not advanced in services and support groups as they have for men. It is likely that for this reason, affected women seek information and connection online. There also appeared to be a stigma attached to sharing female experiences of sexuality even with healthcare professionals: “Maybe we could go to Urology service again, but we feel shy. We cannot talk to anyone; we even do not know how to ask such thing” (Kandemir & Oskay, 2017). Furthermore, the idea that "we have got used to living like this" (Kandemir & Oskay, 2017) speaks to the cost of the stigma and the perception that adequate spaces to share experiences do not exist; Individuals feel forced to tolerate their challenges alone, and perhaps minimise what they are going through as it becomes the norm.

Theme Two: Visual and functional changes from treatment undermining one’s sense of femininity and masculinity

Sense of femininity following bladder cancer treatment was undermined in different ways for patients, for example through visual changes such as hair loss:

“I hate the fact that I lost all my hair with the chemo…it’s just part of a woman’s self-image having hair, and then all of a sudden when you look in the mirror and you see a bald head it just is unsettling” (Gupta et al., 2021).

For others, a loss of femininity was through functional changes, such as how they urinated:

“You have to go to the bathroom like a male and it [the urostomy bag] sort of bounces back on your legs and splatters a little bit sometimes and these are things that I don’t enjoy. Especially in public places like a work environment, you know, quite honestly it [using a catheter to empty neobladder] sounds like you’re a man peeing in a urinal…and your feet are facing the wrong way.” (Gupta et al., 2021).

For some, having a urostomy bag threatened their femininity that was associated with youth, as one person described: “some expressed a fear of embarrassment from potential urostomy bag leakages or smelling “like an old lady.”” (Gupta et al., 2021). Moreover, the fear of a prospective romantic partner being disgusted by changes was present and seemed to be associated with perceived failings to meet gendered body ideals after an RC:

“If it was your husband and he loved you before... he’ll still love you. I don’t think a man will go out with a woman who had a, a hole in her stomach and, you know, a bag on her leg” (Fitch et al., 2010)

For men, reports focused more on sexual function and the possible impact of erectile dysfunction and reduced libido on masculinity. For some, communication and changes to how they engaged in sexual activity helped with these challenges. Furthermore, expressions of weakness and frailty were reported, which possibility connected to fears of emasculation: “I hope they don't pity me but that they accept me… although, it depends on each person's mentality… I have friends who don't even notice it… friends who look at me and say “poor man” (Villa et al., 2018).

Theme Three: Visual and Functional Changes From Treatment Undermining Body Image and Sense of Attractiveness

The impact of the urostomy bag on sense of attractiveness was discussed in several papers, from the appearance of the bag itself, to the connotation with bodily fluids:

“It’s changing the way your body looks forever and there’s nothing you can do about it...having a bag on the outside is certainly not attractive...everybody wants to look as natural as you can, when you go out in public, you don’t want anybody to be able to tell that you have this problem” (Gupta et al., 2021).

There were also reports of how the urostomy bag impacted choice of clothes, which affected body image: “Not being able to wear trousers, having to wear tracksuits day and night still makes me feel uncomfortable” (Kandemir & Oskay, 2017); Additionally, the urostomy bag created a visible bulge of the bag underneath clothing, further affecting individuals’ body image.

Some people talked about the urostomy bag also being a barrier to sexual intimacy, because of its visual appearance:

“Not in a million years would I let anybody close to me with this stoma and bag and all that—and my stomach, oh, I’m disgusting. How it looks… I mean I have a bag of pee hanging on the front of me. You know, like, I find it revolting. I’m sure anybody else would!” (Fitch et al., 2010).

Findings indicated that single people felt apprehensive about starting a new sexual relationship due to fears that the urostomy bag made than less attractive. There was also a sense of disgust and self-consciousness about the opening in the abdominal area:

“The only thing is that when I look at myself in the mirror when I'm changing my clothes, [I feel] a bit of discomfort from the aesthetic point of view. I mean, even from the approaching point of view with my wife, it's not a nice thing, it's that what psychologically disturbs me, it's what disturbs me more than anything else” (Villa et al., 2018); “I felt very ugly after and I still hate to look in the mirror...my whole abdomen changed” (Gupta et al., 2021).

Other bodily function changes also increased self-consciousness which possibly contributed to individuals’ sense of attractiveness: “I could not go anywhere because of uncontrollable gas.” (Yi et al., 2022).

Discussion

Main Findings

The review of quantitative studies provides insights into the impact of bladder cancer and its treatments on body image, highlighting the risk of worsened body image, particularly for women, those who undergo an RC, those with an ileal conduit, and those who have more sedentary lifestyles. It is also noted that improvements often occur longer-term.

Findings on improvements in body image over time are supported by the social-cognitive model of adjustment (Brennan, 2001). The model posits that humans develop an “assumptive world” and when our expectations are disconfirmed, this can elicit feelings of denial and stress, before we adjust our assumptions to incorporate our experiences. Bladder cancer patients’ body image likely reflected the incorporation of their altered physique or functioning into their “assumptive worlds” over time. Indications that women face a higher risk for poor body image after an RC could be reflective of the higher beauty standards and body ideals that exist in society for women compared to men (Buote et al., 2011).

There was an absence of quantitative literature on the sense of masculinity and femininity, and whether this is because it is a construct that is socially bound and thus, hard to quantify, or that it is not a significant part of individuals' experience as they navigate treatment and life after bladder cancer is not known.

The review of qualitative studies led to the emergence of three themes: "*A Lack of Space for the Sharing of Female Experiences", "Visual and Functional Changes from Treatment Undermining One's Sense of Femininity and Masculinity", and "Visual and Functional Changes From Treatment Undermining Body Image and Sense of Attractiveness"*. From the practical changes in how women had to urinate following an RC, to the impact on clothing choices and sexual function for both men and women, treatments for bladder cancer have the potential to undermine people's body image and sense of attractiveness, as well as their feelings of femininity/masculinity.

The first theme, *"A Lack of Space for the Sharing of Female Experiences",* speaks to the assumptions that are made about women's reduced libido and interest in sex being inevitable from menopause onwards (Rostosky & Travis, 2000), which could explain why healthcare professionals don't enquire about these issues. Additionally, research has established that barriers exist to healthcare professionals initiating conversations about sexual health with cancer patients, for example, a lack of time during consultations, assumptions about patients' sexuality, and feelings of discomfort (Canzona et al., 2018; Park et al., 2009; Sporn et al., 2015). If healthcare professionals are not discussing these issues with their female patients, the stigma is likely to be perpetuated.

The impact of bladder cancer and its treatments on femininity/masculinity was explored in the second theme: "*Visual and Functional Changes From Treatment*

Undermining One's Sense of Femininity and Masculinity". The expressed impact of hair loss on femininity is possibly connected to historical ideas about long hair representing health and fertility in women (Krishna, 2017). Furthermore, age and gender appear to interact, indicating a hierarchy of femininity, with youthful femininity positioned higher than being perceived "like an old lady" (Gupta et al., 2021).

Although experiences of femininity/masculinity were more prevalent than in the quantitative literature, they were still reported less compared to literature on other cancers e.g. prostate (Bowie et al., 2022), breast (Mansoor & Abid, 2020), and testicular (Dax et al., 2022). This might be because other challenges, such as incontinence/urostomy bag leakages or the high recurrence rates of bladder cancer could be more pertinent issues to affected individuals than femininity/masculinity. Moreover, it is possible that if data in the reviewed studies was collected at a later point in time, once participants had adjusted to the practical concerns, issues regarding femininity/masculinity could have been more predominant concerns longer-term.

Findings in the third theme, *"Visual and Functional Changes From Treatment Undermining Body Image and Sense of Attractiveness"*, can be understood in the context of other research. The desire to hide the bulge of the urostomy bag and look "natural" (Gupta et al., 2021) reflects pressures to adhere to social norms around appearance, which have been established to exist across genders and be exacerbated by mass media (O'Loughlin, 2013). Moreover, the impact of altered clothing choices after an RC on body image relates to findings that suggest that individuals use clothes to increase self-esteem, particularly when faced with emotional distress (Wenderski et al., 2024). As a result, it is likely that when this coping strategy is not possible due to body changes from an RC limiting clothing options, self-esteem will suffer.

Strengths and Limitations

One of the strengths of this review is the variety of studies included, from the study locations being across multiple continents, and thus, containing culturally diverse samples, to the study designs, with a mixture of quantitative and qualitative. The studies reviewed contain more male than female participants, however, this reflects bladder cancer patient demographics (Macmillan Cancer Support, 2022). The study is limited by only one person having screened and selected studies and analysed the data (including the thematic synthesis), thus leaving room for personal bias in which studies were selected and what data was attended to during the synthesis.

Implications

Findings from this review indicate the value of having conversations before bladder cancer treatments take place about the possible impact on body image with individuals who are at greater risk (women, those due to undergo an RC with an ileal conduit, and those with sedentary lifestyles). Having these conversations before treatment could help to manage expectations about how a patient’s body and their feelings about their body might change. Moreover, research could focus on developing a preventative self-help psychological intervention for bladder cancer patients at risk of developing poor body image resulting from treatments, which could incorporate principles from Brennan’s (2001) social-cognitive model of adjustment. Future research also ought to focus specifically on understanding bladder cancer experiences of femininity/masculinity or a comparative study on the sense of femininity/masculinity across different types of cancers.

In addition to this, healthcare professionals could ensure that they initiate conversations on sexual health with all patients, regardless of what their assumptions might be on the relevance of this. Peer support group facilitators could also assist by acknowledging gender differences in talking about sexual function changes if conversations are focused on male experiences, as well as consider the scope for setting up women-only peer support groups.

Therapists working with bladder cancer patients ought to consider body image during psychological assessment. Formulations could also include consideration of the impact of body ideals that might affect individuals, along with the intersection of gender and age and how this might contribute to psychological distress. Furthermore, therapists could work with patients affected by threats to femininity/masculinity and poor body image by exploring norms and ideals that hold influence, drawing on narrative therapy techniques of deconstructing where these ideals originated and what their functions are (White & Epston, 1990).

Conclusion

In conclusion, the findings from this systematic review indicate some of the effects of bladder cancer and its treatment on body image, however, more understanding is required to understand better the extent to which threats to femininity/masculinity are experienced.

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Part 2: Empirical Paper

Experiences Ater a Radical Cystectomy for Bladder Cancer: An Interpretative Phenomenological Analysis

Abstract

Aims: This study sought to explore individuals' experiences and sense-making of changes to body image, sexuality, and bodily function resulting from a radical cystectomy (RC) for bladder cancer, and how these changes affect their quality of life. By having a better understanding of the meanings of these experiences to those affected, this study aimed to highlight how psychological therapy can be tailored for individuals after an RC.

Method: Six adult participants who had undergone an RC for bladder cancer took part in semi-structured interviews which were then transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: Four superordinate themes were generated through the process of IPA: "*Ways of Coping*", "*Narratives Around One's Bladder, Stoma, and Body*", "*Relationships to Others*", and "*The Role of Information*". Cognitively reappraising challenges and making a deliberate choice to work towards acceptance were identified as helpful coping strategies.

Conclusion: The meaning of changes experienced after an RC varied between individuals. Consideration should be given by healthcare professionals and researchers to ways in which patients can process information about bladder cancer treatments before they make decisions, and how they can help to empower patients to feel able to find adaptations and acceptance after their RC.

Introduction

Context and Setting of Research

In the United Kingdom (UK), the National Health Service (NHS) provides free healthcare to its citizens, which includes the diagnosis and treatment of cancer. The current standards set by NHS England since October 2023 aim for individuals to have cancer ruled out or diagnosed within 28 days of referral, to start treatment within 62 days of an urgent referral, and to start treatment within 31 days of deciding to treat the cancer (National Health Service England, 2023). The NHS Long Term Plan (National Health Service, 2019) outlines its aims to increase the number of people surviving cancer for five or more years, and to ensure that more people are diagnosed at an earlier stage by 2028. In addition, the Long Term Plan sets out to develop an improved means of measuring the impact of cancer on quality of life.

National and global events shape the landscape in which NHS services operate. Oncological and psychological outcomes have been affected since the COVID-19 pandemic emerged in the UK, with cancer screening, urgent referrals, and the commencing of treatment often delayed (Roberts, 2021; Rucinska & Nawrocki, 2022). Increased feelings of depression and loneliness in cancer patients due to lockdown rules and the risks of acquiring COVID-19 were identified (Schellekens & van der Lee, 2020). Simultaneously, the ongoing nursing, doctor, and radiographer strikes have possibly exacerbated worries for patients about accessing treatment and support. Consequently, questions are raised about the impact of these longer waiting times and treatment disruptions taking place over the last few years on the minds and bodies of those living with cancer.

Along with cancer diagnosis and treatment, there is increasing demand for the NHS to provide treatment (both psychological and physical) for the longer-term side effects of cancer treatment, particularly as more people are living longer with cancer or having survived cancer. Macmillan Cancer Support (2013) raised pertinent questions about the negative consequences of cancer treatment on quality of life. Additionally, Hannah Fry explores the “over medicalisation” of cancer in the documentary *Making Sense of Cancer with Hannah Fry* (Bird, 2022), reflecting on her personal challenges with lymphoedema following treatment for cervical cancer.

Harvey (n.d.) talks about the obstacles commonly faced by individuals once their cancer treatments end and they look ahead to the future, such as living with the uncertainty of cancer recurrence and regaining control over one’s life. For these reasons, it is crucial that NHS clinicians understand the difficulties faced in life after treatment to support patients when these emerge, but also to inform patients of possible consequences before they make treatment decisions, to reduce decisional regret, which is associated with symptom burden (Goepfert et al., 2017). This promotion of shared and informed decision-making helps to create more realistic expectations of life after treatment, and thus better adjustment (Feldman-Stewart & Siemens, 2015).

Bladder Cancer and a Radical Cystectomy

Cancer Research UK (n.d.) reports that an average of 10, 292 new cases of bladder cancer emerge each year (between 2016-18), with prevalence higher in men (73% of cases) than in women (27% of cases) and increasing with age (56% of cases are 75 years old and over). One of the main treatments for bladder cancer is called a radical cystectomy (RC), which involves the removal of the entire bladder and surrounding lymph nodes. Depending on a patient’s reproductive organs, the prostate glands, and seminal vesicles are removed, or the womb, fallopian tubes, and occasionally the ovaries and some of the vagina. The removal of a bladder requires a new means to pass urine, which is usually made possible through either a urostomy/ileal conduit and a bag external to the body that collects urine or a neobladder (bladder reconstruction). The recovery period often involves complications resulting in a high number of hospital readmissions within 90 days of the procedure (Stimson et al., 2010). Longer-term, changes to urinary, bowel, and sexual function are common, such as incontinence, erectile dysfunction, pain during sex, and difficulty with orgasm (Bjerre et al., 1998; Escott et al., 2022; Hupe et al., 2018; Kretschmer et al., 2017). In response to these functional challenges, an organ-sparing RC has been developed which appears to improve urinary and sexual function, without any detriment to oncological outcomes (Tan et al., 2022).

Quality of Life After a Radical Cystectomy

Challenges often follow an RC for bladder cancer that threaten to undermine patients' quality of life, affecting several domains, ranging from financial and occupational aspects of life, to social and relational, and sexual and psychological (Donegan & Kingston, 2022; Siracusano et al., 2019; Somani et al., 2009). Furthermore, quality of life and emotional well-being can be influenced by the dynamic relationship between bladder cancer patients and their caregivers' emotional responses to the cancer (Masiero et al., 2021).

Patients' needs and priorities shift throughout treatment and are somewhat dependent on their stage of treatment. Unfortunately, this leads to unmet needs at key points, including psychological needs, particularly post-treatment as the longer-term effects of treatment become more apparent (Mohamed et al., 2014). Additionally, a discrepancy exists between the emotional and social needs of individuals and their use of healthcare services to support these (Rammant et al., 2022). Common mental health problems in bladder cancer patients, such as anxiety and depression, often occur from diagnosis onwards, with severity increasing as prognosis declines; suicidality increases as the stage of disease progresses, particularly among older, single men (Pham et al., 2019).

The challenges of adjusting to body image and bodily function changes after an RC, along with the impact on sexual intimacy have been identified (Fitch et al., 2010). Literature on body image after an RC yields mixed results, with some indication that body image gradually recovers with time (Hedgepeth et al., 2010), whilst other studies report its long-term impact on self-esteem (Medina-Rico et al., 2019).

Other difficulties can arise after an RC, for example, problems during sexual activity, and changes in partner responses such as avoiding sex and feeling dissatisfied with their sex life (Cohen, 1991; Kandemir & Oskay, 2017). In addition to this, individuals undergoing an RC are likely to experience worries about their sexual function and lack of sexual health information specific to their condition (Gupta et al., 2021), and often this is in relation to fears about their partner’s perception of their sexuality (Medina-Rico et al., 2019). A systematic review looking at the quality of life in patients with an ileal conduit following an RC reported a lack of research on sexual well-being; The review also recommended that future research take a qualitative approach to explore the impact on quality of life in greater depth (Donegan & Kingston, 2022). Coping with changes to bodily function after an RC, such as using and changing a urostomy bag (McMullen et al., 2019), and the time taken for stoma maintenance (Klein et al., 2021) is another challenge that can profoundly impact quality of life.

