

# A Qualitative Exploration of Prostate Cancer Survivors Experiencing Psychological Distress: Loss of Self, Function, Connection, and Control

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**PURPOSE:** To explore the experiences of men with prostate cancer identified as having psychological distress and to identify factors influencing distress.

**PARTICIPANTS & SETTING:** 28 men with prostate cancer diagnosed 18–42 months earlier, identified as having psychological distress on survey measures.

**METHODOLOGIC APPROACH:** Semistructured telephone interviews were conducted. Thematic analysis using a framework approach was used.

**FINDINGS:** Men with psychological distress had strong perceptions of loss toward self (identity, sexuality/masculinity, self-confidence), function (physical activities), connection (relational, social, community), and control (future, emotional). Psychological vulnerability appeared heightened in particular groups of men. Maladaptive strategies of emotional concealment, help-seeking avoidance, and withdrawal appeared to contribute to distress.

**IMPLICATIONS FOR NURSING:** Distress in men with prostate cancer is multifaceted. Men with distress should be identified and offered support. Nurse- or peer-led interventions are required.

**KEYWORDS** patient experience; distress; prostate cancer; psychological; qualitative; health care

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Prostate cancer is the second most common cancer among men worldwide (Bray et al., 2018). Although survival rates are high (Allemani et al., 2015), prostate cancer and its treatments can negatively affect quality of life (Punnen et al., 2015; Watson et al., 2016). In the United Kingdom, the setting for the current study, men with localized prostate cancer are commonly offered a choice of treatments, including radical prostatectomy, external-beam radiation therapy, brachytherapy, androgen deprivation therapy (ADT), active surveillance, or a combination of these (National Institute for Health and Care Excellence, 2019). Men with advanced prostate cancer may be offered hormonal therapy, watchful waiting, or chemotherapy. No U.K. prostate cancer screening program currently exists; however, men with family history or symptoms are offered a prostate-specific antigen test and digital rectal examination.

Treatments can significantly affect sexual, urinary, and bowel functioning, and may also lead to fatigue, weight gain, hot flashes, loss of muscle mass, and emotional instability (Blomberg et al., 2016; Punnen et al., 2015; Watson et al., 2016). Meta-analyses of previous studies suggest that, in men with prostate cancer, rates of depression and anxiety post-treatment are 18.4% and 18.5%, respectively (range = 15%–27% across the treatment spectrum) (Watts et al., 2014); these are significantly greater than in the general population. Men are also at increased risk for suicide after a prostate cancer diagnosis, particularly men who are older, unpartnered, or White, or those with metastatic disease (Klaassen et al., 2015; van Leeuwen & Schröder, 2010). Although most men with prostate cancer report good overall

health-related quality of life (Downing et al., 2019), some report unmet psychological needs and lower satisfaction with psychosocial aspects of their health care (Paterson et al., 2017; Watson et al., 2016). Men have reported that their current health care does not provide a holistic person-centered model of care (Paterson et al., 2017).

Treatment side effects can negatively affect masculinity and cause dissatisfaction regarding body feminization (Ervik et al., 2010; Gentili et al., 2019; O'Shaughnessy et al., 2013; Schildmeijer et al., 2019; Stapleton & Pattison, 2015). Men also may encounter many prostate cancer-related uncertainties, as well as distress related to embarrassment and sense of stigma associated with side effects (Matheson et al., 2017; Rivas et al., 2019). Men who are younger, unmarried, gay, or from Black and minority ethnic (BME) groups may be particularly vulnerable to these effects (Matheson et al., 2017; Rivas et al., 2016). Men with advanced cancer and men on combination treatments or ADT are at increased risk for social and psychological distress and report more cancer-related symptoms compared to men on other treatments (Wilding et al., 2019; Wright et al., 2019). Meta-analysis has also shown that men on ADT have a 41% increased risk of depression (Nead et al., 2017). In men on ADT, clinically significant levels of fatigue have been strongly associated with psychological distress (Wilding et al., 2019). However, what is lacking in the literature is a more nuanced understanding of how men with prostate cancer experience psychological distress and what contributes to their distress. This is needed to develop interventions to improve the support provided to men in the future.

