The relative contributions of function, perceived psychological burden and partner support to cognitive distress in bladder cancer

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Abstract

Objective: Bladder cancer is a genitourinary disease of increasing incidence. Despite improvements in treatment, outcomes remain equivocal with high recurrence rates. It is associated with poor psychosocial outcomes due to reduced functioning of the genitourinary system. The objective of these analyses was to query whether reported loss of function or the perception of psychological burden caused by this functional impedance was the key to understanding psychosocial outcomes.

Methods: The sample comprised 119 participants with a confirmed diagnosis of bladder cancer. They completed a self-report questionnaire comprising the Bladder Cancer Index, Mini-mental Adjustment to Cancer Scale, Psychosocial Adjustment to Illness Scale and standard sociodemographic details. Simple mediation and serial mediation were used to explore the potential for psychological burden to mediate associations between loss of function and cognitive distress, and the potential additional contribution of positive partner support on these relationships. Age and duration of cancer were considered as covariates.

Results: Simple mediation demonstrated that the association between function and cognitive distress was fully mediated by perceived psychological burden. Serial mediation, which allowed for the addition of partner support, again demonstrated full mediation, with partner support being the key predictive variable.

Conclusions: These analyses emphasise the importance of an appreciation of individuals' interpretation of the burden occasioned by bladder cancer and the role of a supportive partner. The implications for management discussions and support services in alleviating negative psychological outcomes in bladder cancer are highlighted.

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Introduction

Bladder cancer (BlCa) is a genitourinary disease of increasing incidence [1]. Despite continued improvements in treatment options such as transurethral resection of bladder tumour, intravesical chemotherapy and immunosuppressant therapy, radiotherapy and cystectomy [1], outcomes remain equivocal and entail long-term surveillance with repeated cystoscopies [2,3]. In approximately 30% of cases, the disease is muscle invasive, commonly leading to metastases and death within 5 years despite aggressive treatment [4]. For the remaining 70%, the cancer is superficial and restricted to the bladder. Even among these latter cases, a 50–70% recurrence rate is experienced with the progression to muscle invasion still possible [1]. While treatment seeks to preserve life, it is often at the expense of independence and functional ability, the impact of which can significantly challenge quality of life [3,4]. In addition, despite the awareness of BlCa as a stimulus for psychological distress, the supportive care needs and

psychosocial concerns of patients remain understudied [2,3,5]. Therefore, the overall focus of this study is to examine patients' functional evaluation of BlCa, their perceived psychological burden of the disease and the role of a supportive partner.

Cognitive distress in cancer patients

One way in which the quality of life of patients may be impacted is through cognitive distress, which may incorporate intense worry and be characterised as help-lessness [6,7]. Constant rumination about cancer, coupled with the belief that treatment is futile, encourages doubts and places patients under severe stress [8]. Such negative beliefs may culminate in depression and anxiety [8,9]. Further, cognitive distress may lead to information seeking that does not translate to an adaptive benefit but rather sustained anxiety [6,7] and a fixation on the physical state, with all somatic cues interpreted as cancer related [7].

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Functional evaluation versus perceived psychological burden

The initial aim of the study was to consider potential associations between cognitive distress and both the functional evaluation of BlCa and its perceived psychological burden. At the functional level, there is an almost inevitable impact on urinary, bowel and sexual performance following treatment for BlCa, which can impact, for example, on relationships, employment and self-esteem [4,10,11]. In particular, there is a loss of control over bodily or stoma function leading to changes in urinary frequency, incontinence and leakage [12]. Accommodation of this decreased function can be a difficult, prolonged process. Therefore, the first hypothesis tested was that poorer functional evaluations would be associated with higher levels of cognitive distress (H1).

Separate, albeit related to functional evaluation, may be individual psychological interpretations of the impact of BlCa. These perceptions of psychological burden include an interpretation of the significance of BlCa in individuals' lives [10,13]. In the current study, it was hypothesised that poorer psychological perceptions of BlCa would be associated with higher levels of cognitive distress (H2). It was further hypothesised that psychological burden would mediate the association between functional evaluations and cognitive distress. That is, more positive perceptions of psychological burden (i.e. less burden) would protect against the cognitive distress occasioned by a poorer functional evaluation of BlCa (H3). Age and illness duration were also included as covariates, on the assumption that time with BlCa and maturity may lessen cognitive distress.