Although studies indicate that changes to body image, sexuality, and bodily function can affect an individual's quality of life after an RC, there remains the question of how patients make sense of these changes and what they mean to them and their lives.

Study Rationale, Aims and Research Questions

As mentioned before, the longer people live after a cancer diagnosis and treatment, the greater the need to understand the meaning of these experiences for affected individuals. Three key reasons why this is important for those undergoing an RC are firstly to assist with informed decision-making around possible consequences of treatment, secondly to facilitate the process of adjustment after the procedure by creating realistic expectations of changes, and thirdly to provide adequate psychological support after treatment by understanding in better detail the psychological experiences of patients; Psychological support may take the form of a low-intensity intervention from a Clinical Nurse Specialist (CNS), or high-intensity therapeutic intervention from a clinical psychologist or other psychological therapist. The role of stepped care in the psychological support of cancer patients is recommended by National Institute for Health and Care Excellence (NICE, 2004).

Relatively little research exists on bladder cancer in comparison to other cancers, such as prostate and breast, and most of the literature focuses on the medical and functional impact, rather than an in-depth exploration of psychological experiences. Obstacles to understanding how individuals experience changes after an RC exist; Many studies on experiences of an RC for bladder cancer use quantitative approaches through the administration of outcome measures such as the Female Sexual Function Index (FSFI) (Rosen et al., 2000), the International Index of Erectile Dysfunction (IIEF) (Rosen et al., 1997), the Body Image Scale (Hopwood et al., 2001), and the Functional Assessment of Cancer Therapy – Bladder – Cystectomy (FACT-Bl-Cys) (FACIT, n.d.). Whilst these outcome measures can identify the prevalence of certain changes after an RC, they can fail to capture the diversity of experiences and what these experiences mean to individuals. Additionally, whilst Fitch et al.'s (2010) study provides valuable insight into the experiences of people who had undergone an RC, it took place in Canada over a decade ago, and so does not reflect the current challenges and context in an ever-changing NHS where demands and available resources are in a state of flux. Fitch et al.'s (2010) study, along with other qualitative studies on RC experiences often come from healthcare disciplines other than clinical psychology, such as nursing, or countries outside of the UK. As Michael Larkin (2015, p. 250) writes "meaning is never context-free", thus it is important to understand these experiences of changes in the current UK context through a clinical psychology lens if we are to better support patients psychologically after an RC, be that through a low-intensity intervention during a CNS consultation, or a course of tailored, high-intensity psychological therapy. Furthermore, understanding individuals' experiences in greater detail prevents assumptions being made about patients' distress.

To answer this study's questions on how patients experience changes to body image, sexuality, and bodily function after an RC, Interpretative Phenomenological Analysis (IPA) was used to overcome these obstacles as it is concerned with participants experiences and meanings which may not be captured in quantitative studies using closed-question outcome measures. Furthermore, IPA's emphasis on idiography and inclusion of how participants diverge in their sense-making of experiences provided a different perspective from quantitative studies. IPA pays attention to the context that individuals are situated in, which allows for relevant factors such as the influence of the COVID-19 pandemic and the limited resources of the NHS to be considered when analysing how individuals make sense of their RC experiences at this present time. IPA and the use of semi-structured interviews to collect data enable answers to the questions that are interpretive rather than merely descriptive of what participants have said. Finally, the phenomenological epistemology underpinning IPA means that this study was interested in participants' idiosyncratic meaning-making of their life after an RC, rather than how much their experiences do or do not confirm the position of preexisting (often quantitative) studies which often take a positivist approach.

This study aimed to use IPA to circumvent the obstacles posed and to understand how individuals make sense of changes resulting from a radical cystectomy, namely body image, sexuality, and bodily function, and how these might affect individuals’ quality of life and sense of emotional wellbeing. The following research questions were explored:

- How do patients experience body image changes after an RC?
- How do patients experience changes in sexuality and sexual functioning after an RC?
- How do patients experience changes to bodily functioning after an RC?
- How do these experiences impact the quality of life after an RC?

Methods

Approach

IPA, the approach used in this study, was developed by Smith (1996) and seeks to understand how individuals make sense of their lived experiences, particularly those that feel significant to them. IPA assumes that individuals reflect their sense-making of experiences in how they talk about them, which provides material for researchers to interpret their meaning (Larkin et al., 2021; Smith, 1996). The three epistemological areas underpinning IPA are phenomenology, hermeneutics, and idiography, resulting in an approach that focuses in a highly detailed way on meaning-making done by individuals and seeks to find out how individuals in the sample converge, but also uniquely diverge during this process.

A phenomenological epistemology was considered appropriate for this study as it is interested in the subjectivity of human experiences (Husserl, 1970), welcoming multiple perspectives from participants in how they experience their bladder cancer and RC, rather than seeking to uncover a monolithic and objective reality experienced by all. Given that phenomenology seeks to explore not only what humans experience, but also how they understand their experiences (Heidegger et al., 1962; Van Manen, 2016), it was appropriate for this study which aimed to provide clinicians supporting those going through an RC with a better understanding of how patients perceive their experiences and the meanings they derive from them. Additionally, IPA was used in this study because it moves away from quantitative measures of quality of life and psychological well-being or distress; Instead, IPA allows the experiences of individuals to be captured using their own terms as opposed to language or categories defined by others, unlike most of the research on bladder cancer. Furthermore, given that IPA was developed in a health psychology setting, where objectively similar medical experiences can mean subjectively very different things to individuals (Smith, 1996) it was well-suited to the present study. IPA also looks at idiographic and small, homogenous samples (Smith and Fieldsend, 2021), to understand the particular ways in which individuals make sense of their experiences within a particular social context, which suited this study’s interest in exploring the influence of the COVID-19 pandemic and state of the NHS on experiences of an RC.

Participants

Inclusion and Exclusion Criteria

Individuals were eligible to participate in the study if they had undergone an RC 12 – 42 months before the interview, were aged 18 years or older, were fluent in English, were able to provide informed consent, lived without a relapse in bladder cancer, lived without cognitive impairment or a learning disability, and lived without any other cancer diagnosis or metastasis beyond the urogenital region. Information to assess eligibility was accessed via the participant's self-report during the initial phone call (see the Procedure section). The rationale for participants being 12 – 42 months post-RC was that previous research indicates that this length of time is close enough to the surgery, whilst allowing individuals' quality of life (measured quantitatively) to stabilise after changes occur (Kulaksizoglu et al., 2002). Additionally, individuals with a relapse in bladder cancer or those with cancer beyond the urogenital region were excluded from participating to prevent those factors from confounding how they made sense of their bladder cancer and RC.

Sampling and Recruitment

Participants were recruited via a UK bladder cancer charity through purposive sampling, on their basis of them having undergone an RC for bladder cancer. IPA relies on a homogenous sample, and so all participants were recruited on the basis that they had undergone an RC in the UK's NHS for bladder cancer, within the same timeframe so that contextual factors were similar (Smith & Fieldsend, 2021). The intended sample size was six to 10, as recommended by Larkin et al. (2021) for a professional doctorate**,** with the total sample size being six participants. IPA relies on a high level of richness and detail in the data analysis, and thus, a smaller sample size more easily facilitates this (Larkin et al., 2021; Sandelowski 1995). All participants had undergone an RC with an ileal conduit/urostomy rather than a neobladder. One participant was female (participant 6), and five participants were male. All participants were over the age of 50.

Ethics

Ethical approval for this study was obtained from the UCL Research Ethics Committee (see appendix 1 for a letter granting approval).

Participants received an information sheet (see appendix 3) providing details about what the study and their participation would entail, and then they were asked to provide informed consent to participate. Participants also had the chance to ask questions before providing consent (during the eligibility phone call) and participating (before the interview started).

Due to the interview being about experiences that might have been distressing for some participants, consultation on the interview guide was sought from an individual with lived experience of an RC for bladder cancer to ensure the acceptability of the questions. Participants were briefed on general topics via the information sheet before providing consent to take part in the interview and informed before the start of the interview that they could take breaks during the interview and end the interview at any point. Participants were informed that they were allowed to withdraw from the study at any time up until data analysis commenced, including after the interview took place and was transcribed. Participants were not obliged to provide an explanation for their withdrawal.

Participants were debriefed immediately after the interview. To monitor the status of participants during the interview, I (the interviewer) listened out for changes to the participants' voices indicative of distress, as well as any hesitation or difficulties answering questions. For interviews taking place via video call, I was able to look out for changes to facial expression or body language which might have indicated distress. Due to my experience working therapeutically in mental health services, I was considered to have sufficient ability to respond to any distress that arose during interviews. A distress protocol was devised in case distress was experienced by participants during the interview, however, no participants appeared or reported to experience undue distress during the interview, nor did any participant ask to pause or discontinue the interview.

All participant data remained confidential within the research team. Outside of the research team, data was pseudo-anonymised, and identifiable information was removed.

Procedure

I emailed individuals on a charity mailing list for a bladder cancer peer support group with a recruitment poster (see appendix 2) inviting them to take part in this study and containing my (the researcher's) contact details, so that if they were interested in participating, they could contact me directly by email to arrange a brief screening call to assess eligibility, and for them to ask any questions. To ensure that participants were called at a time when they had access to privacy, I asked them via email to specify a convenient time to contact them for this initial phone call. After a potential participant emailed me to express interest and with their preferred time, I phoned them to explain more about the study, check their eligibility and answer any questions. Before the interviews took place, individuals were emailed the participant information sheet and the link to the consent form (see appendices 3 and 4).

If individuals wished to participate, their written informed consent was recorded online via *REDCap*. Individuals who provided written informed consent were then scheduled to attend an individual semi-structured interview with me via

Microsoft Teams or a telephone call, lasting 30-60 minutes. Two participants had their interviews via video call on *Microsoft Teams*, whilst four participants had theirs via telephone call. At the start of the interview, participants were asked to reconfirm their consent to take part verbally. I audio recorded the interviews using *Microsoft* Teams and transcribed them afterwards. After the interview ended, participants were given the opportunity to ask questions.

Data Collection

Semi-structured individual interviews were used in this study, being an advantageous means of data collection in IPA due to their ability for participants to share their personal experiences in depth and with adequate time to reflect (Reid et al., 2005). Interviews used to gather data for IPA also allow flexibility and deviation from the interview schedule when led by the participant (Larkin et al., 2021). As mentioned earlier, before the interview schedule was finalised (see appendix 5), a member of a support group was consulted to determine the acceptability of the questions. The interview schedule was constructed to avoid assumptions about what changes individuals might have experienced. Once interviews were complete, I transcribed them and removed identifiable details. The below table reflects the notations used during transcription.

Table 1

Notations Used During Transcription

Notation	Meaning
I:	Interviewer
P:	Participant
…	Pause for more than five seconds
(laugh/cough/sigh)	Speaker laughs/coughs/sighs
[Information retracted]	Identifiable information retracted

Data Analysis

Data were analysed according to IPA guidelines (Larkin et al., 2021), after I transcribed all six interviews and retracted identifiable information such as names and locations. I analysed the transcribed interviews one at a time to attend to the idiographic nature of each participant's experiences.

The first step of analysis involved the simultaneous reading of the transcript and listening to the audio recording of the first participant's interview, allowing me to re-engage in the participant's experiences and sense-making. The transcribed interview was then read again several times. Next, step two commenced with exploratory noting of how the participant talked about their experiences and their meanings. The exploratory noting was carried out using the comment function on a *Microsoft Word* document that contained the transcribed interview.

Step three involved the development of experiential statements based on the transcription and exploratory noting, which relied on double hermeneutics (my attempts to make sense of the participant's experience of making sense of what they have lived through). In step four, I sought connections across the participants' experiential statements to create clusters that represented relationships using an online software named *Miro* which facilitated the visualisation and easy movement of statements. Once the clusters of Personal Experiential Themes (PETs) were finalised, they were named and represented in a table as part of step five, which included corresponding quotes from the transcript.

Step six involved repeating this process from step one to five for each of the other five participants, individually. Following this, step seven saw the development of Group Experiential Themes (GETs), which attempted to identify patterns of divergences and convergences across the PETs of each of the six participants, to capture patterns of similarity and difference. GETs were generated firstly by looking at the tables of PETs for each participant and then using *Miro* to cluster and reorganise the statements. The content of the final PETs and GETs was agreed on in supervision with one of my supervisors, Matthew Brown, where reflective discussion also took place on the process of conducting the interviews and data analysis, such as my expectations and reactions.

Validity and Quality

The four characteristics of good qualitative research (sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance), developed by Yardley (2000), were used to assess the validity and quality of this study, as recommended by Larkin et al. (2021).

Sensitivity to Context

Sensitivity to context can be achieved in a number of ways: through awareness of theory and literature in relevant areas to the research subject, which was demonstrated in the introduction of this empirical paper; through recognition of the socio-political landscape that the research exists within, which was made possible through the my work in the NHS and avid following of the news and current affairs; and through the relationship between myself and participants, including the influence of power in this relationship. Sensitivity to the relationship was maintained throughout all stages of the study, from consideration of ethical issues, outlined earlier in this paper, such as reminding participants of their right to withdraw, to consulting an individual with lived experience of an RC to guide the acceptability of the interview questions. Sensitivity to data and the voices of participants were at the forefront of my mind during analysis, ensuring that experiential statements were grounded in the data and accurately reflected the participants' experiences, and accompanying quotes aided this.

Commitment and Rigour

Commitment can be demonstrated by engaging with the research topic for a prolonged period, and rigour by ensuring that data collection and analysis are conducted to an adequate standard. Commitment to the topic is reflected in my interest in cancer, which pre-dates undergoing this Doctorate in Clinical Psychology (DClinPsy), and my request for a cancer placement during this training programme. I undertook reading and watched IPA webinars, given that it was my first time using this approach. Furthermore, I sought supervision from Matthew Brown on the experiential themes to ensure that I followed the methodology with rigour. Data collection finished only once a diverse range of experiences had been captured.

Transparency and Coherence

Transparency involves providing clarity around the research process, whilst coherence relates to the appropriateness of the chosen methodology and epistemology for the research questions. Transparency was upheld in this study by compiling a detailed record of study design, recruitment, data collection, and data analysis and outlining these stages in the methods section of this paper so that replication is possible. Additionally, an excerpt from data analysis (exploratory noting and experiential statements) can be found in appendix 6. I have also considered my own positioning and its potential influence on the research as part of maintaining transparency:

I am a trainee clinical psychologist, who at the time of data collection and analysis, had experience working in cancer and surgical settings. This experience potentially created a bias toward the more difficult experiences surrounding cancer and surgical procedures, as the therapeutic work was with individuals who had struggled with adjustment or felt traumatised by their experiences. I was conscious of this during the process and monitored the influence of overlooking a wider range of experiences. Using a reflective journal to engage in bracketing was useful in this process to notice my assumptions or *fore conceptions* (Heidegger et al., 1962). Spending time noting my thoughts and feelings after each interview, such as previous patients that I have worked with therapeutically that reminded me of a participant, provided an opportunity to consider what were the experiences and meanings of the participants and what were associations from other people. I was also aware of my position as someone who has worked in the NHS for several years and the possible defensiveness that could arise in hearing about complaints from participants of difficult experiences with healthcare teams. When I considered my personal experiences of cancer and surgery, whilst neither myself nor any of my close loved ones have experienced cancer that felt life-threatening, I have undergone surgery. My experience of surgery was a positive one that led to the desired outcome, with no challenges to recovery or adjustment. Additionally, my experience involved no breakdown in trust with healthcare professionals, and no feelings of powerlessness or lack of choice. As a result, it was important that I avoid making generalisations based on my experiences about what surgical procedures are like for others.

Impact and Importance

Yardley (2000) states that research has a responsibility to provide findings that influence the actions and views of others. The discussion section of this paper includes implications that arose from this study's findings, which aim to demonstrate the impact and highlight the importance of further clinical psychology research in this area of cancer care.

Results

Overview

Through the process of data analysis, GETs were produced, resulting in four superordinate themes: "*Ways of Coping"*, "*Narratives Around One's Bladder, Stoma, and Body*", "*Relationships to Others*", and "*The Role of Information"*. Each of the four superordinate themes contains sub-themes which will be outlined in this results section. Appendix 7 contains a Master Table of Group Experiential Themes, with accompanying quotes from participants.