Research shows that, worldwide, men are particularly vulnerable to severe distress, with older adult men (older than age 70 years) from higher-income countries being most likely to die of suicide (Fung & Chan, 2011; World Health Organization, 2014). Men are also less likely than women to seek professional help for psychological distress, because men may be unwilling to admit psychological problems (Bilsker et al., 2018; McCaughan et al., 2011). This may be influenced by traditional masculine ideals of self-reliance, independence, and stoicism (Bilsker et al., 2018; Cecil et al., 2010). Qualitative research indicates that men may come across to healthcare professionals as confident and coping, yet they may be hiding a significant emotional burden (Stapleton & Pattison, 2015). Therefore, the importance of designing gender-appropriate interventions that specifically address men's distress and provide an

emotional outlet has been highlighted (Bilsker et al., 2018; Stapleton & Pattison, 2015; Wenger et al., 2014). A previous meta-synthesis has highlighted coping strategies that men with prostate cancer employ (Spendelov et al., 2017); however, much of the evidence relates to adaptive coping strategies involved in adjustment. The current authors' meta-synthesis of qualitative studies (N = 133) highlighted the often-gendered ways that men dealt with the emotional effects of prostate cancer (Rivas et al., 2019). However, studies generally included men with varying degrees of psychological well-being, and no studies specifically explored a subgroup of men with distress, particularly how these men may be better supported (Rivas et al., 2019).

In individuals with cancer, distress and well-being have been associated with illness perceptions and coping behaviors (Leventhal et al., 2016; Richardson et al., 2017). According to illness perceptions theory, perceiving the illness as controllable or with few consequences is associated with lower distress and better well-being (Leventhal et al., 2016; Richardson et al., 2017). However, the role of individuals' perceptions and coping strategies in relation to distress in men with prostate cancer requires greater attention and is the focus of this article. Little is known about the coping strategies of men with prostate cancer who exhibit distress, so exploring this would highlight how support for men may be optimized, such as through interventions and clinical practice. The current data come from the Life After Prostate Cancer Diagnosis (LAPCD) study, a U.K. population-based mixed-methods study (Downing et al., 2016), that aimed to explore the physical and psychosocial impact of prostate cancer through a survey and interviews. In this qualitative subanalysis, the current authors specifically explore the experiences of men identified as having psychological distress, drawn from the total sample of interviewed men with prostate cancer. The authors aimed to inform how support for these men could be optimized and explore the factors influencing distress.

## Methods

Ethical and regulatory approvals were obtained from the Newcastle/North Tyneside Research Ethics Committee (15/NE/0036), Health Research Authority Confidentiality Advisory Group (15/CAG/0110), National Health Service Scotland Public Benefit and Privacy Panel (0516-0364), and Northern Ireland Research Ethics Office (16/NI/0073). Informed consent was obtained from all interview participants.

## Design

Full methodologic details of the LAPCD study have been previously published (Downing et al., 2016). In brief, men diagnosed with prostate cancer 18–42 months previously were invited to participate in a postal survey addressed to their home. Three cancer registries, the National Cancer Registration and Analysis Service (part of Public Health England), the Northern Ireland Cancer Registry, the Welsh Cancer Intelligence and Surveillance Unit, and hospital activity data in Scotland, were used to identify men.

Data collected by the cancer registries is quality assured. This study is based, in part, on information collected and quality assured by the National Cancer Registration and Analysis Service (part of Public Health England), the Northern Ireland Cancer Registry, the Welsh Cancer Intelligence and Surveillance Unit, and the Scottish Cancer Registry (part of the Public Health and Intelligence Unit of National Health Service National Services Scotland). The work of cancer registries uses data provided by patients and collected by health services as part of

### FIGURE 1. Interview Topic Guide for Men With Prostate Cancer

The topic guide provides a number of questions that the interviewer may use to initiate discussion about a particular topic. However, the interviewer may revise the questions, or alter their order, in light of the interviewee's response to earlier questions.

