

## Living with untreated localised prostate cancer was seen as living under a dark shadow

Hedestig O, Sandman PO, Widmark A. *Living with untreated localized prostate cancer: a qualitative analysis of patient narratives*. *Cancer Nurs* 2003;26:55–60.

**QUESTION:** What does it mean to be a patient living with untreated localised prostate cancer (LPC)?

### Design

Hermeneutic phenomenology.

### Setting

Västerbotten, Sweden.

### Patients

7 men with untreated LPC who were <70 years of age (age range 62–69 y); diagnosed with LPC >3 months but <3 years previously and chose watchful waiting (regular checks of LPC instead of surgery or radiotherapy) as their primary treatment; spoke Swedish; and had no chronic disease that could affect daily life.

### Methods

Men were individually interviewed in their homes for 45–60 minutes about their feelings and beliefs about LPC. The interviews had 2 foci: “tell me about your experience when the disease was diagnosed,” and “tell me about your experience of being a patient with prostate cancer.” Interviews were tape recorded, transcribed, and interpreted by naive reading (first interpretation of the text), structural analysis (validation or rejection of the first interpretation), and comprehensive understanding (a “new way” of understanding the text based on findings from previous steps).

### Main findings

Living with untreated LPC could be understood as living under a dark shadow that was a threat to life. 4 underlying themes were identified. (1) *To be alone with the disease experience*. Men chose to be alone to protect and not worry loved ones. They were afraid that relationships with family and friends would be negatively affected, yet felt sorrow because family members seldom asked about their health. Patients preferred talking about their illness with other patients rather than family or friends to avoid pity. (2) *To be uncertain, afraid, and worried*. Patients felt they were living with the constant threat of the disease. They felt uncertain about whether it would shorten their life, and were afraid that the cancer would become more active or metastasise. Patients’ fears were illustrated when they discussed their cancer using metaphors such as “the shadow,” “the negative,” or “the cell changes.” Uncertainty ranged from a feeling that the cancer was under control to a worry that it could strike at any time or anywhere in the body. Some men wanted information, but others chose not to be informed and have someone else make decisions for them. Some denied the cancer and its threat, whereas others changed their lifestyle. Strategies used by patients to manage uncertainty, fear, and worry included working harder physically, being alone in the countryside, spending more time reflecting or praying to God, and spending more time with family. (3) *A masculine experience*. Men experienced reduced sexual potency and diminished pleasure in ejaculation, and felt that their manhood was

restricted. However, the symptoms of the disease did not affect most patients’ relationships with their wives. Patients had difficulty talking about sexual problems and preferred discussing their impotence with other men. (4) *The physician—a companion*. Routine visits to the same physician who had time to discuss various aspects of the disease helped men to feel safe, secure, and confident. Men perceived relationships with their physicians as close or even as friendships, and talked about “we” when describing discussions of future treatment strategies.

### Conclusions

Living with untreated localised prostate cancer can be understood as living under a dark shadow that is a threat to life. Men described a self chosen solitary life, in which they felt uncertainty, fear, and worry about the constant threat of the disease, and felt that their manhood was restricted. They preferred to share experiences with other male patients, and considered their physicians as companions.

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### COMMENTARY

The findings of Hedestig *et al* offer important insight into the lives of patients with LPC who are managed with watchful waiting (ie, no immediate treatment and subsequent hormonal therapy when the disease progresses).

Patients with LPC need support to address their understanding of the illness, feelings, ineffective coping, powerlessness, social isolation, and negative body image. They should also be encouraged to communicate their concerns and develop realistic hope. However, patients who choose “watchful waiting” appear to have special needs. Whereas women commonly share their stressful experiences, it seems that the men who were interviewed in the study by Hedestig *et al* needed to protect their loved ones from what they were experiencing. Despite this isolation, men seem to want to talk about their experiences. Such a paradoxical need may present a challenge for nurses, particularly when it seems that men prefer to discuss their experiences with people in similar positions.

Successful communication with men will largely depend on how skillfully nurses can raise issues. However, nurses should not expect to solve these issues, especially because the men will be living with LPC for some time. More appropriate strategies may be referral to or organisation of support groups to provide a forum for men to address their ongoing issues of living with LPC. Within such a context, sensitive issues such as sexual function and dysfunction could be explored, with appropriate expert assistance.

Because men may try to protect their families, nurses need also to consider developing information for spouses and families. Previous research has identified that men managed by “watchful waiting” find it difficult to maintain such a regimen when faced with family pressure to seek more active treatment.<sup>1</sup> Information for families may help to alleviate this familial pressure and promote comprehension of the strains of living with LPC.

The study by Hedestig *et al* did not consider what role nurses may have in patient management, although physicians were described as “companions” in the men’s disease. Nurses need to consider whether they too have a role in becoming disease companions. If so, the challenge will be how nurses can become such companions.

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1 Chapple A, Ziebland S, Herxheimer A, *et al*. Is ‘watchful waiting’ a real choice for men with prostate cancer? A qualitative study. *BJU Int* 2002;90:257–64.