Table 2

Summary of Group Experiential Themes

Superordinate Theme	Sub-Theme
Ways of Coping	Finding the Positives
	Acceptance Being an Active Choice
	Adaptations and Adjustments
Narratives Around One's Bladder, Stoma, and Body	Loss
	The Gift of Prolonged Life
	Relationship to the Stoma
	A Challenge to Be Overcome
Relationships to Others	Trust in Healthcare Professionals
	Understood and Supported
	Alone and Neglected
	Impact of COVID-19
The Role of Information	Receiving Information From Healthcare Professionals
	Uninformed and Unprepared
	Taking Matters Into Your own Hands
	Expectations

Theme One: Ways of Coping

The first theme represents experiences of adjusting to the RC and coping with its effects. In the interviews, several participants talked about the changes that had emerged, for example, their clothing choices, changes to sexual function, hernias developing around the stoma, and managing urostomy bag leaks. For many, these changes were experienced not only as challenges but also as situations where coping strategies could be implemented to manage such difficulties; Some participants drew on preexisting strengths and skills, whilst others seemed to uncover a new sense of resilience. The sub-themes within this were: "*Finding the Positives*", "*Acceptance Being an Active Choice*", and "*Adaptations and Adjustments*".

Finding the Positives

For some participants, experiencing life after an RC meant identifying gratitude for how fortunate they had been, whether that was around familial or professional support, or finding adequate products for their stomas and avoiding leaks. It seemed that for such individuals, it felt important to make sense of what they had undergone (the RC) in terms of what it made possible, or what was going well, rather than rather than ruminating on challenges. This seemed to be how some participants automatically perceived other situations in life; For others, it appeared to be a more deliberate, intentional effort brought about by a life-changing experience.

Participant 6 provided an example of identifying a benefit that emerged after having an RC and urostomy:

> *For me, best thing of all out walking the dogs out walking the dog, I can just go behind a tree like he does and do a standup wee. (14/479-481)*

For some, how they understood their experience of an RC was in relation to how others had experienced it. Making comparisons between themselves and others appeared to be a means to acknowledge their own fortune, thus eliciting relief from the possibility that their experience could have been a lot worse, as Participant 5 described:

> *I've taken to it quite well really. It's only since I've actually started getting involved with, um, a couple of other groups and sort of heard the experiences of other people that I've realized how lucky I’ve been really (laugh). (3/74-76)*

Additionally, humour was used to make sense of visual changes that emerged after the RC and share these during the interview without too much weight and emotion. This was possibly done around subjects that had the potential to elicit shock, fear, disgust, or embarrassment, to make sense of them in a less threatening, shameful way, as Participant 2 demonstrated:

> *You've bits bits are inflated and you know I was joking and said it looked like an African bullfrog you know (laugh). (8/259-260)*

Acceptance Being an Active Choice

Participants who appeared to be coping well after their RC talked about taking on the challenges and accepting the changes as an active, intentional decision, which was often accompanied by a sense of determination to face up to what had happened and persevere with life, as opposed to engaging in denial or identifying as a victim. There was a sense from some that they needed to take control of the situation, for example, by developing expertise around stoma management, actively engaging in research and decision-making, or chasing healthcare professionals, otherwise, the situation would take control of them. The cultural and generational expectations of men and their need to be stoic and unemotional could have informed these responses. Participant 3 talked about the choice that they had:

> *You either let them beat you and become a uh real victim, or you take them on board and say, well, you know um it's happened, let let's see what we can do. (19/627-628)*

Rethinking their self-image to incorporate the stoma and the changes was a first step towards acceptance for some, such as Participant 2, who expressed a drive to not be defeated by the stoma, but to accept it as part of who they were:

> *I think the key thing for me is that you have to take control of it yourself, you have to go “this is me now and I can take control and I'm gonna work for me, it’s gonna work for me.” (21/717-719)*

Adaptations and Adjustments

Rather than the RC representing something that limited one’s life and meant that activities were no longer possible, many participants experienced it as something that merely required adaptations so that they could continue to do things and connect with people who mattered to them. For those who saw the possibility and were willing to make adaptations, this led to a sense that whilst changes from the RC (predominantly managing the urostomy) existed and presented challenges, these did not have to define or hinder them. For some, such as Participant 3, adaptations involved planning, particularly around toilet access:

> *We'll play golf at [retracted location]. There are, there are toilets on the course. Um and if I run short one of them, there’s plenty of bushes on the course (laugh). We we find a way around that. So no, it really affect me at all. It's not like I would be concerned about going anywhere um in case there wasn't a loo. I just, you plan ahead. If I go to a concert, I will go to the loo before it starts at at the interval, whether I need to or not. Just to make sure everything’s good. Once it's done, you can relax. (13/407-419)*

For others, adaptations involved how they managed the presence of the urostomy bag, for example, Participant 2 experienced the need to adjust how they and their partner had sex, and yet this seemed to represent something that was not to be dwelled on, but just a necessary change that was possible to make:

> *The other thing that I do actually, just is the intimacy side of things is for that I used to have a t-shirt, to keep the pouch tucked out of the way. What I tend to do now is, I now put that around my middle. And where the pouch hangs down like that. I just sort of fold that out of the way and just rest that little bit on your belly, and I put this over the top and that's just keeps it getting in the way. Little things like that you know and again, okay, it's things that are maybe not spontaneous as they might have been before, but you know it's still can be a bit. So, you, you gotta get creative with these things. (30-31/1068-1081)*

Conversely, for some participants, the changes and the need to adapt were a source of great sadness, as opposed to an inconvenience that could be overcome. Participant 4's perception contained a high estimation of all the possible problems that could occur, along with a low estimation of their ability to cope with these:

> *Well to start with you don't wanna go anywhere. You know, you basically want to… I suppose it's partly depression and partly, you know feeling that you just can't cope with things. Um but yeah, you can't you've got if you're thinking about public transport, you've, if you've got to get a bus or a train anyway, you gotta think about how long you going to be on, whether you need, whether there's gonna be any delays and problems that could ensue from the delay. (7-8/237-245)*

Whilst for others, such as Participant 6, the need to adapt was manageable only when in familiar surroundings or routines, otherwise, it elicited anxiety and represented threat:

> *I think the biggest thing for me is that I do need to know where a toilet is all the time and I get a bit panicky if I'm in a if I'm in a strange place or a town. (14/468-470)*

Theme Two: Narratives Around One's Bladder, Stoma, and Body

The second theme explores how participants made sense of what it meant to have cancer identified in their bladder, to have their bladder removed, to have a stoma created, and to exist in their body post-RC. Sub-themes within this were "*Loss*", "*The Gift of Prolonged Life*", "*Relationship to the Stoma*", and "*A Challenge to be Overcome*".

Loss

Experiences of loss were present for several participants, manifesting in different ways. For some, the RC represented a last resort and a loss of options after other treatments had failed to work. For others, the RC meant losing parts of their identity that were tied to their bodies and what their bodies used to be capable of, such as sex, or in the case of Participant 5, exercise:

> *I turned to food, so I've put on quite a bit of weight, which does um upset me a bit. I was always very fit. Um, sort of a couple of weeks before me surgery, I was like up a mountain in [location retracted]! (laugh) And uh that's sort of all gone by the by now. (4/110-116)*

For Participant 1, the sense of loss resulting from the RC was so great that they made sense of their decision as something filled with regret due to their belief that their personality and life had altered to such an extent. For them, the regret was accompanied by frustration and self-blame that they had gone ahead with something that felt represented life-changing devastation:

> *It's it's just completely changed me all this. And and and sometimes I am thinking, why the hell did you do this? Why did you have this operation? Um it it seems so barbaric, it's just it's just not, yeah, I it's just yeah it's just horrendous. Horrendous. (23/761-769)*

Themes of existential loss were also part of how participants made sense of their RC, such as the loss of control over decisions and one's body, particularly in relation to adjusting to a new urinary function and managing urostomy bag leaks. The threat of loss of life was also something that had been experienced by many participants, even after the RC had passed, and as they approached follow-up scans, as Participant 4 shared:

> *Things start to go through your mind "you might not be around for an awful long time", um "that you it might be worse than they're saying", or "it might not be as clean cut if excuse the pun (laugh) as I expected". No, you just you know, it's very difficult not to descend into some form of a depression really. Because the the outlook is very bleak. (4/116-124)*

The Gift of Prolonged Life

For some participants, taking meaning from the RC and the removal of their bladder as a life-saving measure seemed to have several functions: it helped them come to terms with what was happening, it mediated the challenges that it also presented, and it protected them from decisional regret. For Participant 5, the removal of their bladder was not only life-saving but also life-enhancing. After several years of challenging symptoms, their RC represented liberation from long-term suffering:

> *I was just matter of fact, to be honest. Um happy if anything um, I was uh when they sort of got all the details of them, the scans the detailed scans and whatever it turned out that they thought my bladder cancer was muscle invasive. So really it took a lot of the other options off the table, and it was it was basically the only decision to be made um I yeah, I I saw it as I'd be rid of me bladder at last. All the problems that it has brought me so yeah, I wasn't too distressed at all. (1/23-29)*

Similarly, Participant 6 made sense of their RC as something that saved them from their bladder, which took the form of a vilified object in their mind and allowed them to carry on living. They even spoke about the losses that occurred (such as penetrative sex) as acceptable to them, given that they had been given a longer life expectancy:

> *I thought of my bladder like a fruit bowl, and it had got rotten fruit in it. And I thought I just want it out. I just want it out and I don't want to try and save my bladder. It's trying to kill me at the end of the day and that's how I that's how I that's how I processed it really. (7/229-235)*

Relationship to the Stoma

The way in which participants related to and characterised their stoma varied. For some the relationship was one that improved with time; Participant 6 initially perceived their stoma as an unfamiliar and foreign part of their body, however, this transformed over time and the meaning of the stoma became less threatening:

> *And I do think if I say to you, I called my stoma the "alien", it will tell you a bit about how I felt about it. You know, I was I was cross that it had happened to me, and not "why me?", because "why not me?". But you know why? You know this you know this little stoma; it looks like a strawberry on my tummy, you know, but I look at it now and I still, I still call it the alien, but with much more affection, you know [laugh]? And actually, I can't imagine my life without it now. And I very often say it hasn't changed my life for the better, but it hasn't changed my life for the worst either. And that's how I genuinely feel. But I recognise in the first year, I didn't feel like that at all. (12/404-416)*

Others experienced their stoma and urostomy bag as militant, dominating, and the reason for arduous and embarrassing experiences, as Participant 4 described:

> *You have to get into this regime where you are changing it every few days and they don't get- it doesn't actually take um, it's not something that you could just say "okay, take one off, put it on it". It um it it takes the best part- by the time you've you've sorted all the bits and pieces out by the time you've cleaned yourself up, by the time you've managed to get all you know, get the original one off. And prepared the um your you know the surrounding skin and everything, ready to receive the new and then tidied up afterwards. You know the best part of an hour's gone. (6-7/197-207)*

However, for some, whilst the relationship with their stoma was not straightforward and free from problems, there was a sense of playfulness in how they related to it, that seemed to alleviate resentment even if there were still challenges present, such as Participant 5:

> *I've even given him a name, he's called "Stomy" [laugh]. I'd characterize him as a sort of wilful child if you like (laugh). (3/86-88)*

A Challenge to be Overcome

There was a sense of pragmatism in the way some participants spoke about what the RC meant for their lives now. They made sense of the changes to their body as challenges that they could find solutions for and overcome, rather than changes that they merely felt resigned to tolerate, for example Participant 5:

> *And that was it, you know, so it was just buckle down and get on with it really. (2/63)*

Many participants experienced the process of adjustment after an RC as a long one, where confidence grows with time and practice. Participant 2 even made sense of mistakes with their urostomy as opportunities to learn and develop better strategies for the future:

> *I had the bad one on the on the New Year's Eve and that had leaked in the night. Um what I did there was 'cause it was a the the the bathroom we had there was it was a wet room. So, I just I actually up until that point I had always showered with my pouch on. Um but I just took the pouch off, and I and I showered with it without it. And actually, found that much better to clean round it and everything. (14/468-478)*

Theme Three: Relationships to Others

Relationships with others were part of how all participants experienced processes before and after the RC. Some of these relationships were professional, and involved care, trust, and understanding, or the absence of these qualities, whilst others were personal, and explored ideas of support, isolation, and feeling like a burden. The impact of the COVID-19 pandemic and the lack of NHS resources available for support underpinned the context in which many participants made sense of these relationships. The sub-themes were: "*Trust and Dependence on Healthcare Professionals*", "*Understood and Supported*", "*Alone and Neglected*", and "*The Impact of COVID-19*".

Trust and Dependence on Healthcare Professionals

Several participants experienced the need to put their faith in healthcare professionals. Doing so could feel challenging given that several participants felt vulnerable throughout the RC process and were in an unfamiliar situation, having never encountered cancer before (personally or professionally). There was a sense for some of taking a passive, passenger-like role, dependent on professionals to move them through the process, as Participant 6 put it:

> *And again, lots of you know more sort of cardio tests and a morning at the hospital for all the pre assessment checks and meeting the stoma nurse and uh yeah, and yeah, just it just felt like I was in this I don't know on this path, and I was just gently being nudged along. And I couldn't quite put the brakes on and stop it (laugh). (8/260-265)*

Trust seemed to underpin professional relationships, given their own lack of expertise in cancer treatments and the high mortality rates of bladder cancer. For some, such as Participant 1 who felt misled and misinformed by a consultant, the impact of broken trust elicited fear and anger:

> *I mean (sigh) for all intents and purposes, the cancer might’ve spread within that eight weeks, you know he was playing with my life basically, I was really, really ‘cause I was on here, I had no one to talk to at home. I felt, yeah, I felt sort of, well scared, really scared. And um I felt angry about the uh, you know, the chap. (7/205-211)*

Meanwhile, others experienced a sense of frustration when questions were unanswered, concerns were dismissed, and they felt unable to trust healthcare professionals to move them forward through diagnostic tests and treatments, such as Participant 4:

> *For some reason they resisted going for something as simple as an ultra-scan, which came up with well from my point of view the wrong answer, but you wonder if it had been if it had, how long, how much longer it, or how much worse it would have been if it hadn't been done at that stage. (16/530-533)*

Understood and Supported

Understanding and support were reported by participants to take many different forms. For some, support came from partners, family, and friends, whilst for others it was from healthcare professionals. Above all, the value of peer support stood out, perhaps reflecting a need to feel less alone in what one was experiencing. As Participant 2 described, peer support provided a level of mutuality and understanding that was incomparable:

> *You learn as much really from people that are um doing the sort of same thing in the same situation 'cause as much as the sort of the the the medical teams and the stoma nurses are very knowledgeable about it. They don't have, they're not living with it. And they'll pick things up from people, but they know they don't you know, not living with it they don't quite understand, you know. (19-20/668-676)*

Peer support seemed especially helpful for one participant who lacked other social support and helped normalise the challenges they had minimised. Peer support also offered a sense of fulfilment to a few participants, who found meaning and connection in being able to share their experience with others, such as Participant 5:

> *And through them, I've talked to a lot of people. That's how I've sort of met people who've had sort of similar problems. (9/288-289)*

Although there was a sense from a few participants that professional support was limited due to demands on the NHS, Participant 3 who accessed a private consultation early in the RC process spoke about the value of this in answering their questions and feeling more informed about what lay ahead. It is also possible that the process of their concerns being listened to, and the relational value of this was equally as beneficial as the content of information that they received:

> *When I first contacted the doctor in [retracted location], it was early stages of the uh (cough) the non uh non-muscle invasive bladder cancer and she actually had plenty time to sit with me and my wife. (8/261-263)*

Alone and Neglected

The high prevalence of cancer support charities in the media is likely to have influenced some participants' expectations of what support would be available, however, some felt that they were facing challenges alone and that there was a lack of meaningful support as Participant 1 put it:

> *It's just the loneliness. It's the being on me own with all this stuff to to contend with uh it again, you know there's no magic Macmillan holding your hand sort of thing. (28/915-916)*

It seemed that some wanted support in making sense of what they were going through, be that practically or existentially, and that to experience something that felt life-changing without guidance, answers, or solutions to problems by healthcare professionals elicited feelings of loneliness. Participant 4 reported:

> *It's a learning curve and it gets quite, it's quite steep at first. And and they don't. The problem is they don't tell you very much. And you're left you're left on your own to work it all out for yourself. (7/219-223)*

Experiences of a lack of support from healthcare professionals also encompassed frustration towards the wider system, such as the lack of preventative and proactive treatments. Participant 6 talked about the unsettling contrast between being surrounded by care and attention before the RC, and then afterwards feeling abandoned and possibly afraid:

> *But I think for me sort of mentally afterwards it was it was hard because all of a sudden there was nothing. You know, I'd gone through all these tests and treatments and chemo and the big surgery and the check up in after the six-*

> *week check-up, and then it was sort of like nothing and it was like I'd had sort of the best part of seven or eight months of being the everybody's focus and then. And it and I found that quite hard to come to terms with everything that had happened to me. (12/392-401)*

The Impact of COVID-19

For some, undergoing an RC during the COVID-19 pandemic provided a reason to stay at home and recover in their own time. The COVID-19 pandemic also placed restrictions on visitors, both at home and in the hospital, which was experienced as a relief for those who wanted to focus on rest and recovery, as Participant 2 stated:

> *The days fly by and actually it was in lockdown so we couldn't have visitors. And it yeah, looking back now I'm kind of glad really. It would have been a bit of a nuisance. It'd have been a nuisance because my wife would have felt she had to come and drive over to [location retracted] anyway and obviously you talk to people on the phone. (6/188-195)*

On the other hand, for others, the COVID-19 pandemic represented a burden that required them to attend face-to-face consultations alone, without a loved one by their side when they received a diagnosis, resulting in painful conversations where they shared the news afterwards. Furthermore, the pandemic meant that some friends and family had to be told online without the comfort of physical presence and connection as Participant 6 put it:

> *We were so isolated because, you know, we weren't seeing anybody like everybody else and he couldn't come to any appointments. He drove me*

> *there. Just sat in the car park for you know, sometimes hours and waited for me. And you know, we we ended up having to tell our family by phone call or, you know, on a on a on a zoom or FaceTime type thing. And that was incredibly incredibly difficult and had a massive impact. Yeah, massive impact because we couldn't we didn't, I mean, it was such a bombshell anyway, and we couldn't soften the blow by, you know, just sort of all having a hug sort of thing. It was a tough, you know, that was a tough time. (2/42-56)*

Theme Four: The Role of Information

The final theme captured participants' experiences around information – from receiving information from healthcare professionals, to seeking it out themselves and the functions of these efforts, to the effects and meanings drawn from not being informed. The sub-themes were: "*Receiving Information From Healthcare Professionals*", "*Uninformed and Unprepared*", "*Taking Matters Into Your own Hands*", and "*Expectations*".