- Could you start by telling me what life has been like for you since your diagnosis of prostate cancer?
- Could you tell me about the impact that prostate cancer has had on your life?
  - Your quality of life?
  - Social life?
  - Relationships with spouse, family, or peers?
  - Work, life, or voluntary roles?
  - Physical problems?
  - Finances and insurance?
  - Psychological and emotional?
  - Feelings toward body?
  - Future worries?
  - Sexual relationships and functioning (and impact on partner)?
  - Confidence?
  - Masculinity?
  - Coping strategies to manage?
  - Complementary therapies, diet, and exercise?
- Can you tell me about your experience of health and social services since your diagnosis?
  - What services did you use (e.g., charities, counseling or psychologist, benefits advice, Internet)?
  - What worked well? Less well?
  - What could have been done better?
  - How easy was raising concerns (e.g., talking to doctor, nurse)?
  - How were you treated by healthcare professionals?
  - Decision making regarding treatment?
  - Experience of follow-up?
  - Prepared and aware of what to expect?
  - What support was received for side effects or problems (e.g., psychological, physical, sexual problems)?
  - What information was received for side effects or problems (e.g., psychological, physical, sexual problems)?
  - Did you access any other resources to help cope (e.g., specialist nurse, general practitioner, incontinence clinic, sexual clinic, websites, booklets)?
  - Was more support or information needed at any point?
  - Involvement of your general practitioner, in terms of information, support, and satisfaction?
  - Confidence to manage prostate cancer and its effects?
- Are there any things you would change about the care and support you have received from health or social services and staff?
  - Additional services?
  - What services could be put in place in the future?
  - Alternative models of follow-up (e.g., nursing, telephone versus face-to-face, remote follow-up, hospital- versus primary care-based)?
- Can you tell me about the support you have had from sources other than health services?
  - How has your partner helped you to cope?
  - How has prostate cancer affected your partner, wife, or family?
  - Peer support from other men with prostate cancer?
  - Support groups?
- Can you tell me about any other problems or issues you have had to deal with alongside the effect of prostate cancer?
  - Important aspect of life? Any changes at all?
  - Impact of prostate cancer in relation to other things that have happened (e.g., other life events, comorbidities, effect of these)?
  - Positive outcomes?
  - How do you feel about having prostate cancer at this point in your life?
- Is there anything else you would like to add that I have not asked you but that you think is important, or anything else you think I have missed?

their care and support. Survey respondents indicated if they were willing to also be interviewed by telephone. Consolidated criteria for reporting qualitative research guidelines were followed (Tong et al., 2007).

### Data Collection

**Sampling:** Men consenting to interview were contacted following completion of the LAPCD survey. A purposive sampling framework was developed to include men with different treatment types and a range in terms of age, ethnicity, and sexual orientation, as well as physical or psychological problems, as indicated by their survey responses. One hundred forty-nine men were interviewed. Data reported came from a subsample ( $n = 28$ ) of this larger interview dataset comprising all men who were identified as having psychological distress on one or both of the following validated measures of psychological distress from the LAPCD survey: the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) (Stewart-Brown et al., 2009) and the six-item version of the Kessler Psychological Distress Scale (K6) (Kessler et al., 2002). The SWEMWBS (Stewart-Brown et al., 2009) aims to measure psychological well-being, and the full version has been widely used in national surveys (Morris & Earl, 2017) and in cancer research (Clarke et al., 2019). Scores of 19.25 or less are suggested to indicate poor well-being (Ng et al., 2006). The K6 is a measure that assesses nonspecific psychological distress and has been used previously in individuals with cancer (Oba et al., 2017; Rim et al., 2019; Zhao et al., 2013). A cutoff score of 19 or greater indicates severe psychological distress (Prochaska et al., 2012).

**Interviews:** Semistructured telephone interviews lasted one hour, on average, and were conducted by two postdoctoral (L.M., J.N.) and two senior (R.W., C.R.) health researchers. Interviewers came from broad disciplinary backgrounds, including nursing, sociology, and psychology, and included one man (R.W.). A comprehensive interview topic guide was developed (see Figure 1) in collaboration with the LAPCD clinical and patient user advisory groups (UAGs) and informed by the authors' meta-syntheses of qualitative studies (Matheson et al., 2017; Rivas et al., 2016, 2019). Men were interviewed about the psychosocial and physical impact of prostate cancer, and their healthcare experiences. Questions were open-ended, and researchers used prompts to encourage participants to expand on answers.

### Analysis

Interviews were recorded by a software program (Audacity®) and transcribed verbatim. Sensitive or personal information was de-identified at the point of transcription. All data were stored in a secure university repository only accessible from a password-protected computer. Thematic analysis, involving the seven-stage framework approach (Gale et al., 2013) was undertaken for all interviewed men for the main LAPCD study. Following familiarization, five initial transcripts were independently coded and then discussed within the research team and the LAPCD patient UAG, as several user group members reviewed selected transcripts and provided feedback. A coding framework was developed as themes emerged. The framework was further developed and adapted following analysis of subsequent interviews and group discussion. Transcripts were uploaded and managed using NVivo, version 11.0. Double coding in NVivo was conducted (C.R., E.W., and R.W.) on 10% of all interviews, with final kappa scores of greater than 80% across all themes for all researchers. All interview transcripts were indexed into the framework in NVivo involving identification of each section of data that corresponded to each theme in the framework. Data were then summarized into coding summaries in the framework (J.N., L.M., C.R., and R.W.). The authors' analysis was rooted in a social constructivist paradigm.