Partner support

Finally, the role of psychosocial support in adaptation to cancer was considered, with lower cognitive distress expected among those patients reporting positive relationships with a life partner [14,15]. Results from previous studies, for example, have noted reduced hospital stays in cystectomy patients, improved laboratory results and survival rates, lower depression and decreased rates of alcohol and tobacco abuse among married patients, whereas increased use of mental health facilities is evident among non-married patients [16,17]. It was hypothesised, therefore, that higher levels of partner support would be associated with lower levels of cognitive distress (H4) and a more positive (lower) psychological evaluation of the burden of cancer (H5). The potential for positive partner support to act as a protective mediator in the association between functional evaluations of BlCa and cognitive distress was also tested. Specifically, partner support was entered as the first mediator in a serial mediation model, with its action proposed to mediate the association both between functional evaluations and psychological

burden and between functional evaluations and cognitive distress (H6). Age and illness duration again were entered as covariates.

Methods

Participants and procedure

Approval was granted by both the authors' institutional research ethics committee (for community-based participants) and a local governmental research ethics committee (for the use of a hospital database). Potential participants had a diagnosis of BlCa, were at least 18 years of age and had a sufficient command of English to allow completion of a self-report questionnaire. Three main strategies were used for recruitment. First, access to a local hospital BlCa database was sought. Second, the study was presented to members of community-based support groups. These included specific BlCa organisations (e.g. Ileostomy Association), other related health groups (e.g. Continence Nurses Society, Urology Nurses Association and Continence Resource Centre), general cancer support groups (e.g. Cancer Council SA) and general age-based community organisations (e.g. senior citizens clubs). Third, a modest number of community-based participants were accessed through private urology clinics.

Contact with potential participants was by telephone, by mail or in person depending on the recruitment source. In all cases, the study was briefly described, and those willing to participate were provided with a more complete study description, questionnaire and reply-paid envelope for its return.

Measures

A questionnaire was compiled specifically for the current study, comprising sociodemographic and disease-related questions and the following validated scales.

Bladder Cancer Index

The Bladder Cancer Index is a reliable and valid 36-item scale that is applicable to both men and women and also participants with either a native bladder or cystectomy [2,12,18]. Both degree of function (functional evaluation) and bother (perceptions of psychological burden) are assessed across the three domains of urinary (14 items), bowel (10 items) and sexual health (12 items). Issues covered include frequency, leakage and dribble (urinary domain); urgency, stool consistency and pain (bowel domain); and desire, ability to achieve orgasm, pain and frequency (sexual domain).

Participants were asked to evaluate the relevance of each issue surveyed over the past 4 weeks using both 4-point and 5-point response scales, which were summed and standardised to produce final scores in the range of 0–100, with higher scores denoting better function and

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less burden, respectively. For the current study, total functional evaluation and psychological burden scores were calculated across urinary, bowel and sexual health items. Internal reliabilities (α) were 0.80 and 0.84, respectively.

Psychosocial Adjustment to Illness Scale

The self-report version of the Psychosocial Adjustment To Illness Scale (PAIS-SR; [14]) was developed from an earlier interview tool. Its reliability and validity have been demonstrated across an array of diseases [19–22]. The PAIS-SR surveys a number of psychosocial domains observed to be associated with adjustment to medical illness. Participants responded with reference to the past 30 days using 4-point response scales specific to individual items to quantify the extent of adjustment in each domain. For the current analyses, only domestic environment (difficulties posed by illness relating to home or family including communication, value of relationships and financial issues) was reported as a measure of partner support. It comprised eight items, with total scores ranging from 8 to 32 and higher scores representing better partner support. The current sample provided an internal reliability figure of 0.79.

Mini-mental Adjustment to Cancer

The Mini-mental Adjustment to Cancer is an abridged 29item version of the Mental Adjustment to Cancer Scale, designed to measure 'cognitive and behavioural responses' to coping with cancer [6,7]. It is a reliable tool for use with various types of cancers and has become a well-recognised measure of adaptation for use in psychooncology [23-25]. Respondents indicate how applicable each item was to them in the past 4 weeks using a 4-point scale ('definitely does not apply', 'rarely applies', 'often applies' and 'definitely applies'). In the current study, cognitive distress, as reported by Hulbert-Williams et al. [26], was used as the outcome measure. It comprises 12 items predominantly from the original 'helplessnesshopelessness' and 'anxious preoccupation' scales. Scores may range from 12 to 48, with higher scores indicative of greater cognitive distress. Internal reliability was 0.84.