Receiving Information From Healthcare Professionals

For some participants, receiving their bladder cancer diagnosis was a huge shock that stayed with them. Experiences of a lack of empathy being conveyed, along with the absence of warning and preparation for what they were about to hear could feel hurtful and careless; These experiences represented a desensitisation born out of healthcare professionals having had countless conversations over time and losing sight of the effects on patients. There was a sense in these moments of feeling like one of thousands of patients who would be delivered a cancer diagnosis each year, rather than an individual. Participant 3 described:

> *The way I was told wasn't very good either. I went, I went, I had an appointment to go to [retracted hospital name]. Um for a flexible cystoscopy, to see the extent of or see about this this um tumour that that they had spotted. But when I went there (cough) the nurse said "no, you're here to see a doctor", I said "no, I'm here to get this procedure". She said "no, you're here to see the doctor". Now, the doctor I saw said I can I can arrange for you to have one if you wish, but I can tell you looking at the ultrasound scan that you have bladder cancer. Just like that! (Laugh) And and and no, no preparation. No no warning. (1/25-42)*

Participants also spoke about shock and denial making it hard to process information about possible side effects of the RC. There was often a sense of wanting to avoid leaflets and information they might consume in their own time before the RC as it felt too overwhelming and there was no certainty over how they would be affected. Consequently, some felt unprepared for changes when they emerged after the procedure, which Participant 4's experiences reflected:

> *When they tell you, they break the news to you. They don't tell you very much, but they just offer you a brochure or booklet and say you know "read this" - well, the last thing you want to do is sit and read what they are, a load of um literature on something that may or may not affect you, and at that time you're in denial. You don't want to believe that it's it's happening to you. So, you don't want to read it. The last thing you want to do is to pick it up and find out what it's all about. (9/286-297)*

Uninformed and Unprepared

Those who felt that they had either not received adequate information from healthcare professionals or had been unable to process that information seemed to experience having an RC as though they had control taken from them, or that they had been unable to make informed decisions. Participant 1 talked about the anger they experienced around not having a choice in their treatment, feeling misled, and that valuable time was wasted:

> *I had two appointments. I had one with the the surgeon and then that was on the Friday. And then there was an- and a meeting with the radiotherapy woman on Monday and I was led to believe that then I had a choice between having the surgery or having radiotherapy. And so I went to the surgeon on the Friday and he said, yeah, you need the operation. And I said, well, I'm going to see the radiotherapist on on Monday. He says, well, yeah, you you can go, you know, you need to go and find out uh but it turned out that radiotherapy wasn't an option. Completely not an option. It was a point I I felt I was wasting NHS time by seeing the person that it was blatantly obvious that the NHS, that it was, it was not an option. Again, I was angry. (8-9/268-283)*

For Participant 4, their experience of feeling inadequately informed appeared to elicit mobilising anger and sense of injustice around systemic problems that motivated involvement with peer support. They used the following analogy to describe the ideal scenario:

> *Whether it's inevitable or not, you still like to know, you know when you're on this desert island, whether or not the tides, how soon the tide’s coming in, and whether you're gonna be swamped. (14/471-473)*

Taking Matters Into Your own Hands

A sense of control seemed to be brought about for several participants by seeking information and researching the RC and ways to manage side effects, both before and after the RC, to cope with the fear and uncertainty, such as Participant 2:

> *It's like trying to preempt what might happen, and obviously you get a bit of advice from people beforehand and and you pick things up as you go along and and and I’ve I've read various forums and things like that um and that's all helpful. You know so, and I am I we do have a locally a stoma support group. (19/658-662)*

Despite information-seeking being a helpful coping strategy for some, when it was not possible to obtain information and thus eliminate uncertainty, a lot of anxiety and hypothetical worrying could be experienced. Such was the case for Participant 3 ahead of a new procedure after the RC:

> *There was this one new test that I didn't know anything about, hadn’t been given any information, this is all about lack of information. Nobody had explained to me what it was, what they would do, how they would introduce this camera to check things. (17/540-543)*

Expectations

There was a sense of bladder cancer being outside of the public’s awareness, and other cancers being more prominent in societal discourse, which seemed to add to the feeling of shock on receiving the diagnosis, as it was not a condition that they expected to experience, as Participant 6 described:

> *I don't think it was out in the in the public domain or I wasn't aware of it. I've never seen anything with symptoms or anything. Didn't cross my mind, to be fair to the GP who sent me down the gynae route I I thought "well, you know, I'm 58. I know I'm I've gone through the menopause, but you know, maybe there's a bit of a, you know, sort of bleeding every now and again". And so, I didn't really think too much about it. You know, looking back, I think how how naïve, how stupid you know? Because maybe if I'd gone, you know, six, nine months previously when the first symptom occurred, I think the problem was I had this little episode of this sort of pink on the toilet tissue and then nothing happened for a month or so so I just disregarded it and I think that I don't think that's uncommon. But had I heard of bladder cancer and known of the symptoms maybe I would have twigged and thought I wonder, but who knows? Never gonna know. It's just not out there. It's not like breast or bowel cancer. It's just it's getting there; it's getting better and people like [charity name retracted] and [charity name retracted] and [charity name retracted]. They're they're doing fantastic work, you know now. And it is getting there. But I still think there's a long way to go. I don't I don't know why. I don't know why there seems to be a reluctance to talk about it. (3/79-105)*

In contrast to Participant 6, Participant 5 experienced long-term problems with their prostate, and so the bladder cancer diagnosis felt more expected, perhaps even inevitable:

> *I was almost expecting it. I first or how it came about was that I've had a benign prostate problems for many years. So, um was used to having sort of pain on urination and urgency, and all the things that go along with that. Um*

> *but I started getting much more severe pain and so I went to the doctors who um put me on antibiotics for a urinary tract infection, but also took um urine samples. Um turned out that that the urine samp- samples were sterile, but I had white blood cells in them. So, uh I suspected then cancer, and I went and had a cystoscopy which confirmed it. (1/4-13)*

Furthermore, Participant 3 reflected on expecting to struggle physically and emotionally more than they did, possibly due to narratives in society about having cancer, such as how one will look and feel. Additionally, medical and surgical advancements in recent decades mean that for many people, their cancer experiences will be very different from their ancestors' experiences, which might have influenced their expectations:

> *You think if suddenly someone says you you've got cancer, you know "the big C" and all that kind of stuff that you might you might um really be concerned about, but it was just a matter of fact. I was told it was there, I think one of the good things was I was still feeling alright. You know, I I it hasn't affected me physically. I was still, you know, I was still carrying on as normal. So, it wasn't like I was really ill. (10/324-334)*

Discussion

This study aimed to explore changes resulting from an RC, in particular, changes to body image, sexuality, and bodily function; This study was also interested in how these changes might affect individuals' quality of life and sense of emotional wellbeing. Through the process of IPA, interviews with six participants who had undergone an RC for bladder cancer generated four superordinate themes:

“*Ways of Coping”*, “*Narratives Around One’s Bladder, Stoma, and Body*”, “*Relationships to Others”,* and “*The Role of Information”*. Each of these themes will be discussed in relation to the research questions, and existing literature, and finally, limitations and implications of this study will be presented.

Main Findings

Ways of Coping

The first superordinate theme, “*Ways of Coping*”, captured participants' experiences of managing changes after an RC, ranging from taking proactive and preventative measures to cope, to responding reactively after difficult situations had occurred. Body image changes were experienced by a few participants as a source of humour, which seemed to defend against possible difficult emotions, consistent with literature on the role of humour as a coping strategy for psychological distress in cancer patients (Akhtar et al., 2021; Samant et al., 2020). Those that were able to integrate the stoma into their self-image seemed to experience more acceptance and cohesiveness with it than those who viewed the stoma as something separate from their body.

For some, changes to sexual function were coped with by making adaptations to how they had sex, whereas for others for whom sex was no longer possible, this was met with a sense of it being a worthwhile cost to having their life saved. Making positive cognitive reappraisals of challenges that emerge during cancer treatment has been identified as a coping strategy associated with post-traumatic growth (PTG) (Yeung et al., 2020), and PTG combined with patient resilience can result in positive life changes during and after cancer (Seiler & Jenewein, 2019). Coping around changes to sexual function also seemed to be impacted by participants’ preexisting values of sex and intimacy.

Changes to bodily function after the RC and the loss of control were coped with by planning to avoid leaks, and a sense of ownership over finding solutions and managing the challenges. Participants who could accept the changes from the RC and actively take the adjustment process into their own hands seemed able to live a better quality of life than those who had not yet accepted the changes and felt unable to find adaptations. Increased self-efficacy is significantly associated with higher health-related quality of life after an RC for bladder cancer (Rammant et al., 2022), which could partly explain why those who sought to take control and perceived there being a choice around acceptance and moving forward with their lives were better able to cope. Furthermore, ideas around acceptance have been applied to cancer psychological care through Acceptance and Commitment Therapy (ACT) with reviews indicating its effectiveness in improving psychological well-being for cancer patients (Salari et al., 2023; Zhang et al., 2023) and the development of self-help guides, such as *Facing the Storm* (Owen, 2022).

Narratives Around One's Bladder, Stoma, and Body

The second superordinate theme, "*Narratives Around One's Bladder, Stoma, and Body",* spoke to the meanings of losing a bladder, gaining a stoma and urostomy bag, and the effects on the body. For some, the RC represented immense loss, and even regret, because of urinary and sexual function changes, which impacted their ability to do previously meaningful activities. In their review, Szproch and Maguire (2022) highlight factors associated with decisional regret following cancer treatments, such as side effects, physical health status, and lack of information about possible side effects at the treatment decision-making stage. As a result, it is crucial to prepare patients for side effects and changes to prevent a sense of loss that is accompanied by regret. Moreover, Compassion-Focused Therapy (CFT) (Gilbert,

2009) could effectively intervene with the shame and self-critical thinking that some patients experience alongside decisional regret.

The sense of losing one’s identity that some participants experienced is reflected in other research, such as Matthieson and Stam (1995). The impact of cancer treatment on one’s sense of self has been explored in another study that looked at different identities (“*patient”*, “*person who has had cancer”*, “*victim”*, and “*survivor”*) that individuals relate to after having cancer (Park et al., 2009); Findings suggested that those who identified as a “*survivor”* took a more active role in treatment and experienced better psychological well-being. This might explain why some individuals experienced a greater sense of loss in this present study if they identified as a “*victim”,* as they might have experienced their cancer and RC as robbing them of important things, such as their former positive body image or sex life.

The loss of one’s bladder represented something different for others: an opportunity to live for longer and be rid of a threat (the cancer). The meanings of the urostomy changed with time for most participants, moving from something that represented a foreign, uncontrollable, and unpredictable source of worry, to something more familiar, known, and even life-saving. Giving one’s urostomy a name to facilitate acceptance has been identified as a helpful strategy (Cook & Hatton, 2018), particularly if feelings of shame around the urostomy exist (Diebold, 2016). The sense of change and loss that occurred to their body image and functioning appeared to be a source of despair, whereas, for others, challenges could be managed with a pragmatic and accepting stance.

In his talk *After Treatment Finishes – Then What,* Peter Harvey (n.d.) speaks about losing trust in one’s body after cancer, and how worries of cancer recurrence, hypervigilance, and checking behaviours can be a consequence of this. Whilst fears of recurrence (Butow et al., 2018) were talked about, the idea of losing trust in one's body was not named explicitly, however, it seemed to underpin experiences of changes to bodily functions, for example, unpredictable urostomy bag leaks and a lack of control over one's urinary function.

Relationships to Others

The third superordinate theme, "*Relationships to Others"*, reflected experiences around support (or lack thereof) and meanings taken from this, such as feeling vulnerable and dependent, a lack of trust in healthcare professionals, and feeling cared for and understood versus feeling abandoned and neglected.

For some, there appeared to be a relational element to coping and adjustment to changes in body image, sexuality, and body function. Those who felt understood and were given time and information to make sense of what was happening appeared to cope better and maintain a better quality of life than those who did not have those support resources, through feeling prepared for changes or feeling supported and less alone when challenges did emerge. On the other hand, these changes were experienced as more challenging when mistrust or neglect was present in relationships with healthcare professionals, possibly due to feeling alone in trying to manage difficulties or angry and resentful that such changes had occurred. Previous research has highlighted that patients often experience unmet needs in relation to psychological distress and adjusting to functional changes after an RC (Mohamed et al., 2014), which speaks to the sense of abandonment and neglect that some participants experienced.

These experiences of relationships relate to principles of Trauma-Informed Care (TIC) developed by the Substance Abuse and Mental Health Services

Administration (2012). The importance of trust and transparency as patients go through a significant procedure with possibly life-changing side effects is crucial, along with a sense of safety (encompassing physical, psychological, and relational safety) and choice in what happens with their treatment and to their bodies.

Although the sample consisted only of individuals who attended a peer support group, and thus the findings are not entirely generalisable, there was a resounding message about the value of it providing a sense of belonging and being in it together. Many also experienced peer support groups as a helpful means of receiving information and normalising the changes that were happening in their bodies, which is consistent with literature that finds that patients who attend peer support groups have a higher level of cancer-specific knowledge (Ziegler et al., 2023). Despite this, the overall evidence on the effectiveness of peer support in cancer settings is inconclusive, thus indicating a need for more research in this area (Jablotschkin et al., 2022; Kiemen et al., 2023; Ziegler et al., 2022).

An aspect of relationships with others that was not as prevalent as preexisting literature might suggest was the role of social support from family and friends, with this being a factor positively associated with quality of life after an RC (Li et al., 2016; Rammant et al., 2022). The reason for this could be because of the COVID-19 pandemic and the need to social distance, thus moving social support to the periphery of individuals' experiences.

The Role of Information

The final superordinate theme, *"The Role of Information",* captured the experiences of receiving information from healthcare professionals, which for some lacked empathy and time to adequately process and make sense of what they were being told. The effects of shock and denial on avoiding information and feeling unprepared for changes resulting from the RC were identified and can be understood in the context of psychodynamic defences to fears of death (Straker & Wyszynski, 1986). In a systematic review, findings emerged suggesting that patients undergoing an RC can be provided with too much information with not enough time to make sense of it (Stahlgren et al., 2022).

Furthermore, the function of information-seeking was explored, which involved eliminating fear and uncertainty, as well as providing a sense of control over what was happening to participants' bodies and their changing functions. This finding supports the relationship between anxiety, worrying, and intolerance to uncertainty (Dugas et al., 1998). Trauma-Informed Care ideas around transparency and feeling informed during decision-making about the RC are relevant to this theme, so that collaboration and choice can be exercised.

Research on prostate cancer patient experiences reveal that uncertainty around one's cancer influences physical and mental well-being, along with quality of life (Guan et al., 2020). The context in which participants experienced uncertainty about how changes from the RC would affect them over time was possibly exacerbated by the uncertainty posed by the COVID-19 pandemic (Young et al., 2020).

The social-cognitive transition model (Brennan, 2001) is often used in cancer contexts to explain how when our assumptions and expectations are disconfirmed through lived experience, this can evoke a sense of threat, which can ultimately be overcome through a process of adjusting our assumptions. This model is relevant to the role of information in conceptualising the shock and denial experienced by some which drive information avoidance as a response to assumptions being disconfirmed, and the subsequent sense of threat. Moreover, it suggests that through adjusting our assumptions, for example, about our health, mortality, and life trajectory, it is possible to overcome the initial distress.