Analysis of the subsample involved collation of the coding frameworks of all men with psychological distress, which were then examined across and between participants to explore within-group convergence and divergence in more detail (L.M., J.B., and E.W.). The analysis was discussed at team meetings and with members of the UAG. Through this process, the authors were also able to consider the subsample within the context of the larger sample of interviewed participants. Data saturation was achieved. Sociodemographic and treatment information, as well as information on comorbidities, was also obtained from the LAPCD survey and during interviews.

### Results

The characteristics of the subsample of men ( $n = 28$ ) with distress are shown in Table 1. This subsample comprised 19% of the 149 men interviewed overall. Nineteen of the 28 men had received ADT either alone ( $n = 8$ ) or as an adjuvant treatment ( $n = 11$ ). For the subsample of men with distress, two overarching themes are presented.

**TABLE 1. Sample Characteristics (N = 28)**

Characteristic	$\bar{X}$	Range
Age (years)	65.9	46–87
Characteristic	n	
Age group (years)		
Younger than 55	2	
55–64	10	
65–74	12	
75–84	1	
85 or older	3	
Nation		
England	17	
Wales	7	
Northern Ireland	2	
Scotland	2	
Marital status		
Married or civil partnership	19	
In a relationship	3	
Divorced or widowed	3	
Single	3	
Sexual orientation		
Heterosexual	24	
Gay or bisexual	4	
Ethnicity		
White British	26	
Black British	2	
Disease stage		
I	12	
II	–	
III	5	
IV	6	
Missing data	5	
Number of long-term conditions		
0	9	
1	6	
2	4	
3	5	
4	4	
Treatment		
Adjuvant ADT only	8	
EBRT plus adjuvant ADT	6	
Radical prostatectomy only	6	
AS or watchful waiting	2	
EBRT plus adjuvant ADT plus chemo	2	
Surgery plus adjuvant ADT	2	
Continued in the next column		

**TABLE 1. Sample Characteristics (N = 28)  
(Continued)**

Characteristic	n
<b>Treatment (continued)</b>	
Brachytherapy only	1
Surgery plus EBRT plus adjuvant ADT	1
ADT—androgen deprivation therapy; AS—active surveillance; chemo—chemotherapy; EBRT—external-beam radiation therapy	

**Theme 1: Perceptions of Loss**

Men with psychological distress had strong perceptions of loss, relating to loss of function, connection, self, and control, and displayed ongoing difficulties coping with these bodily and biographic disruptions. This theme of loss was also evident, but to a much lesser degree, in non-distressed men in the wider sample of all interviewed men ( $n = 121$  of 149), who often described acute yet largely transient distress around diagnosis.

**Perceptions regarding loss of function:** The severity of perceptions of loss in men in the distressed subsample regarding physical functioning varied depending on the type of treatment received and, in a few cases, on stage of disease. A few were distressed if they had ongoing and severe unresolved problems regarding urinary or bowel functioning following surgery or radiation therapy, particularly if this significantly affected their daily activities. These problems were worrying and embarrassing to men and could be a barrier to social participation. Some struggled to cope with changes to their sexual relationships following treatment, and, in comparison with non-distressed men in the wider sample, struggled to use strategies, such as acceptance and reappraisal, that appeared adaptive. Holding strong values and expectations regarding traditional or hegemonic masculinity also seemed to influence distress, particularly regarding men's response to sexual dysfunction, as well as the loss of physical strength and fitness. One participant said,

It's just not right. It's the self-esteem, not feeling like a complete man . . . not just the sex side of things, it's the strength to do things. You're trying to lift things that you used to think nothing of before, and you can't do it anymore. Climbing mountains, you can't do that like you used to do. So it's all a bit tough really. (60 years old, married, stage IV)

However, sexual functioning was not a priority for all men, with some on ADT describing less bother over this issue, attributed by men to the ADT-related loss of libido. Men with advanced prostate cancer reported distress over feeling socially and physically restricted by side effects, such as pain and fatigue, and the subsequent immobility experienced.