Sociodemographic and disease-related details

Data such as gender, age, education level, marital status and employment status were sought along with self-reported confirmation of a diagnosis of BlCa and duration of the disease in years. Treatment outcome was also requested: own (native) bladder, ileal conduit/ostomy, neo-bladder and continent urinary diversion/catheterisable pouch (e.g. Indiana, Koch and Miami). With the exception of age and illness duration, these variables were used only to characterise the obtained sample.

Statistical analyses

Data were analysed using SPSS version 22.0 (IBM Corp., Armonk, NY, USA). Simple mediation and serial mediation were tested using the procedures of Preacher and Hayes [27,28] using a purpose-built macro (PROCESS v2.12.1). For simple mediation, regression coefficients are calculated for the proposed mediator on the predictor (a), the outcome on the predictor (c') and the outcome on the mediator (b). The significance of the indirect effect is determined using a bootstrapped confidence interval (95% CI) following 5000 iterations (c). Serial mediation involves the additional calculation of regression coefficients as described earlier involving the second mediator (a₂ and b₂) and for the second mediator on the first (a₃). The significance of three indirect effect estimates (the predictor on the outcome via mediator 1, mediator 2 and the serial effect of both) was determined using the earlier bootstrapping procedure. For both simple mediation and serial mediation, path c represents the magnitude of the total indirect effect between the predictor and outcome by way of the mediator or mediators, while c' quantifies the direct effect. The use of covariates in these models involved the calculation of coefficients for the proposed mediator(s) and the outcome on each covariate. Prior to these analyses, variables were standardised to enable the interpretation of derived coefficients as β .

Results

Data were obtained from 119 participants whose mean age was 70.7 years (standard deviation (SD)=9.6; range 38–92). They had BlCa for between 1 and 55 years (mean = 8.2, SD=8.8). Treatment outcomes comprised ileal conduit (n=67,56.8%), neo-bladder (n=4,3.4%) and catheterisable pouch (n=3,2.5%), while 44 (37.3%) had retained their native bladder. The majority of the sample was male (n=88,73.9%), married (n=103,86.6%) and retired (n=85,72.6%). Marital relationships ranged between 3 and 64 years (mean = 37.6, SD=15.3). The modal category for education was 'secondary schooling' (n=50,42.4%).

Table 1 summarises the key study variables in terms of range, mean and standard deviation and presents bivariate correlations among these variables. Age was positively associated with illness duration and negatively related to functional evaluation. Reported cognitive distress also significantly increased with illness duration. A more positive functional evaluation was associated with the perception of less psychological burden and better partner support. With regard to hypothesised associations, a poorer functional evaluation was associated with higher reported cognitive distress (H1), and a higher perceived psychological burden was related to higher levels of cognitive distress (H2). There were also strong significant associations in

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Table 1. Descriptive statistics and correlations among study variables

	Range	М	(SD)	I	2	3	4	5
I. Age	38–92	70.7	(9.6)	_				
2. Illness duration (years)	1-55	8.2	(8.8)	0.24**	_			
3. Functional evaluation	17–91	53.1	(15.8)	-0.27**	-0.16	_		
4. Psychological burden	32-100	76.9	(14.9)	0.05	-0.17	0.58***	_	
5. Partner support	16-32	28.3	(3.5)	0.09	0.01	0.35***	0.49***	_
6. Cognitive distress	12-44	16.9	(6.0)	0.06	0.27**	-0.31***	-0.42***	-0.60***

SD, standard deviation

the predicted direction between partner support and cognitive distress (H4), while better levels of partner support were related to lower perceived levels of psychological burden (H5).