Limitations

The first limitation of this study concerns the sample; In line with IPA guidance (Larkin et al., 2021), a small homogenous sample of six participants was used, to facilitate richness and depth in the analysis and understanding of experiences, however, this means that caution should be exercised before transferring these findings to others going through an RC. The reason for this is that IPA seeks to understand idiographic experiences and sense-making, rather than a shared and objective “truth” experienced by all. Secondly, participants were recruited via a bladder cancer charity, and although it was not an eligibility criterion, all participants attended bladder cancer peer support groups facilitated by the charity. This possibly created a bias in how experiences were being communicated, as participants were likely used to talking about them and had also incorporated others’ experiences that they had heard about into how they made sense of what they had lived through. Similarly to the first limitation, the findings from this homogenous sample ought to be considered without making hasty generalisations.

The third limitation of this study is that in using IPA as a methodology, assumptions were made about what language can represent, and how capable participants were of reflecting on their experiences and meanings, and then communicating these verbally during the interview (Willig, 2008). Despite this limitation, all participants attended peer support groups where experiences were talked about with others, suggesting a sufficient capacity for verbal communication. Fourthly, some qualitative researchers recommend that participants review their transcripts before data analysis (Reissman, 1993), however this did not take place in the present study. Although this could have helped to reduce the power differential between the researcher and participant, and to act as an additional measure of ensuring that they felt comfortable with their data being used in the study, it could have undermined the researcher's recollection and sense-making of the interview if changes to a transcript were suggested by a participant. Instead, it could have been beneficial to consult with participants at the analysis and dissemination stage of the research,

The final limitation is around the interview process: firstly, the researcher conducted all the interviews independently from anyone else on the research team, and so despite careful bracketing throughout the process, there was room for bias in what was being attended through follow-up questions during the interviews and what was not. Secondly, participants could have made assumptions about the research team's affiliation with the NHS, and this could have deterred some from sharing the full extent of their experiences and meanings.

Implications

Clinical

The theme of Ways of Coping indicate that therapists could also help by normalising the myriad ways that patients might respond to having cancer, along with the long adjustment process after an RC, which could include psychoeducation on the social-cognitive transition model (Brennan, 2001).

The theme of Narratives Around One's Bladder, Stoma and Body suggest that there could be value in therapeutic work involving cognitive reappraisals to reframe challenges and identify benefits for some patients, whilst a focus on acceptance and identifying adaptations to continue living a meaningful life might be more useful for others, in line with an ACT approach. Using CFT techniques to work with decisional regret and shame that some feel towards having the RC and their stoma, or narrative therapy techniques to deconstruct stories that patients have told themselves about their body image and self-worth could be helpful. The findings within this theme also indicate that therapists supporting individuals who have undergone an RC ought to hold in mind the possible need to explore experiences of loss and grief over one's bladder and life before the RC. Additionally, therapists should be alert to experiences of loneliness that the patient might arrive at therapy with if they feel neglected and unsupported after the procedure by healthcare teams.

Taking time to explore the patient's relationship to their stoma, such as what it represents to them, and how they would characterise or personify it is another area for therapists to consider when offering psychological assessments and interventions to individuals after an RC. Developing an illness narrative that facilitates meaning-making for a patient and engages them in managing the condition has been recommended for fibromyalgia (Davies et al., 2020) and could have useful applications in adjusting to one's stoma after an RC.

The theme of Relationships to Others highlights the relevance of trauma-informed principles to supporting patients before and after an RC. Ensuring that relationships between healthcare professionals and patients are ones of trust and safety, offering transparency and collaboration in decision-making processes, and encouraging empowerment and patient choice wherever possible. Additionally, it is important to facilitate peer support to normalise challenges and provide a space to be understood and share information (be that in formal groups, or “buddy” schemes).

The Role of Information theme indicates that across society, a greater awareness of bladder cancer, including its symptoms, treatments, and what life after an RC can look like would hugely benefit individuals who go through these experiences.

Figureheads for bladder cancer, or at least prominent figures who are vocal about their experiences could help with this. This theme also suggests that clinicians working with bladder cancer patients should recognise how much patients depend on them to make the right decisions in their best interests when they are faced with such an unfamiliar situation. Healthcare professionals also ought to take care with how and when they share information with patients so that they have the best possible chance to process it rather than emotions interfering with what they encode and store in their memory Furthermore, by answering questions and not dismissing concerns, healthcare professionals can make patients feel listened to and informed to prevent them from feeling alone in finding solutions post-RC. When there are limited resources available to provide all types of information to patients, connecting them to peer support or forums could be beneficial. Moreover, if information-seeking plays a significant role in coping, the function of this and the extent to which a patient is intolerant of uncertainty should be considered during a psychological assessment.

Research

Given the value that participants have found from peer support, future research could explore experiences of this in more depth, including what drives individuals to access it, and why some do not. Future research could also evaluate psychological interventions for specifically managing body and stoma-related distress, such as narrative therapy, ACT, and CFT, as well as interventions for managing intolerance of uncertainty and information-seeking.

More understanding of how to empower patients to increase their self-efficacy and thus, their ability to make an active choice in taking control of the situation would also be beneficial. Finally, it would be useful to develop strategies for preparing patients for side effects when they avoid information before an RC or denial prevents them from processing it during a consultation before the procedure.

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Part 3: Critical Appraisal

Overview

This critical appraisal explores some of the factors influencing the research process in greater depth. It then outlines challenges encountered throughout the process, some of which resulted in limitations that are discussed. It ends by reflecting on how my views have been shaped by conducting this research. Walsh’s (2003) four components of reflexivity will underpin this critical appraisal of the research: personal, interpersonal, methodological, and contextual reflexivity.

Influences on how I Approached the Research

Before starting this Doctorate in Clinical Psychology (DClinPsy) I worked in a general hospital, sharing an office with clinical psychologists in cancer and palliative care. I was struck by some of the challenges to my assumptions when they talked about their work, for example, about patients' desires to withdraw treatment and to die. Sharing an office with this team made me eager to gain experience working in a cancer or end-of-life settings to deconstruct the assumptions that I held about how patients experience illness and dying; It was also a significant factor in my decision to undertake this research project.

During the DClinPsy itself, I spent six months working in a cancer and palliative care service, and a particular conversation with my placement supervisor stayed with me: she talked about the fact that we were seeing people who had gone through some of the most challenging experiences with their cancer and treatments and that it was important not to lose sight of the fact that our clients were not a representative sample of everyone living with and surviving cancer. This conversation came to mind a lot as I was designing the empirical study, and afterwards when I was engaging in personal reflexivity. I thought about my bias towards the most emotionally distressing experiences of cancer and how much I expected to hear about and analyse those during the interviews and data analysis, however, the reality for some participants was different.

For my final DClinPsy placement, I have been based in a psychology service for surgical pathways in a general hospital, and part of this has involved helping to develop a pre-operative project using Trauma-Informed Care (TIC) principles (Harris & Fallot, 2001; Substance Abuse and Mental Health Services Administration, 2012) to reduce anxiety prior to surgery. This has honed my focus on patients’ need for control, choice, and information, as well as the value of trust between patients and healthcare professionals as I analysed the interviews. Furthermore, the relational focus in individual therapy on this placement has made me more aware of what *‘What kind of relationship does my client need?’* (Markin, 2014, p.331) as I interpreted participants' experiences of support, be they present or absent.

Prior to and throughout DClinPsy training I have not been wedded to any one theory; however, the following approaches are likely to have influenced the way I analysed the data and the literature that I situate the findings in during the discussion: Experience of using Cognitive Behavioural Therapy (CBT) and framing distress around cognitive distortions (Beck, 1963; Beck, 1979), along with the relationship between worrying and intolerance of uncertainty has underpinned some of my interpretations (Dugas et al., 1998); The third-wave CBT approach of Acceptance and Commitment Therapy (ACT) which I had experience using in the cancer placement also shaped the generation of themes around acceptance and continuing to live a meaningful life guided by one’s values by making adaptations (Hayes et al., 2006); My interest in psychodynamic approaches influenced how I thought about the function of denial for some participants (Straker & Wyszynski, 1986); Attempting to use systemic ideas, I thought about the concept of relationship to help (Reder & Fredman, 1996) as participants spoke about experiences and meanings of their interactions with healthcare professionals, personal support and even volunteering to participate in the empirical study. Possibly the reason why *Ways of Coping* was the first superordinate theme presented in the empirical study is my passion for narrative therapy, which seeks to uncover dominant, problem-saturated narratives in individuals' lives and to identify and amplify preferred narratives of strength and resilience (White & Epston, 1990). The social-cognitive transition model (Brennan, 2001) undoubtedly influenced my assumptions regarding the process of adjustment and recalibrating expectations, particularly regarding urostomy bag management.

Through the process of contextual reflexivity, I have considered the influence of how cancer is thought about in British society, from the growing presence of adverts by cancer charities and celebrities sharing their experiences of cancer, to the use of "militaristic language" to describe the "fight", "battle" and "survival" of cancer (Boyle & Johnstone, 2020). Additionally, I have been becoming more aware, possibly due to my parents moving closer to retirement and being more affected by ageism, of the assumptions that exist around what is important for older people, such as their appearance, relationships, and sexuality. This made me interested in carrying out research that might shed light on some of these assumptions, given that bladder cancer is more likely to develop in older people. A final part of implementing contextual reflexivity was thinking about the point in history that this research sits in, for example, the influence of the COVID-19 pandemic and how that affected participants' experiences, along with the developments in medicine and surgery that make it possible for people to for live longer with and after cancer.

Dilemmas Encountered During the Research

Originally, I planned to use Thematic Analysis as a methodology for the empirical study, however, after some consideration and reading about Interpretative Phenomenological Analysis (IPA), I decided to use this instead, as a more in-depth analysis felt necessary. Despite this change, and adjustments to the research questions, I felt concerned after finishing the empirical study using IPA that it lacked depth and presented more breadth instead. Perhaps a more homogenous sample could have been used, or I could have sought to explore just one area of life after an RC to achieve greater depth. Another dilemma that arose concerned the ethics process; Before embarking on recruitment, I had initially proposed to conduct a prospective quantitative component to the empirical study, in addition to the qualitative component, seeking to identify risk factors for poorer quality of life after an RC, however, due to the lengthy NHS ethics process, this was not possible within the time available and so this component did not go ahead. Nevertheless, I wonder if I could have circumvented this challenge by recruiting from a charity instead of the NHS, and thus apply for UCL ethics.

I encountered challenges with recruitment, and as a result decided to expand eligibility criteria on two occasions, firstly by allowing patients with additional cancers inside the urogenital region, and secondly by extending the time that participants could have undergone an RC. These amendments felt necessary to increase the desired minimum sample size for professional doctoral IPA research, however, I wondered if I had started recruitment earlier or attended peer support groups if it could have been avoided. A possible explanation for the difficulties recruiting is that it took place by a poster being circulated via email, with no researcher present in support groups. Whilst engaging in methodological reflexivity, I was conscious of decisions around the recruitment and ethical approval processes being made in the interest of time.

During the interviews, it felt difficult to shift from the position of a therapist to one of a researcher and often I felt the urge to normalise experiences, validate emotions and provide psychoeducation. It often felt hard to remain more “neutral” and not respond in these familiar reflexive ways.

Cognizant of the power dynamics between myself and participants through the process of interpersonal reflexivity, I reflected on what the impact was on participants not reviewing their transcripts before data analysis commenced, due to time constraints, and how this relinquished their ability to identify perceived inaccuracies. Furthermore, I wondered whether some participants were reticent in sharing their experiences given that they might have assumed that I worked for the NHS, and thus would have a conflict of interest.

Throughout data analysis, I often struggled to hold in mind the need to be analytical rather than descriptive. As I wrote up the results section, I worried about selecting quotes that would best capture the themes being explored. I felt that there were so many important things that participants shared and was disappointed about not being able to honour all of these in the empirical paper. Statements that at the time of the interviews or initial reading of the transcripts felt pertinent, but that I then did not include in the results section made me feel that I was somehow letting down those experiences expressed, but this perhaps speaks to the evolving nature of IPA as one moves through each step and stories and connections unfold. Although I was apprehensive that themes would not represent enough of the important experiences shared by participants, I can recognise the need for depth rather than breadth.

The Influence of the Research Process on my Views

Through the process of conducting this research into an RC for bladder cancer, I have become aware of the risk in medical and surgical literature of patients being reduced to their bodies or organs. Often papers on surgical techniques and oncological outcomes would refer to “the bladder” and the person having their bladder removed felt absent. Understandably, a study on such a topic would not be commenting on patients’ feelings of acceptance versus denial, for example, however, it has been established that objectifying patient bodies carries risks (Svenaeus, 2023). Furthermore, it made me wonder about how this influences interactions with patients when they are conscious and what patients experience if discussions with this language occur. Increasingly in the field of clinical psychology we are considering the connections between the mind and body, as opposed to looking at either one in isolation and so it felt jarring to read papers that objectify the bladder to this extent and remove the rest of the person.

Although a small sample of six participants was interviewed for the empirical paper, I gained an appreciation of how varied patients’ experiences are, along with the meanings they take from these experiences and their responses to them. This idea of individuality is central to IPA (Larkin et al., 2021) but it was also something that a couple of participants expressed explicitly, as well as being evident just from reading all six transcripts.

I was struck by the experiences of participants who had been unaware of bladder cancer as a phenomenon prior to their diagnosis, or who could not make sense of what had caused their bladder cancer, as though it came out of nowhere. These experiences expressed in interviews made me more conscious of the sense of control and trust that I have had in my body, but also the recognition that this could suddenly change, that I could be confronted with my mortality and faced with existential uncertainty that is “is always there, lurking in some hidden ravine of the mind” (Yalom, 2011, p.5).

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Appendices

Part 1: Literature Review

Appendix 1: Systematic Review Search Terms

Database	Search Syntax
Web of Science (searched on 13/10/2023)	Bladder cancer OR bladder neoplasm OR bladder tumour OR bladder malignancy OR cystectomy AND Masculin* OR feminin* OR gender identity OR male OR female OR "body image" OR self-concept OR self-esteem OR self-image OR self-perception OR psychosexual
PsychINFO (searched on 13/10/2023)	Bladder cancer OR bladder neoplasm OR bladder tumour OR bladder malignancy OR cystectomy AND Masculin* OR feminin* OR gender identity OR male OR female OR "body image" OR self-concept OR self-esteem OR self-image OR self-perception OR psychosexual
Med Line (searched on 13/10/2023)	Bladder cancer OR bladder neoplasm OR bladder tumour OR bladder malignancy OR cystectomy AND Masculin* OR feminin* OR gender identity OR "body image" OR self-concept OR self-esteem OR self-image OR self-perception OR psychosexual

Appendix 2: Quality Assessment Ratings

Rater 1 Quantitative Quality Assessment

	Karvinen et al., 2007	Hedgepeth et al., 2010	Shim et al., 2013	Bjerre et al., 1995	Clements et al., 2022	Aboumohamed et al., 2014	Hao-yu Zou et al., 2022	Volz et al., 2022	Bahlburg et al., 2023	Hart et al., 1999	Imbimbo et al., 2015	Ben Hassine et al., 2019	Gacci et al., 2013	Huang et al., 2015	Hart, 1997	Bjerre et al., 2009	Poch et al., 2014
1. Question / objective sufficiently described?	2	2	2	2	2	2	2	2	2	2	2	1	2	2	2	2	2
2. Study design evident and appropriate?	1	1	1	2	1	2	2	2	2	2	2	2	2	2	2	2	2
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	1	1	1	1	1	2	2	2	2	1	2	2	1	2	2	1	1
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	2	1	2	2	2	2	2	2	2	1	1	2	1	2	2
5. If interventional and random allocation was possible, was it described?	N/A	N/A	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
6. If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement /misclassification bias? Means of assessment reported?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	1	1	2
9. Sample size appropriate?	2	1	1	1	1	1	2	1	2	1	1	1	1	1	2	1	1
10. Analytic methods described/justified and appropriate?	2	2	2	2	2	2	2	2	2	2	2	1	2	2	2	2	2

11. Some estimate of variance is reported for the main results?	2	0	2	N/A	2	2	0	2	2	2	2	N/A	2	2	2	2	1
12. Controlled for confounding?	2	2	0	2	2	2	0	0	0	2	2	N/A	0	2	1	1	1
13. Results reported in sufficient detail?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
14. Conclusions supported by the results?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Summary score	**0.91**	**0.77**	**0.77**	**0.85**	**0.86**	**0.95**	**0.64**	**0.86**	**0.91**	**0.91**	**0.95**	**0.78**	**0.77**	**0.95**	**0.86**	**0.82**	**0.82**

Rater 1 Qualitative Quality Assessment

	Osborne et al., 2016	Villa et al., 2018	Mohamed et al., 2013	Fitch et al., 2010	Kandemir & Oskay, 2017	Yi et al., 2021	Gupta et al., 2020
1. Question / objective sufficiently described?	2	2	2	2	2	1	2
2. Study design evident and appropriate?	1	2	2	2	1	2	2
3. Context for the study clear?	2	2	2	1	2	2	1
4. Connection to a theoretical framework / wider body of knowledge?	2	2	2	2	2	2	2
5. Sampling strategy described, relevant and justified?	2	2	2	2	2	2	2