**Perceptions regarding loss of self:** Men reported a strong sense of loss of self and identity changes, which appeared to influence their distress. In those with substantial physical health problems, from advanced prostate cancer or comorbidities, the loss of the active self was particularly difficult to accept. Some men struggled with their declining ability to participate in valued activities, such as working, walking, or gardening, and the transition to a more sedentary lifestyle. A loss of self-confidence was reported in their health, social, or work situations. Prostate cancer also affected some men financially, who felt distress over being in debt or on a low income. Younger men, in particular, found this impact of prostate cancer harder to accept and held concerns regarding their role as provider. Sexual dysfunction from prostate cancer treatment was common and led to a sense of loss of the sexual and masculine self, which led men to report a loss of self-confidence and feelings of failure and inadequacy, as evidenced by the following participant quote: “No matter how understanding one’s partner is . . . you still feel as though you’ve failed. . . . You are no longer the man you thought you were” (69 years old, married, stage I).

ADT-related symptoms, such as breast enlargement, mood swings, and loss of muscle mass, also contributed to a sense of loss over the masculine self, and some men felt that ADT was the cause of their distress, because of the direct impact on mood. One participant said,

After the hormone treatment kicked in, I had a change in personality. And I lost confidence in myself as a person, especially in the work that I’d been doing before that. And that has continued, so personality-wise, it’s been a kick in the teeth. (75 years old, married, stage I)

**Perceptions regarding loss of connection:** Men held strong perceptions regarding a sense of loss of connection to others. A sense of loss over a much-diminished social life was attributed to physical health limitations from prostate cancer and/or comorbidities, a result of feeling depressed, or due to lower self-confidence to engage in social activities. According to one participant,

The confidence hasn’t come back. So life’s quieter these days. I used to do a lot of [theater work] . . . and I’ve stopped doing that completely, because I don’t have the confidence to do it anymore. So the social side of my life has diminished. (75 years old, married, stage I)

A few men felt they had lost friendships or become distant to friends, which was distressing. A loss of connection with their partners was reported by some men in this subsample, as they struggled with conflict or strain on their relationship. A few felt that sexual problems had led to arguments or emotional distancing or, in one case, had directly led to relationship breakdown: “The relationship ended because, basically, I was told, ‘Well, because you can’t perform [sexually], not interested, it’s time to call it an end’” (54 years old, single, stage III).

Being without a partner at diagnosis often exacerbated distress as men described loneliness dealing with prostate cancer alone. One participant said, “It has been a very lonely journey for me” (58 years old, widowed, stage I). Being unpartnered also contributed to distress and worry over potential future intimate relationships because of erectile dysfunction and fears of rejection.

**Perceptions regarding loss of control:** Men held strong perceptions regarding a sense of loss of control caused by prostate cancer, such as a lack of bodily control. Men receiving ADT felt that this treatment contributed to the loss of emotional control they experienced: “It’s just spontaneous. I just all of a sudden feel sad and want to cry” (66 years old, married, stage III). For a few men with advanced disease, this had led to suicidal thoughts: “I wanted to end my life. I was totally depressed with it all” (67 years old, married, stage IV). Other men discussed a sense of loss of control over the future, and having to learn to live with greater uncertainty. Men often held negative perceptions toward cancer, regardless of their prognosis, such as feeling they had low control over prostate cancer. Some struggled with controlling rumination over negative thoughts surrounding prostate cancer and fears of recurrence, despite having a good prognosis in some men: “It is purely this perpetual feeling that it could come back and haunt you. . . . I try to shove it to one side. But it is there again . . . at the back of your mind” (69 years old, married, stage I). According to another participant, “You’ve kind of lost your shield, and you do feel vulnerable. You say once it’s happened to you once, it can happen again” (48 years old, in a relationship, stage I).

A few men felt that more emotional support from healthcare professionals, particularly a little more time and reassurance during and in addition to follow-up appointments, would help alleviate anxiety: “There doesn’t seem to be any structure that will trigger somebody to ring the patient . . . to say how are things going, do you need to talk or do you want chat about anything?” (60 years old, married, stage IV).

**Exacerbating factors of psychological vulnerability:** In addition to the factors already described, including younger age, being unpartnered, and having a high symptom burden, other factors also appeared to exacerbate distress. These related to preexisting psychological or physical issues. Preexisting psychological problems, such as clinical depression or anxiety, prior to the prostate cancer diagnosis were reported by some men: “I had a bit of depression before, but it’s increased since” (63 years old, in a relationship, stage I). For a few, these were perceived as more of a problem than prostate cancer-related distress. Some also attributed personality traits as contributors to their distress, such as having anxious or depressive personalities or being pessimistic. Being treated with ADT (n = 19) rendered men with a particular vulnerability to be distressed: “I’m on antidepressants at the moment, because the [ADT] makes you down. It’s made me more a worrier I think” (60 years old, married, stage IV). Participants with multiple comorbidities often

felt they were more distressed about these other illnesses than prostate cancer.