The results of the simple mediation analyses (H3) are presented in Figure 1. Psychological burden fully mediated the association between functional evaluation and cognitive distress ($F_{(4,97)}$ =6.91, p<0.001; R^2 =0.22). That is, cognitive distress was attributable more to perceptions of psychological burden occasioned by BlCa than the functional evaluation of the cancer. With respect to the covariates, age and psychological burden were moderately associated, demonstrating that psychological burden was lower among older participants and illness duration was positively associated with cognitive distress. That is, participants reported more cognitive distress with increasing duration.

Serial mediation (H6) is depicted in Figure 2. The inclusion of partner support still resulted in the demonstration of full mediation of the association between functional evaluation and cognitive distress ($F_{(5,87)}$ =13.91, p<0.001; R^2 =0.44). This provided evidence that both a lower perception of psychological burden and higher partner support were protective against cognitive distress. However, inspection of the three component paths that comprise this total indirect effect further indicated that

the mediation was entirely attributable to the path from functional evaluation to partner support to cognitive distress (-0.14, p < 0.05). In this model, age did not make a significant contribution as a covariate. However, increasing illness duration remained associated with higher cognitive distress.

Discussion

Living with any chronic illness requires adaptation to the demands of that illness [13,14]. This is particularly challenging when more significant functional changes occur, as in the case with BlCa [10,13]. Further, inter-individual differences are to be expected in the degree of success with which patients adapt and evaluate their adaptation. The current study sought to explore whether functional changes per se, or perceptions of the burden occasioned by these changes, were more relevant to understanding this adaptation, defined in terms of cognitive distress. The importance of this enquiry lies in the need to understand whether interventions and other support services should be considered on the basis of functional declines, psychological interpretations of the disease or a combination of these issues [29,30]. Additionally, the current study examined whether having the support of a positive partner impacted on these associations.

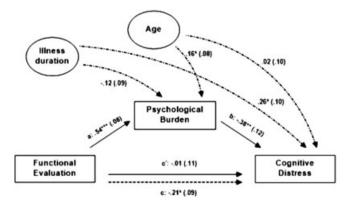


Figure 1. Schematic representation of the simple mediation of the association between functional evaluation and cognitive distress by psychological burden (* $p \le 0.05$; ** $p \le 0.01$)

^{*} $p \le 0.05$;

^{**}p≤0.01;

^{***} $p \le 0.001$ (two-tailed).

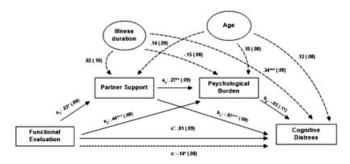


Figure 2. Schematic representation of the serial mediation of the association between functional evaluation and cognitive distress by partner support and psychological burden, respectively (* $p \le 0.05$; ** $p \le 0.01$; ** $p \le 0.001$)

The results of the bivariate analyses provide strong, although not unequivocal, support for the proposition that the functional declines associated with BlCa are related to greater cognitive distress. Such an outcome is unsurprising given the loss of urinary, bowel and sexual abilities implied by the functional decline as assessed in the current study. Such declines involved in BlCa have also previously been noted to be associated with negative cognitive and emotional responses. Studies that have evaluated outcomes after radical cystectomy [12] or both surgical and intravesical therapies [2], for example, have echoed the results of the current study in that poorer function was noted to lead to more negative outcomes in terms of poorer quality of life [2] and more negative body image [12].

Similarly, in the current study, the hypothesised relationships between a greater perception of psychological burden and more cognitive distress were upheld. However, when these associations were entered into multivariate simple mediation models, it was the perception of psychological burden rather than the functional evaluation of BlCa that was more predictive of cognitive distress. That is, greater cognitive distress was more evident on the basis of an increase in perceived psychological burden than participants' functional evaluations of their condition.

The importance of perceived health to disease adaptation is a common theme [29] and has previously been observed among BlCa survivors [11]. Perceived burden of somatic symptoms was noted to have a direct effect on adaptation, negatively affecting both depression and anxiety. More generally, the salience of perceived burden relative to objective health state mirrors the stress appraisal model of Lazarus and Folkman [13], which highlights that the significance of a threat (stressor) is measured by the individual's evaluation of the potential mismatch between required and available resources to deal with the threat. The current data illustrate that loss of function, per se, is less threatening than the perceived psychological burden of BlCa.