6. Data collection methods clearly described and systematic?	2	2	2	2	1	2	2
7. Data analysis clearly described and systematic?	2	2	2	2	1	2	2
8. Use of verification procedure(s) to establish credibility?	2	2	2	2	0	2	2
9. Conclusions supported by the results?	2	2	2	2	2	2	2
10. Reflexivity of the account?	0	1	1	2	0	0	1
Summary score	**0.85**	**0.95**	**0.95**	**0.95**	**0.65**	**0.85**	**0.9**

Rater 2 Quantitative Quality Assessment

	Karvinen et al., 2007	Hedgepeth et al., 2010	Shim et al., 2013	Bjerre et al., 1995	Clements et al., 2022	Aboumohamed et al., 2014	Hao-yu Zou et al., 2022	Volz et al., 2022	Bahlburg et al., 2023	Hart et al., 1999	Imbimbo et al., 2015	Ben Hassine et al., 2019	Gacci et al., 2013	Huang et al., 2015	Hart, 1997	Bjerre et al., 2009	Poch et al., 2014
1. Question / objective sufficiently described?	2	2	2	1	2	1	2	1	1	2	2	2	2	2	2	2	1
2. Study design evident and appropriate?	1	1	1	2	2	2	1	1	2	2	2	2	2	1	2	2	2
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	1	1	1	1	1	1	1	1	1	2	2	2	1	1	2	1	1
4. Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	2	2	2	2	2	2	2	1	2	2	2	2	1	2	2
5. If interventional and random allocation was possible, was it described?	N/A	N/A	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

6. If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7. If interventional and blinding of subjects was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	0	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement /misclassification bias? Means of assessment reported?	2	2	2	1	2	2	1	1	2	1	2	2	2	2	1	0	2
9. Sample size appropriate?	2	2	1	1	2	2	2	2	2	2	2	1	1	1	2	1	1
10. Analytic methods described/justified and appropriate?	2	2	2	1	2	2	2	2	2	2	2	2	2	2	2	2	2
11. Some estimate of variance is reported for the main results?	2	1	2	N/A	2	2	1	2	2	1	1	N/A	1	1	2	2	1
12. Controlled for confounding?	1	1	1	2	1	1	2	1	1	1	1	2	1	2	1	1	1
13. Results reported in sufficient detail?	2	2	2	2	2	2	2	1	2	2	2	2	2	2	2	1	2
14. Conclusions supported by the results?	2	1	2	2	2	2	2	1	1	1	2	2	2	2	1	1	1
Summary score	**0.86**	**0.77**	**0.82**	**0.75**	**0.91**	**0.86**	**0.64**	**0.68**	**0.82**	**0.77**	**0.91**	**0.95**	**0.82**	**0.81**	**0.82**	**0.68**	**0.73**

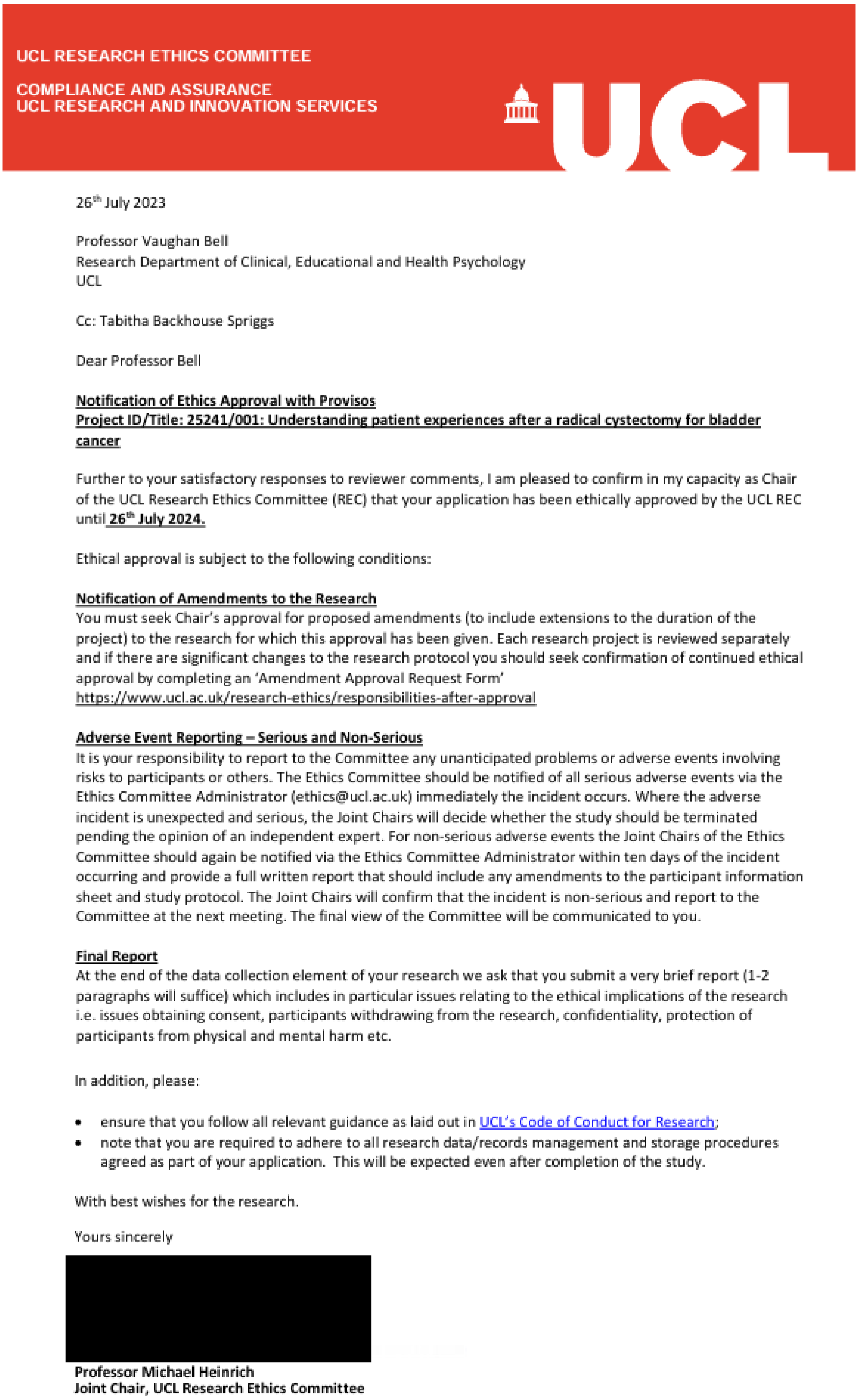
Rater 2 Qualitative Quality Assessment

	Osborne et al., 2016	Villa et al., 2018	Mohamed et al., 2013	Fitch et al., 2010	Kandemir & Oskay, 2017	Yi et al., 2021	Gupta et al., 2020
1. Question / objective sufficiently described?	2	2	2	2	2	2	2

2. Study design evident and appropriate?	2	2	2	2	2	2	2
3. Context for the study clear?	2	2	1	2	2	2	1
4. Connection to a theoretical framework / wider body of knowledge?	1	2	1	1	1	1	1
5. Sampling strategy described, relevant and justified?	1	2	1	2	1	1	1
6. Data collection methods clearly described and systematic?	1	1	1	2	1	2	2
7. Data analysis clearly described and systematic?	1	2	1	2	1	2	2
8. Use of verification procedure(s) to establish credibility?	2	2	2	2	0	2	2
9. Conclusions supported by the results?	1	2	2	1	2	1	2
10. Reflexivity of the account?	0	1	1	2	0	0	1
Summary score	**0.65**	**0.9**	**0.7**	**0.9**	**0.6**	**0.75**	**0.8**

Part 2: Empirical Paper

Appendix 1: Official Letter Granting Ethical Approval



UCL RESEARCH ETHICS COMMITTEE

COMPLIANCE AND ASSURANCE
UCL RESEARCH AND INNOVATION SERVICES

UCL

26th July 2023

Professor Vaughan Bell
Research Department of Clinical, Educational and Health Psychology
UCL

Cc: Tabitha Backhouse Spriggs

Dear Professor Bell

Notification of Ethics Approval with Provisos
Project ID/Title: 25241/001: Understanding patient experiences after a radical cystectomy for bladder cancer

Further to your satisfactory responses to reviewer comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your application has been ethically approved by the UCL REC until **26th July 2024.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research;
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix 2: Recruitment Poster

Are you interested in participating in a study looking at people's experiences of life after a radical cystectomy?

Am I Eligible?

- Had a radical cystectomy (surgery to remove your bladder) for bladder cancer between 12 – 42 months ago
- Aged 18 year or older
- Fluent in English
- Living without a relapse in bladder cancer
- Living without a cognitive impairment (significant problems with your memory and concentration) or a learning disability

What Does It Involve?

1. An initial telephone call with the researcher to:
   - Check that you are eligible to take part
   - Give you the opportunity to ask any questions about the research before agreeing to participate
2. Online consent form
3. 30-60 minute one-to-one interview over the telephone or Microsoft Teams (video call)

The Research Team

- The Study will be carried out by Tabitha Backhouse Spriggs (Trainee Clinical Psychologist at UCL) and supervised by Prof. Vaughan Bell (Associate Professor in Clinical Psychology at UCL, vaughan.bell@ucl.ac.uk) and Dr Matthew Brown (Consultant Clinical Psychologist at UCLH, matthewbrown1@nhs.net)
- Ethical approval for this study has been obtained via UCL Research Ethics Committee. Ethics ID Number: 25241/001
- Data Protection Number: Z6364106/2023/01/96 health research

How Can I Take Part?

Email Tabitha Backhouse Spriggs at: ucjutb4@ucl.ac.uk to arrange an initial telephone call at a time that suits you.

UCL

Appendix 3: Participant Information Sheet

Participant Information Sheet

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Understanding patient experiences after a radical cystectomy for bladder cancer.

UCL Research Department of Clinical, Educational and Health Psychology

You are being invited to take part in a doctoral research project. Before you decide it is important for you to understand why the research us being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

This study aims to understand how changes to sexuality, bodily function, and body image impact patient's quality of life after a radical cystectomy (RC). The research findings should provide clinicians with a better understanding of patients' experiences, thus enabling them to provide better support to those patients accessing psychological therapies in relation to their treatment. The study hopes to have a sample size of 20 individuals.

This study has been approved by the UCL Research Ethics Committee.

Ethics ID number: 25241/001.

Why have I been chosen?

You have been invited to participate in this study as you have undergone a radical cystectomy 12-42 months ago. To take part in this study you must be aged 18 or over, fluent in English, and able to provide informed consent. You will not be able to take part in this study if you have any other cancer diagnosis outside of the genitourinary area, a relapse in bladder cancer, a cognitive impairment, or a learning disability.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw your data at any time after participating up until 12/04/2024 when data analysis commences. If you decide to withdraw from this study, you will be asked what you wish to happen to the data that you have provided up to that point, and you do not need to provide a reason for withdrawing.

What will happen to me if I take part?

If you decide to take part in the study, you will be asked to attend an interview via telephone or video call, lasting between 30-60 mins. You will be asked about your experience of having bladder cancer, undergoing a radical cystectomy (RC), and the impact of the RC on several areas of life and wellbeing such as body image, bodily function and sexual function. Questions might include “what has your experience been since having an RC?” and “How did you feel when you discovered that you would have an RC?”.

What if something goes wrong?

If something goes wrong and you wish to raise a complaint you can contact either Tabitha Backhouse Spriggs or Vaughan Bell (contact details on the last page), however, if you feel that the complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

What are the possible disadvantages and risks of taking part?

Because this study is hoping to better understand the psychological impact of undergoing a radical cystectomy, and how it effects quality of life, there is the potential for some of the interview topics to be experienced as distressing, for example, if they bring up memories of difficult times after the procedure or prompt you to reflect on some of the challenges of adjusting to life afterwards. If at any point during the interview you feel distressed, you are allowed to pause or end the interview. The interviewer will check-in throughout the interview to ask how you are feeling and if you would like to continue. After the interview ends, the interviewer will have a debrief with you and signpost you to support if needed.

Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. To keep your data confidential, it will be pseudo-anonymised, which means that your interview transcript will be labelled by a participant number and all identifiable personal information will be removed from it. All you’re your identifiable personal data will be stored on a password encrypted spreadsheet on UCL Data Safe Haven, along with corresponding participant numbers. The audio recording of your interview will be deleted as soon as it has been transcribed, and the transcription will be stored on UCL Data Safe Haven.

Limits to confidentiality

Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. Examples of such reasons include evidence of wrongdoing or potential harm being uncovered, or indication that someone might be in danger of harm in the future. If this was the case, we would inform you of any decisions that might limit your confidentiality.

What will happen to the results of the research project?

The results of this study will be presented with a Doctorate in Clinical Psychology thesis and submitted for publication in research journals in 2024/5. You will not be identified in any report or publication. Your data will be deleted five years after the doctoral training is completed (due to end in September 2024).

Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, please see more information here:
https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'Public task' and 'research purposes' will be the lawful basis for processing special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data, you provide we will undertake this and

will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk

Special category data collected in this study will be concerning health (cancer diagnosis and treatment, impact of cancer and treatment on mental health) and sex function as the focus of the study is how a radical cystectomy impacts sexual functioning, bodily functioning, and body image, and how these areas impact overall quality of life. Personal data collected in this study will be of participant's name, email address and telephone number for the purposes of recruitment and scheduling individual interviews.

Who is organising and funding the research?

This study is part of a doctoral thesis at UCL and is being sponsored by UCL Research Department of Clinical, Educational and Health Psychology.

Contact for further information

If you have any questions or would like to discuss participation further, then please contact the following:

Name and contact details of researcher: Tabitha Backhouse Spriggs, tabitha.spriggs.21@ucl.ac.uk

Name and contact details of Chief Investigator: Vaughan Bell, vaughan.bell@ucl.ac.uk

If you wish to take part in this study, you will be given a copy of the information sheet and a signed consent form to keep.

Thank you for reading this information sheet and for considering to participate in this research study.

Appendix 4: Informed Consent Form

CONSENT FORM

Please complete this form after you have read the Information Sheet

Study Title: Understanding patient experiences after a radical cystectomy for bladder cancer.

Department: UCL Research Department of Clinical, Educational and Health Psychology

Name and contact details of researcher: Tabitha Backhouse Spriggs, tabitha.spriggs.21@ucl.ac.uk

Name and contact details of Chief Investigator: Vaughan Bell, vaughan.bell@ucl.ac.uk

Name and contact details of UCL Data Protection Officer: Alexandra Potts, data-protection@ucl.ac.uk

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

Item number	Potential consent item	Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction	
2.	I understand that I will be able to withdraw my data at any point up until 12/04/2024 when data analysis commences.	
3.	I consent to participate in the study. I understand that my personal information will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing, and 'research purposes' will be the lawful basis for processing special category data.	
4.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that my data gathered in this study will be linked to a pseudonym and stored securely. It will not be possible to identify me in any publications.	

Item number	Potential consent item	Tick Box
5.	I understand that my participation is voluntary and that I am free to withdraw at any time until 29/02/2024 without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
6.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
7.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
8.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
9.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
10.	I hereby confirm that: (a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and (b) I do not fall under the exclusion criteria.	
11.	I agree that my GP may be contacted if any unexpected results are found in relation to my health.	
12.	I am aware of who I should contact if I wish to lodge a complaint.	
13.	I voluntarily agree to take part in this study.	

________________________ ________________ ____________________

Name of participant Date Signature

This study has been approved by the UCL Research Ethics Committee. Ethics ID number: 25241/001

Appendix 5: Interview Schedule

Interview Schedule

Reminders Before Starting

- 30-60 minutes.
- Stop at any point.
- Take breaks whenever you want.
- Recorded.
- Personal details remain confidential within research team and would be removed from transcript.
- Reconfirm consent orally

Questions

- Can you tell me about your experience of being diagnosed with bladder cancer.
- How did you feel when you discovered that you would have an RC?
- What has your experience been since having an RC?
- *PROMPT: If any changes are mentioned, ask about impact on quality of life.*
- *PROMPT: If any changes are mentioned, ask about impact on emotional/psychological wellbeing*
- Is there anything else that you would like to add, either on an earlier question or on something that I have not asked about?