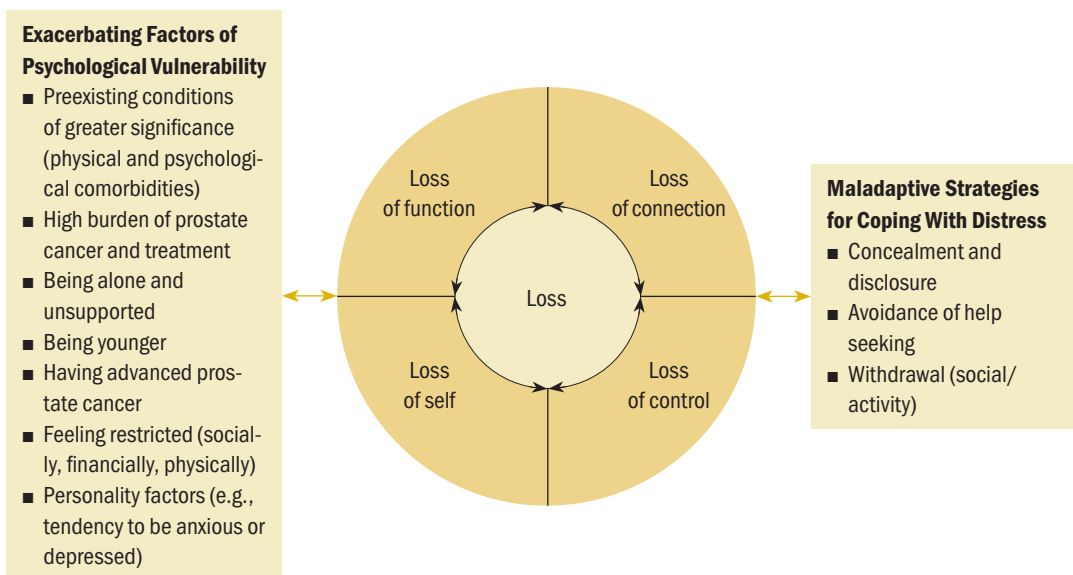
## Theme 2: Maladaptive Strategies for Coping With Distress

Some men in the subsample used strategies that helped them cope, including seeking professional support, taking antidepressant medication, and talking to partners and those in their social networks. However, compared to the wider sample, the men in this subsample were more likely to use strategies that could be maladaptive.

**Concealment of distress:** Men commonly discussed concealing their distress from others, and some put on a brave face for their families specifically. Some men attributed their behavior to generational as well as gendered norms and ideals surrounding masculinity, including stoicism, self-reliance, and emotional concealment: “We’re old-generation, so you don’t talk about things” (60 years old, married, stage IV). Another participant said, “I have to watch my emotions at times. They can take over. I can walk around and look as tough as anybody, but inside I’m probably falling apart” (67 years old, married, stage IV).

**Avoidance of help seeking:** Some men avoided seeking professional help for distress, stating reasons such as not wanting to take medication, not wanting to talk to or feel they were bothering healthcare professionals, dismissing talking therapies as a waste

**FIGURE 2. Perceptions of Loss: A Model of Psychological Distress Experienced by Men With Prostate Cancer**



of time, a preference for talking to their partner or friends, or feeling they should be self-sufficient. According to one participant,

It's just a grayness in life, I don't think there's much [healthcare professionals] can do about it. Feels as though one is moaning when one's still alive. . . . You feel you're bothering people . . . should really sort it out myself. (75 years old, married, stage I)

Despite this, men discussed various ways in which they felt they could have done with more emotional support, either from a psychologist or a specialist nurse who could also provide help with physical problems:

A bit of counseling, both before and after the treatment . . . a psychologist really. But then you've got the physical problems that need to be coped with as well. One or the other or all rolled into one. One would expect that if there was a nurse counselor, they'd be equipped to deal with both sides. (75 years old, married, stage I)

**Withdrawal (social/activity):** Some men reported withdrawing from social situations and daily activities and becoming more sedentary and isolated: "I have become a bit of a loner" (67 years old, married, stage IV). For some, this appeared to be an element of their depressive state, and for others, this was affected by lower self-confidence, the physical impact of prostate cancer, and comorbidities, such as fatigue or loss of mobility, and was an unwanted change: "I am becoming a recluse. I mean, I've got [x] children and a load of grandchildren, but I hardly ever see them. I'm inclined not to go out very much" (65 years old, married, stage I).