The role of partner support was also able to be evaluated using the current data, with more positive partner support being associated with lower perceptions of psychological burden and less cognitive distress in the

bivariate analyses. The contribution to health of social support generally [10] and a positive, supportive partner specifically [17] is well documented. The literature suggests that such benefits are wide ranging and, in the context of BlCa, may include improved quality of health care, earlier diagnosis, improved treatment choices at better medical facilities, less health risk-taking behaviour (e.g. smoking) and lower rates of depression [16]. Earlier hospital discharge, more likelihood of organ-confined disease and less lymph node involvement have also been noted [17].

Further, the noted associations translated into a significant indirect path from functional evaluation, through partner support, to psychological burden to cognitive distress in the serial mediation model. This result may be interpreted as reinforcing the protective roles of both partner support and psychological burden from the negative effect of a decline in function. However, closer inspection of all indirect paths clearly demonstrated that partner support was in fact the key protective factor over and above the more biological state of the disease (functional evaluation). In summary, both the current results and previous studies highlight the importance of the role of emotional support, linked to commitment and attachment, which may positively influence health [8,14–17].

The earlier discussion highlights the context, in terms of previous research, within which the current results are to be understood. However, the findings extend such previous research in as much as the mediation models presented offer a multivariate and more refined consideration of the putative associations among the studied variables. Notwithstanding this observation, a number of caveats need to be highlighted by way of caution. Key among these are the modest available sample size and the heterogeneous nature of the sample. First, the relatively small sample size limited the potential for more complex multivariate analyses such as structural equation modelling. While the mediation results are encouraging, future research should strive to provide a more complete set of paths of the hypothesised associations among the variables studied. A larger sample size will facilitate these investigations.

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Second, the heterogeneity of the sample, particularly in terms of disease duration, draws into question the relevance of the chosen measures to some participants. Those whose diagnosis was more recent may be yet to fully appreciate the strictures of BlCa and its management and be still at relative ease, responding accordingly, while those with a long-standing diagnosis may fully realise the demands of living with BlCa. Having noted this concern, it is pleasing that, in the models presented, the impact of disease duration was only modest. Nevertheless, a larger sample size would allow for comparisons between groups of participants at different stages of disease progression, thus allowing the issue of duration to be formally addressed. While acknowledging these limitations, it must be noted that given the nature of BlCa and its treatment, it is perhaps not surprising that recruitment was challenging. For example, it may be speculated that members of the target population experience a significant decrease in health over time [1,3,11] and that the motivation to participate in research may be particularly reduced among those with muscle-invasive disease [4].

A final caution about the current results concerns the functional evaluation measurement available to the study. Presented as an 'objective' measure of the impact of BlCa on participants, it nevertheless was obtained by way of self-report. While an argument can be made that patients themselves are the best judges of their functional limitations, the study would have been stronger had there been the opportunity to obtain functional data from an independent source such as medical records. Unfortunately, given the multiple sources of participants and treating specialists, this was not possible. Future research, however, would benefit from the implementation of such a strategy.

The findings concerning the role of a positive partner suggest that fruitful future research and interventions may involve addressing the needs of both members of the dyad. Given the identified importance of partners, their greater role in more holistic care may be explored. Future research might evaluate whether partner support becomes even more protective of negative disease outcomes in patients who do not have a partner available, those with a partner but exposed to standard care and those for whom their partner is fully engaged in healthcare discussions and decision-making.

Clinical implications

Given the results of this study, the inclusion of psychological testing to standard care in urology clinics, to assess the potential perception of burden, may assist the multidisciplinary team in supporting patients' adaptation to BlCa. Similarly, psychological screening for partners may provide equally beneficial results leading to improved dyadic adaptation. The care of psychological distress in addition to normal management of functional decline may reduce negative outcomes. Urology and oncology nurses on the front line of care and information dissemination should support patients and their partners in the adaptation to reformed bodies, changed roles and new coping skills [5].

Conclusion

Despite the awareness of BlCa as a stimulus for impaired function, psychological burden and maladaptive outcomes, to date, these concerns remain understudied [2,3,5]. The current research has shown that while BlCa can have significant functional effects on the everyday lives of individuals, a positive perception of burden and support from a partner can assist in negating such effects. Additionally, it has been noted that management discussions and support services might usefully recognise the role of psychological burden and partner support in tailoring interventions designed to alleviate negative psychosocial outcomes in BlCa.

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