Appendix 6: Analysed Transcript Excerpt

Transcript	Exploratory notes	Personal Experiential Themes
P: And it and I found that quite hard to come to terms with everything that had happened to me, and I did find a very good counsellor and and met up with her for almost a year and she was brilliant, really helped me see myself in a different light.	Emotional adjustment, difficulty accepting situation. Professional support was useful. Long relationship with counsellor. Self-perception changed after the RC.	
I: Mmm.		
P: And I do think if I say to you, I called my stoma the “alien”, it will tell you a bit about how I felt about it.	Naming the stoma. Stoma felt other-worldly, foreign, unwanted initially.	Relationship to stoma: foreign, invading and unknown.
I: Yeah.		
P: You know, I was I was cross that it had happened to me, and not “why me?”, because “why not me?”.	Angry about situation	
I: Yeah.		
P: But you know why? You know this you know this little stoma; it looks like a strawberry on my	“Little” implies that it doesn’t feel too invasive. Use of fruit imagery again – feels less threatening. Changing relationship with stoma.	

tummy, you know, but I look at it now and I still, I still call it the alien, but with much more affection, you know [laugh]? I: Yeah, yeah [laugh]. P: And actually, I can't imagine my life without it now. And I very often say it hasn't changed my life for the better, but it hasn't changed my life for the worst either. And that's how I genuinely feel. But I recognise in the first year, I didn't feel like that at all.	Affectionate acceptance. Room for good and bad parts/mixed emotions towards stoma (as it was not renamed). Adjustment, acceptance, normality. Process of adjustment was not instant. It was challenging at first.	Relationship to stoma: less threatening, affectionate acceptance. A new sense of normality over time.

Appendix 7: Master Table of Group Experiential Themes

Ways of Coping - Finding the Positives

Participant	Extract (page/lines)
2	I reeled off her telephone number and so he rang my wife [name retracted] and said um yes, he's back with us, he's he's it all went very well, and would you like to speak to him?" And apparently, I was very incoherent, as you can imagine (laugh). (5/170-172) You've bits bits are inflated, and you know I was joking and said it looked like an African bullfrog you know (laugh). (8/259-260) I have got a bit of a bit of a hernia around it, not as horrendous as some people, but I've got- it does kind of protrude a little bit. (10/327-328) Um but so I was, you know, I was able I actually was probably better off than people in a normal situation, and I did take my own night bag in as well because when they said alright, we need a bag to go on this and she brought one, I said no, that's not got the right end for this, you know? (24/821-824) I've been very lucky with uh, the products that I've used, I've not had a lot. I'm still using the same bag that I used in in in hospital uh I was discharged with 'cause I've not had a problem really with leaks. (12/406-409) My stoma's fairly consistent and it's it's out. But I've heard of people having actually I know somebody who had one that went in, in the end that was redone, but yeah so that that's, on a day-to-day basis I pretty much manage that well. (15-16/531-534) It's a winter hand warmer as well now! (28/988) And and then and now it's um I went I went down to Southampton to see a customer and I was going all the way down there and and it was when my wife wasn't working for a few days then so she came with me and and we stayed over and we stopped at the stone henge, and had a weekend in Bath on the way back, but when we were driving down (laugh), she says "do you think we can stop at some point because you might not need the toilet but I really do!" (laugh) (29/998-1003)
3	Yeah, you know it is what it is and without it um oh well I frankly could have been dead by now. (7/215-216) I'm just not the type of person who is going down the "poor me" route, you know, "why me?" and all that kind of stuff. (11/359-360) You know, I've got a wife, I've got son, daughter-in-law, three granddaughters. So, you got lots to live for. (11-12/366-368) We booked, we booked a cruise in January, so we're going on a cruise. So, things are coming back to some sort of normality. (12/382-384) Yeah, keeping busy and I mean I can honestly say that the majority of the time now I don't even think about the fact that I've got stoma. (12/391-392)
5	Yeah, I was to be honest, quite shocked at sort of how bad some of the people's experiences had been and uh really grateful that all had gone well with me. (3/94-95)

	I've taken to it quite well really. It's only since I've actually started getting involved with, um, a couple of other groups and sort of heard the experiences of other people that I've realized how lucky I've been really (laugh]. (3/74-76) I'm still taking diuretics to try and shift some of it, but um it it doesn't me leg sort of really swells up, I call it me elephant leg (laugh). (5/161-163) When it was bad I could always think well it could be worse, so (laugh). (8/278-279) I suppose that it's brought me some benefits recently in that I got approached by um a charity uh [charity name retracted] they're called. (9/285-286)
6	Because some people get to hospital and they go through all that and then they're told there's not a high dependency unit bed for them, so they get sent home. So I was very lucky, you know, and it was all systems go. (9/299-302) For me, best thing of all out walking the dogs out walking the dog, I can just go behind a tree like he does and do a standup wee. (14/479-481) I've got a very good friend who's got MND, who's the same age as me, and she's unfortunately, you know, very incapacitated. And and you know if ever I'm feeling a bit like "oh should I go swimming or not?", I think "yeah, get off your arse and go and get in that pool, because [name retracted] would give her eye and teeth to be swimming in that pool". (17/570-574)

Ways of Coping - Acceptance Being an Active Choice

Participant	Extract (pages/lines)
2	I decided very early on that I had to kind of I thought this is me now I have to kind of take control of it. (7/243-244) I think the key thing for me is that you have to take control of it yourself, you have to go "this is me now and I can take control and I'm gonna work for me, it's gonna work for me." (21/717-719) So you you've got you've got a kind of take ownership of it and be prepared I think. (24/829-830)
3	Clearly, the stoma is a real nuisance, uh but it's something you've just got to learn to live with and manage and cope with. And and not let it hold you back. Just just um move on. (5/141-145) I think I think if you are positive about it and and decide that it's not going to um radically change your life. (6/195-196) So it it really so my attitude and my wife's attitude has been very much one of well, it's there, we just have to live with it. And we have to deal with it. (10/310-313) It it is me, it was me. And I've just gotta get on with it. (11/362-364) You either let them beat you and become a uh real victim, or you take them on board and say, well, you know um it's happened, let let's see what we can do. (19/627-628)
5	I've come to terms with it and I don't have any sort of lasting emotional trauma or whatever you call it (laugh). (8/269-270)

	I was up for it, wanting to get on with it, basically. It was sort of a positive attitude to it I suppose that incapsulates it. (11/376-378)
6	The minute I walked through those doors in the hospital, I was very focused and I thought this is gonna happen and I've just gotta get on and there's nothing I can do, and crying's not gonna help me now. (9/310-312) I just went into a different mode and thought I've gotta get on with this and you know, I wasn't being brave. I was just it was just self-preservation really. There's no point crumbling, even though I felt like it, you know [laugh]. (10/324-327) I make myself go on aeroplanes because I want to go to Greece and I want to do all these things and otherwise it it it'll defeat me. So, I haven't let it. (15/503-505)

Ways of Coping - Adaptations and Adjustments

Participant	Extract (pages/lines)
2	I now use these more than anything, if I’m exercising or anything I use these. (10/348-349) But what we did very early on and still do is we have a a very good quality mattress protector that goes on. It doesn't feel like a plastic. Like that. And then we put a bed sheet over that. So, if we go away or anything like that, we always take them with us. (12/421-427) I have a night bag; night bag I have um I keep one under my car seat. So, if I go any distance in the car. (16/536-538) And and if I am anywhere where there’s a toilet before you know if I go out uh for if you know we go to um I don’t know a restaurant or something I always empty before when I leave. Or even sometimes shopping I go “oh there's a toilet”, I’ll just go over and empty one here. (16/545-550) I have a like a little man bag thing that I've got that will take a couple of these in it and some wipes and things. So, if I were to have a problem and now I can actually even slip (if I roll them up tightly) a t-shirt and a pair of shorts in there, if I need to. (18/630-634) The other thing that I do actually, just is the intimacy side of things is for that I used to have a t-shirt, to keep the pouch tucked out of the way. What I tend to do now is, I now put that around my middle. And where the pouch hangs down like that. I just sort of fold that out of the way and just rest that little bit on your belly, and I put this over the top and that's just keeps it getting in the way. Little things like that you know and again, okay, it's things that are maybe not spontaneous as they might have been before, but you know it's still can be a bit. So you, you gotta get creative with these things. (30-31/1068-1081) When I go for like spin class or I’m out on the bike I've got I've got like Lycra shorts that are padded shorts that I wear, but I now just put a pair of shorts on over the top and for a long time I was just putting those shorts on and putting that over the top of my pouch. (31/1087-1090)
3	We'll play golf at [retracted location]. There are, there are toilets on the course. Um and if I run short one of them, there’s plenty of bushes on the course (laugh). We we find a way around that. So no, it really affect me at all. It's not like I would be concerned about going anywhere um in case there wasn't a loo. I just, you plan ahead. If I go to a concert, I will go to the loo before it starts, at at

	the interval, whether I need to or not. Just to make sure everything's good. Once it's done, you can relax. (13/407-419) Um not really as a as a slight bulge there on the on the right-hand side of my tummy. But you adapt you know what I mean? (6/205-206) I mean, I think I, the things I do have to think about, like we're going on this cruise, I we're we're we sail out of Southampton, I would have normally flown that, but I can't I can't risk losing a bag with all my paraphernalia because I need. (14/258-260)
4	Well to start with you don't wanna go anywhere. You know, you basically want to… I suppose it's partly depression and partly, you know feeling that you just can't cope with things. Um but yeah, you can't you've got if you're thinking about public transport, you've, if you've got to get a bus or a train anyway, you gotta think about how long you going to be on, whether you need, whether there's gonna be any delays and problems that could ensue from the delay. (7-8/237-245)
6	I think the biggest thing for me is that I do need to know where a toilet is all the time and I get a bit panicky if I'm in a if I'm in a strange place or a town. (14/468-470)

Narratives Around One's Stoma, Bladder, and Body – Loss

Participant	Extract (pages/lines)
1	I said it at one of the meetings, I said you know, like sex is not the be all and end all and everyone just turned around says well, it's part of you, you know. It's part of being a human (laugh). And especially since I've, you know, I started up a new relationship, which is sort of you know (laugh). You can't do anything (laugh). (22-23/736-744) I used to I used to run marathons, I used to be really fit. (25/810) It's it's just completely changed me all this. And and and sometimes I am thinking, why the hell did you do this? Why did you have this operation? Um it it seems so barbaric, it's just it's just not, yeah, I it's just yeah it's just horrendous. Horrendous. (23/761-769)
4	Depressed. Shocked. The the reason, I mean, we didn't go down that route to start with. I was trying to push for uh, something a little simpler and less invasive. Less, less radical. (1/22-30) Things start to go through your mind "you might not be around for an awful long time", um "that you it might be worse than they're saying", or "it might not be as clean cut if excuse the pun (laugh) as I expected". No, you just you know, it's very difficult not to descend into some form of a depression really. Because the the outlook is very bleak. (4/116-124)
5	It had been like a nightmare. I'd have to rush to the loo, and I was peeing myself, it was horrible. So yeah, it finding it was going, I was quite chuffed, to be honest. (2/36-39) I turned to food, so I've put on quite a bit of weight, which does um upset me a bit. I was always very fit. Um, sort of a couple of weeks before me surgery, I was like up a mountain in [location retracted]! (laugh) And uh that's sort of all gone by the by now. (4/110-116)
6	But confidence wise it it, yeah, it took all my confidence away, really, and just just a just that I think because I felt quite helpless, I couldn't do anything particularly for myself. (11/369-371)

	And I thought I'm gonna take six months or whatever it's gonna t- take. I knew I'd get be able to get signed off on sick leave and I just wanted to focus on myself, and I thought I'm too young to to to give in to this. (6/184-186)

Narratives Around One's Stoma, Bladder, and Body - The Gift of Prolonged Life

Participant	Extract (pages/lines)
4	And the whole thing, you know, it's completely life changing. You know, nothing, nothing's going, the only thing that you think about later, not at the time is well at least you're alive, you know. You've managed to postpone things. (4/128-133)
5	I was just matter of fact, to be honest. Um happy if anything um, I was uh when they sort of got all the details of them, the scans the detailed scans and whatever it turned out that they thought my bladder cancer was muscle invasive. So really it took a lot of the other options off the table, and it was it was basically the only decision to be made um I yeah, I I saw it as I'd be rid of me bladder at last. All the problems that it has brought me so yeah, I wasn't too distressed at all. (1/23-29)
6	I thought of my bladder like a fruit bowl, and it had got rotten fruit in it. And I thought I just want it out. I just want it out and I don't want to try and save my bladder. It's trying to kill me at the end of the day and that's how I that's how I that's how I processed it really. (7/229-235) Some of it is just an acceptance bit in a way, because you're so grateful to come through it, you're so grateful to wake up after the operation, you're so grateful for this you know chance of life again. You know, this is without doubt I wouldn't be sitting talking to you today. It was that aggressive. It was that serious. I I wouldn't be here. So, and that to me is, you know, my stoma to me is everything and uh and I think yeah, I think it's it's just you know the loss of any sex life is for me is is a I'm happy to pay that price you know [laugh]. (19/663-671)

Narratives Around One's Stoma, Bladder, and Body - Relationship to the Stoma

Participant	Extract (pages/lines)
2	And at that point I'd obviously, you know, you see this stoma on the side of you and you've got to deal with it, and you're very aware of it, and you, you don't know how to treat it. (7/222-224)
3	As you get more confidence in the whole thing, I mean for a start when we were going out, I would take a bag with a spare urostomy pouch and and all the parts I would need to change it in case that leak. Of course, if you have a leak, it means you got take a change of clothing. So, I did that for a start, just because it was common sense. But but the more confidence I've got now that that doesn't happen. (14/434-441)
4	But if you have a different mechanism like a bag that's filling up you, you can't avoid it because the next thing that happens is you get a leak, and it bursts. That's so embarrassing when that happens. (6/183-186) You have to get into this regime where you are changing it every few days and they don't get- it doesn't actually take um, it's not something that you could just say "okay, take one off, put it on it". It um it it takes the best part- by the time you've you've sorted all the bits and pieces out by the time you've cleaned yourself up, by the time you've managed to get all you know, get the original one off. And prepared the um your you know the surrounding skin and everything, ready to receive the new and then tidied up afterwards. You know the best part of an hour's gone. (6-7/197-207)

5	I don't find the the urostomy a problem at all, really, I just manage it as part of my daily routine. (3/71-72) I've even given him a name, he's called “Stomy” (laugh). I'd characterize him as a sort of wilful child if you like (laugh). (3/86-88)
6	So, um yeah, quite um funny, but I, you know, I think I did have a, I wouldn’t say I hated it, but I had a bit of a love hate relationship with my stoma at first and and of course you're getting used to trying to um you know, getting used to changing the bag. At first, it seemed like forever and and you know my stoma, you know, obviously it wees when it wants to wee, you know you've got no control. (7/435-439) And I do think if I say to you, I called my stoma the “alien”, it will tell you a bit about how I felt about it. You know, I was I was cross that it had happened to me, and not “why me?”, because “why not me?”. But you know why? You know this you know this little stoma; it looks like a strawberry on my tummy, you know, but I look at it now and I still, I still call it the alien, but with much more affection, you know [laugh]? And actually, I can't imagine my life without it now. And I very often say it hasn't changed my life for the better, but it hasn't changed my life for the worst either. And that's how I genuinely feel. But I recognise in the first year, I didn't feel like that at all. (12/404-416)

Narratives Around One’s Stoma, Bladder, and Body - A Challenge to be Overcome

Participant	Extract (pages/lines)
2	I had the bad one on the on the New Year's Eve and that had leaked in the night. Um what I did there was ‘cause it was a the the the bathroom we had there was it was a wet room. So, I just I actually up until that point I had always showered with my pouch on. Um but I just took the pouch off, and I and I showered with it without it. And actually, found that much better to clean round it and everything. (14/468-478) So, I am conscious that so far, I've been very lucky, but I also I'm conscious that things might change in the future, which is why I I'm always keen to sort of share my my experiences and things that I’ve tried, and hear from other people. (20/692-694)
3	Being a realist, as I get older, I didn't want any problems with a neo bladder. That would give me ongoing issues as I got older. (5/149-152) I mean we we looked on the whole experience as a matter of fact, I I had a lot of friends who um, that were facing um prostate cancer issues, et cetera. (9/298-299)
5	And that was it, you know, so it was just buckle down and get on with it really. (2/63) I was just matter of fact, to be honest. Um happy if anything um, I was uh when they sort of got all the details of them, the scans the detailed scans and whatever it turned out that they thought my bladder cancer was muscle invasive. So really it took a lot of the other options off the table, and it was it was basically the only decision to be made um I yeah, I I saw it as I’d be rid of me bladder at last. All the problems that it has brought me so yeah, I wasn't too distressed at all. (1/23-29)
6	So it's just a case of persevering really and having a good stoma nurse who will say we'll try this and try this. (23/789-790)