Figure 2 illustrates how men's perceptions of loss were central to their distress, and the four elements of loss were often interconnected. Men's perceptions seemed to be influenced by, and affected by, the maladaptive strategies they employed, as well as the exacerbating factors that appeared to heighten vulnerability to distress.

## Discussion

The majority of men 18–42 months post-prostate cancer diagnosis in the wider sample did not exhibit psychological distress. Analysis of this subsample of 28 men in the context of the larger sample highlights how distressed men held stronger perceptions

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## KNOWLEDGE TRANSLATION

- A significant minority of men with prostate cancer report distress 18–42 months following diagnosis; screening tools for psychological difficulties may help identify men in need of further support.
  - The authors' conceptual model highlights preexisting and treatment-related factors, as well as maladaptive coping strategies influencing distress; greater support with restoring self-identity and confidence is needed.
  - Nurse-led patient education and information on managing psychological and physical concerns, as well as posting information to peer support, community, or online support groups, is required.
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regarding a sense of loss, and how this was affected by maladaptive coping strategies. The current findings demonstrate that two key elements of illness perceptions theory, illness consequences and control (Leventhal et al., 2016), seemed to influence distress in men with prostate cancer. Men's sense of loss regarding the negative impact to self, functioning, and relationships is in line with research showing that perceptions of an illness having considerable consequences and symptoms are related to greater distress (Richardson et al., 2017), as are perceptions of having low control over illness (Richardson et al., 2017). Loss of self (Charmaz, 1995) has frequently been reported by individuals with chronic illness, and adapting to a changed self, particularly to loss of confidence, is a crucial part of recovery from cancer (Foster & Fenlon, 2011). This was evidently a struggle for distressed men in the subsample. The current findings illustrate that men with distress may experience greater biographic disruption (Bury, 1982) and threat to their identities, and a greater struggle to overcome these, than non-distressed men in the wider sample.

The conceptual model may be useful for understanding distress in people with other cancers. Previous work has indicated some similarity in themes, such as loss with individuals with head and neck cancer (Lang et al., 2013), as well as rumination and low social support in women with breast cancer exhibiting persistent distress (Lam et al., 2017). Many of the other exacerbating factors identified, such as comorbidities and ADT treatment, have also been previously associated with distress (Chambers et al., 2017; Nead et al., 2017; Wilding et al., 2019). Men who were younger or unpartnered or those with financial problems have also been shown to be particularly vulnerable to distress (Chambers et al., 2017; Collaço et al., 2019; Matheson et al., 2017).

These findings highlight that distressed men's strategies for coping, including avoidance, concealment, and social withdrawal, may be linked to mental health and well-being issues. Although, in many cases, it may be unclear whether the distress preceded the prostate cancer diagnosis, it appears that the subsample of distressed men was more likely than the main sample to adhere to dominant masculine ideals (Cecil et al., 2010). Comparisons with the main sample of nondistressed men suggest that these coping strategies appeared to sometimes be problematic. This confirms previous work suggesting that strategies of concealment, stoicism, and avoidance can contribute to negative adjustment, information deficits, and social isolation in men with cancer (Brunton et al., 2012; Matheson et al., 2016). These strategies are also problematic if used excessively or rigidly, because they leave men vulnerable by being less able to access support networks (Bilsker et al., 2018). This is echoed previously in wider mental health research; rigidity in men's coping and identities, in terms of hegemonic masculine scripts, has been theorized to explain why older men of European descent are particularly vulnerable to suicide (Canetto, 2015). Further research in larger samples is required to quantify whether this is a significant moderator of distress in men with prostate cancer. These findings are also in line with research that demonstrates the importance of flexibility surrounding masculine identity (Spendelov et al., 2017). Approaches such as mindfulness-based cognitive behavioral interventions (Chambers et al., 2016; Kabat-Zinn, 2013) may promote psychological flexibility and reduce rumination on negative thoughts, which have been shown previously to worsen distress (Williams & Kuyken, 2018). However, it is unclear whether such interventions would be acceptable to this population, so additional studies are needed.

### Limitations

Telephone interviews were useful for eliciting sensitive information and were more feasible than face-to-face interviews because of issues of distance; however, the authors were not able to pick up on non-verbal cues. The authors did not collect quantitative data on whether men had received diagnoses or treatment for clinical depression. Measures of distress were generic rather than prostate cancer-specific and were not diagnostic or screening tools; however, this did capture all participants who discussed significant distress during interviews. A disproportionate number of men in this subsample were younger and receiving ADT; however, this highlights the vulnerability of

these groups and how they could be supported better. It is possible that men closer to diagnosis may be more distressed and for different reasons; however, this study provides a snapshot of the experiences of men 18–42 months postdiagnosis. The gender of the interviewers (three women, one man) may have influenced the findings; however, the authors do not feel this is the case, and interviews were generally rich and approximately an hour in length. The authors had difficulty recruiting men from BME backgrounds ( $n = 2$ ), so further research is warranted. There is also the potential for nonresponse bias, because men with distress may be more or less likely to volunteer to complete the survey and be interviewed.

### Implications for Nursing

Screening for distress at clinical appointments may be useful if followed by enhanced discussions of psychosocial concerns (Meijer et al., 2013; Schuurhuizen et al., 2018; Smith et al., 2018), which evidence suggests can improve well-being. The National Comprehensive Cancer Network Distress Thermometer has been shown to be an acceptable screening tool in men with prostate cancer (Chambers et al., 2014). Nurse navigation targeted at distressed women with breast cancer indicated promising improvements in psychological health (Mertz et al., 2017), but there is a need for studies with men with prostate cancer, which should be the focus of further research. Tailored holistic needs assessments (HNAs) would also enable nurses to identify those who have ongoing or unresolved physical problems that may be related to distress. Online HNAs for men with prostate cancer, currently being trialed, may also have the potential to help men overcome barriers to talking about psychological concerns (Nanton et al., 2018).

Participants described how they wanted someone to take time to listen to them and provide reassurance. A simple approach, such as facilitating discussions with a knowledgeable and empathetic nurse, can lead men to feel more emotionally supported, as shown in an evaluation of a psychoeducational telephone intervention for men with prostate cancer (Watson et al., 2018). The importance of targeting such interventions at men with greater need has been highlighted (Watson et al., 2018). Therefore, discussions during follow-up appointments that routinely ask men about their psychological health in addition to any ongoing or unresolved physical health issues, as well as follow-up telephone discussions, may be useful. Nurses can support men with distress to adapt and adjust to changes in their sexual functioning, masculinity, confidence,

and self-identity by posting information to relevant and available services that help meet their needs. Online mental health resources may be useful for nurses working in psycho-oncology (International Psycho-Oncology Society, 2019). Specialist cancer nurses are well positioned to counsel and help unravel the complex psychological concerns that men with prostate cancer may face and can provide a gateway to other psychological and specialist services. These services include sexual rehabilitation clinics for erectile dysfunction, oncology rehabilitation clinics to improve incontinence issues, and community groups and local charities offering support. Nurse-led clinics during and after treatment for prostate cancer could also provide advice regarding stress management, exercise, well-being, and staying active, and could provide a forum for peer-to-peer social interaction and support, either through face-to-face meetings or online forums (Huber et al., 2018). Peer-led support interventions have been shown to be effective (Newby et al., 2015), so nurses could encourage men to use their social networks and facilitate peer support, such as buddy systems, if appropriate. Individuals who experience loss of self-confidence may find it difficult to access support (Foster et al., 2015). Therefore, interventions that promote patient empowerment to seek support are warranted, particularly for hard-to-reach groups, such as men who avoid help seeking, BME men, or unpartnered men who may be particularly isolated (Matheson et al., 2017; Rivas et al., 2016). The lack of studies addressing vulnerable and high-need individuals with cancer has been highlighted, so further research is needed (Crawford-Williams et al., 2018).

Interventions that incorporate peer support, cognitive behavioral therapy, and tailored supportive care were shown to reduce distress in men with prostate cancer (Crawford-Williams et al., 2018). Nurses are well placed to identify which individuals with cancer may benefit from cognitive behavioral therapy (Daniels, 2015) or counseling services and could refer particularly vulnerable men for specialist support, as required.

## Conclusion

A multifaceted theme of loss was magnified in men with psychological distress at least 18 months following prostate cancer diagnosis. Relatively simple ways that nurses may identify and support such individuals are highlighted. Screening to identify those with distress is warranted. To alleviate distress, nurse- or peer-led support could provide greater emotional

support through providing more time and reassurance, supporting with ongoing physical effects, giving men opportunities to talk, and posting information to psychological or rehabilitation services, where appropriate.

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