Relationships to Others - Trust and Dependence on Healthcare Professionals

Participant	Extract (pages/lines)
1	So the consultant the before you know eight weeks before didn't know what he was talking about. He was telling me something that wasn't true. (laugh). (6/197-202) I mean (sigh) for all intents and purposes, the cancer might've spread within that eight weeks, you know he was playing with my life basically, I was really, really 'cause I was on here, I had no one to talk to at home. I felt, yeah, I felt sort of, well scared, really scared. And um I felt angry about the uh, you know, the chap. (7/205-211) Apparently, there wasn't um, there wasn't a doctor on the call, which there should have been by by law, there should have been a doctor on call for that ward. And so these alarm bells are going. (13/413-417) And and the misinformation or not information that within the NHS is just it's not good. It really isn't good. Really isn't good. (24/800-803)
4	Why I've got involved in the bladder group is that um (sigh) because there isn't this help, that there needs you need to be there for people to ease ease them through this process. And and then it's up to them to ask the question. But you you know, unless unless there's somebody there that they can trust and get reasonable answers for, they're on their own again. (15/491-497) For some reason they resisted going for something as simple as an ultra-scan, which came up with well from my point of view the wrong answer, but you wonder if it had been if it had, how long, how much longer it, or how much worse it would have been if it hadn't been done at that stage. (16/530-533)
6	I can only explain waiting for that phone call for them to give me the date was like you're desperate for it to happen because you just want to get on and get it over with. And the other part of you, the other part of me was absolutely terrified every time my phone went and it was like number, no known number or whatever it came up, and you just know it's the hospital or the doctor. And it's like the worst phone call, but also a bit like the best phone call because it meant I could get on and fight this part. (8/246-254) And again, lots of you know more sort of cardio tests and a morning at the hospital for all the pre assessment checks and meeting the stoma nurse and uh yeah, and yeah, just it just felt like I was in this I don't know on this path, and I was just gently being nudged along. And I couldn't quite put the brakes on and stop it (laugh). (8/260-265)

Relationships to Others - Understood and Supported

Participant	Extract (pages/lines)
1	I've since joined in a urostomy um group. They do have, we have had a couple of meetings. We've talked through stuff and we have gained information from each other. You know fellow “urostomates” as it were (laugh. (19/625-629) I got some counselling. I'm supposed to have six, but I ended up having 18! (laugh) 18 sessions! Until eventually I just I did feel a bit better having that. 'Cause I had someone to talk to. It was some someone to get everything off your chest. (23-24/776-785)

	So, I sat down with this chap and we had, you know, a few glasses of wine. And we actually talked about our situation, which was great because I think that's the problem with males as well that they don't they don't talk, you know, they don't talk to other people about it. So that was a fantastic opportunity to do that. (30/980-985) Because I have I've met with this chap, and I have talked about it. It did feel good. You know that at least someone else understands. (30/998-999)
2	And you know it when you hear about the different things that people do it you think oh, I might try that and it makes you feel this isn't so bad. (20/975-976) You learn as much really from people that are um doing the sort of same thing in the same situation 'cause as much as the sort of the the the medical teams and the stoma nurses are very knowledgeable about it. They don't have, they're not living with it. And they'll pick things up from people, but they know they don't you know, not living with it they don't quite understand, you know. (19-20/668-676) I've had a colleague as well, who I work closely with and she's been through bowel cancer and and and that stuff. So, she she was a big we kind of were a big help to each other and uh in in that respect. (24/840-844)
3	I mean the opportunity to talk to other people who'd been through the same thing, was was one of the best things. You could talk to you could talk to clinical um people, consultants, as long as you like. But you know, talking to people who've actually gone through it. And are facing the day-to-day issues of living with the stoma or neo bladder or whatever. Um, I found the the most helpful for me. (20/644-651) Uh so I'm very lucky that the support I've had from my wife has been excellent. Um, because not having that um support, um you know, you could have handled it totally differently. (10/315-318) I um reached out for some help and support and advice which I got through Macmillan. And I I've got nothing but praise for them, they they were fantastic and they are fantastic. (18/589-593) When I first contacted the doctor in [retracted location], it was early stages of the uh (cough) the non uh non-muscle invasive bladder cancer and she actually had plenty time to sit with me and my wife. (8/261-263)
5	After the surgery um I had um a lot of help from the family getting me out and I was walking every day and sort of really started getting uh quite fit again. (4/130-132) I mean, the family have been brilliant really. Uh my brother actually works abroad a lot and he was living in [location retracted] at the time and he actually came home with his wife to sort uh of help out and sort of look after me during the surgery. (5/172-175) So, no, family they have been sort of huge huges um sort of boost to me really. (6/188) The um the fellow they put me in touch with, um he was fantastic. We ended up going down the pub and having a couple of pints and having a real good chat about it. And um he gave me well he the one piece of advice that got me through it was that he said "look, I'm not gonna lie, it ain't very nice after the surgery and the physios will come and drag you around and make you do things, and you will not want to do it, but persevere. It really will help you an awful lot". And when I was in the post operative stage um, I thought to what he said and I felt like I'd got someone with me who'd been there before, sort of thing. (10-11/347-357)

	It's been a huge help. Cause until I met them I did feel a bit like I was a sort of on me own, really. But yeah, getting out there in the world and uh finding out about other people helped me a lot as well so. (9/311-315) And through them, I've talked to a lot of people. That's how I've sort of met people who've had sort of similar problems. (9/288-289)
6	You need a good stoma nurse. And I was very lucky, I had a brilliant stoma nurse. (22/771-772) I mean, I'm lucky I've got a very supportive husband and um yeah he's he's great. And and I would, you know, he has been the linchpin to my recovery, without a doubt. Without a doubt, yeah. Couldn't have done it on my own. I don't know how people get through something like this if they are on their own. (15/510-515)

Relationships to Others - Alone and Neglected

Participant	Extract (pages/lines)
1	It's just the loneliness. It's the being on me own with all this stuff to to contend with uh it again, you know there's no magic Macmillan holding your hand sort of thing. (28/915-916) Yeah, it's the isolation kind of it's a big killer. It's it's just, it's horrendous. (28/921) But if I was to not have that relationship and try to form a new one, I now look like a 25 stone chap with a bulging stomach. Who has no sex life, who has to carry a duffel bag around with him if he goes out for a meal or a pint or a concert. And so, what chance have I got? You know, which is really depressing. Who's gonna take all that lot on? So, I think that makes me feel really lonely now that that just eugh. (25/827-839) Yeah, and so she got all the support in the world (laugh), but I I didn't. Uh so when I rang up Macmillan and people, it was just, “yeah, we'll send some booklets out”. (4/110-113) I’m having me BCG and the nurses were you know, really nice but yeah. But yeah, it’s just “ah yeah you’ll” and I’m like well, what happens next? Well, they’ll give you a call sort of thing. (Laugh) So there was no. Yeah, no no support really. (4/119-124) And as like a day patient in [location retracted]. That was one thing when I was going through it, I I I felt like I was… You know, there's all this thing about Macmillan and stuff like that holding your hand while you're going through it. I just felt like a day patient and there was no support really and, at all. (3/86-90) And he said about the hernia he says “well you just live with it” and away he goes sort of thing (laugh). (16/542-543)
3	I thought communications were very poor. And they, you know, I think there was, I think he handed me one leaflet about that that that will tell you some information about bladder cancer, but that was about it, I wasn’t offered any any help or any any any number that I could call. For any information or support. (2/52-58)
4	It's a learning curve and it gets quite, it's quite steep at first. And and they don't. The problem is they don't tell you very much. And you’re left you’re left on your own to work it all out for yourself. (7/219-223)
6	But I think for me sort of mentally afterwards it was it was hard because all of a sudden there was nothing. You know, I'd gone through all these tests and

	treatments and chemo and the big surgery and the check up in after the six-week check-up, and then it was sort of like nothing and it was like I'd had sort of the best part of seven or eight months of being the everybody's focus and then. And it and I found that quite hard to come to terms with everything that had happened to me. (12/392-401)

Relationships to Others - Impact of COVID-19

Participant	Extract (pages/lines)
1	It was during COVID time, so I had no visitors. But I witnessed, uh one story I've got I I was laying in bed, sort of you know, I couldn't get out of it 'cause I was attached to all these monitors, but I witnessed, 'cause I could see into the corridor, uh there was a group of of nurses came in with their outer outer clothing and they said "oh, yeah, we've just been working on the COVID ward", and they came in and they hugged the the nurses who were who were looking after me! That! I mean, I'm just laying there thinking I (laugh) just thought, well, that that's just ridiculous! (Sigh) I just, I couldn't. I just wanted to get out of there. Because that was frightening. So, I mean at the time COVID was, like, killing people off. And I thought, well, I'm quite susceptible here now, like these nurses are are hugging people that have been on the covid ward with their outer clothing on, that's that's not right. (10/331-347)
2	The days fly by and actually it was in lockdown so we couldn't have visitors. And it yeah, looking back now I'm kind of glad really. It would have been a bit of a nuisance. It'd have been a nuisance because my wife would have felt she had to come and drive over to [location retracted] anyway and obviously you talk to people on the phone. (6/188-195)
3	Um luckily, my wife is with me. But it it was the start of covid, so she was in the car, she couldn't come in with me, so I had to go out and tell her in the car that, you know, I've been diagnosed with bladder cancer. (2/44-48) Most of my initial meetings with him were video calls. Because because of covid. Um the video call where he and his colleague uh were wearing masks! (21/681-685)
6	We were so isolated because, you know, we weren't seeing anybody like everybody else and he couldn't come to any appointments. He drove me there. Just sat in the car park for you know, sometimes hours and waited for me. And you know, we we ended up having to tell our family by phone call or, you know, on a on a on a zoom or FaceTime type thing. And that was incredibly incredibly difficult and had a massive impact. Yeah, massive impact because we couldn't we didn't, I mean, it was such a bombshell anyway, and we couldn't soften the blow by, you know, just sort of all having a hug sort of thing. It was a tough, you know, that was a tough time. (2/42-56) Yeah in a way, it was the worst time for us to be diagnosed, but in a way, when I look back on it now, it was actually in retrospect, it was quite good because we were left alone and there weren't people fussing around us and just dropping in and saying, oh, we know, you know, can, you know, we see you for a cup of tea when actually we were really struggling. And so, it it was a double edged sword, I suppose is the best way to describe it. (2/62-68)

The Role of Information - Receiving Information from Healthcare Professionals

Participant	Extract (pages/lines)
3	The way I was told wasn't very good either. I went, I went, I had an appointment to go to [retracted hospital name]. Um for a flexible cystoscopy, to see the extent

	of or see about this this um tumour that that they had spotted. But when I went there (cough) the nurse said “no, you're here to see a doctor”, I said “no, I'm here to get this procedure”. She said “no, you’re here to see the doctor”. Now, the doctor I saw said I can I can arrange for you to have one if you wish, but I can tell you looking at the ultrasound scan that you have bladder cancer. Just like that! (Laugh) And and and no, no preparation. No no warning. (1/25-42)
4	When you look at what professionals do, you get a 10, 15-minute appointment and that’s it. You get a face-to-face. You're in there for maximum 15, maybe 20 minutes. That's that really is a long time, but they don't, they don't have very much to say. They're just outline what's what and see you next on whatever it is. You know they, to them they’re just, it's very black and white, and they're just doing their job. They don't seem to have any much empathy for the patient, really. (15/503-511) It's upsetting, it’s um it's something you feel you know you can't do- angry comes mind you get yeah you get angry that that you're not getting more help. It's not been explained properly or that you just left with a brochure, you know. It feels cruel too as well. (16/514-519) To get a doctor to ringing you up at nine o'clock in the morning. When you're half asleep because you've had, you know you you didn't have much sleep the night before. And saying is that whoever it is, you know your name? Yes. Well, we've got the ultrasound results back, you've got cancer! (16-17/540-547) The fact that it was done on a telephone call that time, you know, that will live with me for the rest of my life. (17/559-560)

The Role of Information - Uninformed and Unprepared

Participant	Extract (pages/lines)
1	I had two appointments. I had one with the the surgeon and then that was on the Friday. And then there was an- and a meeting with the radiotherapy woman on Monday and I was led to believe that then I had a choice between having the surgery or having radiotherapy. And so, I went to the surgeon on the Friday and he said, yeah, you need the operation. And I said, well, I'm going to see the radiotherapist on on Monday. He says, well, yeah, you you can go, you know, you need to go and find out uh but it turned out that radiotherapy wasn't an option. Completely not an option. It was a point I I felt I was wasting NHS time by seeing the person that it was blatantly obvious that the NHS, that it was, it was not an option. Again, I was angry. (8-9/268-283)
3	There was this one new test that I didn't know anything about, hadn’t been given any information, this is all about lack of information. Nobody had explained to me what it was, what they would do, how they would introduce this camera to check things. (17/540-543)
4	You don't find that this out until afterwards, really. It's not (sigh) it becomes a possibility that it's life changing, but you don't understand what life changing is until afterwards. When it's happened. (5/141-146) They don't tell you very much, but they just offer you a brochure or booklet and say you know “read this” - well, the last thing you want to do is sit and read what they are, a load of um literature on something that may or may not affect you, and at that time you're in denial. You don't want to believe that it's it's happening to you. So, you don't want to read it. The last thing you want to do is to pick it up and find out what it's all about. Um, and one of the things they don’t tell you is that, well you can read it in parts of it, you know you, I’ve not only had uh a uh a radical cystectomy, I’ve also had a uh ended up with uh the prostate being

	removed as well so that that was the double whammy. Um which has resulted in being completely impotent. So… When you talk about life changing. (9/288-306) Whether it's inevitable or not, you still like to know, you know when you're on this desert island, whether or not the tides, how soon the tide's coming in, and whether you're gonna be swamped. (14/471-473)
6	And maybe some of that is me think when I look back, maybe some of that was me thinking that might be something, but I wasn't allowing myself to think that actually it could be something more serious, maybe, I don't know. You know, sort of try trying to ignore it and bury my head. (5/147-151)

The Role of Information - Taking Matters (of Information Seeking) into Your Own Hands

Participant	Extract (pages/lines)
2	It's like trying to preempt what might happen, and obviously you get a bit of advice from people beforehand and and you pick things up as you go along and and and I've I've read various forums and things like that um and that's all helpful. You know so, and I am I we do have a locally a stoma support group. (19/658-662) I knew I have this cancer inside of me and and and that that anxiety that you have about I want rid of this, I want this out, I need this so you know it's and and and and I did a lot of um chasing up myself and ringing people pushing for the you know really being taking ownership myself really and finding out how what was out there and and and what to expect and I think that probably prepared me well. (4/119-123) It's the beforehand was probably worse than the after. That six months before, because it's the fear of the unknown. You don't know and you're thinking oh my God I'm going to be walking around with a plastic bag stuck to my belly for the rest of my life, how's that gonna be like? I'm probably gonna get leaks cause people try and warn you about, you know, I've still got literature here that they gave me, you know, with all the uh it's about uh well, that's prostate cancer. And then I've got these things that that I I got from the the you know the hospital and I tabbed the pages that I thought were relevant to me at the time. And and then you're looking at forums online and things like that and and trying to figure things out and you take yourself down rabbit holes. (24-25/846-860)
3	Um it was um very worthwhile and it it um it answered lots of questions that were going through my head and my wife's head at that time. You know, clearly you don't know anything about these things. (10/274-277) There was this one new test that I didn't know anything about, hadn't been given any information, this is all about lack of information. Nobody had explained to me what it was, what they would do, how they would introduce this camera to check things. (17/540-543)

The Role of Information - Expectations

Participant	Extract (pages/lines)
1	Once someone mentions the big C word you sort of you, especially the experience I'd gone through with me wife. (4/129-130)
3	You think if suddenly someone says you you've got cancer, you know "the big C" and all that kind of stuff that you might you might um really be concerned about,

	but it was just a matter of fact. I was told it was there, I think one of the good things was I was still feeling alright. You know, I I it hasn't affected me physically. I was still, you know, I was still carrying on as normal. So, it wasn't like I was really ill. (10/324-334)
5	I was almost expecting it. I first or how it came about was that I've had a benign prostate problems for many years. So, um was used to having sort of pain on urination and urgency, and all the things that go along with that. Um but I started getting much more severe pain and so I went to the doctors who um put me on antibiotics for a urinary tract infection, but also took um urine samples. Um turned out that that the urine samp- samples were sterile, but I had white blood cells in them. So, uh I suspected then cancer, and I went and had a cystoscopy which confirmed it. (1/4-13)
6	I don't think it was out in the in the public domain or I wasn't aware of it. I've never seen anything with symptoms or anything. Didn't cross my mind, to be fair to the GP who sent me down the gynae route I I thought “well, you know, I'm 58. I know I'm I've gone through the menopause, but you know, maybe there's a bit of a, you know, sort of bleeding every now and again”. And so, I didn't really think too much about it. You know, looking back, I think how how naïve, how stupid you know? Because maybe if I'd gone, you know, six, nine months previously when the first symptom occurred, I think the problem was I had this little episode of this sort of pink on the toilet tissue and then nothing happened for a month or so, so I just disregarded it and I think that I don't think that's uncommon. But had I heard of bladder cancer and known of the symptoms maybe I would have twigged and thought I wonder, but who knows? Never gonna know. It's just not out there. It's not like breast or bowel cancer. It's just it's getting there; it's getting better and people like [charity name retracted] and [charity name retracted] and [charity name retracted]. They're they're doing fantastic work, you know now. And it is getting there. But I still think there's a long way to go. I don't I don't know why. I don't know why there seems to be a reluctance to talk about it. (3/79-105)