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Quality of Life and Urinary Diversion



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KEYWORDS

• Urinary diversion • Health-related quality of life • Improving quality of life

KEY POINTS

- Health-related quality-of-life outcomes after urinary diversion vary significantly.
- Preserving and even improving health-related quality of life are highly relevant to urinary diversion.
- Life after urinary diversion is fundamentally different than before.

INTRODUCTION

Urinary diversion, performed either as a standalone reconstructive procedure or in conjunction with radical cystectomy, is associated with a host of functional, metabolic, and physical changes that combined affect quality of life. 1,2 Health-related quality-of-life (HRQOL) outcomes after urinary diversion, however, vary significantly depending on the extent and burden of patient symptoms, problems and health status before and after surgery, and the reason for and objective of the diversion surgery itself. Performed to palliate symptoms or manage severe bladder dysfunction, for example, urinary diversion can alleviate burdensome symptoms, reduce patient suffering, and significantly improve overall quality of life.3,4 In contrast, when performed as part of a radical cystectomy in cases of bladder cancer, urinary diversion may lead to quality-of-life deficits, principally as a result of the loss of normal body function, unanticipated physical and functional challenges that persist after surgery, or unavoidable permanent consequences, such as altered body image associated with some forms of urinary diversion.5-8

Whether positive or negative, several facets of HRQOL are affected by urinary diversion. Often referred to as domains, these areas reach beyond physical concerns and involve self-image, emotional well-being, and even social function. Consider an example of a healthy and fully functional man treated with cystectomy and urinary diversion who experiences erectile dysfunction, incontinence, and bowel dysfunction after surgery. Life after urinary diversion is fundamentally different than before. His sexual dysfunction may strain his relationship with his spouse. Problems with urine leakage and lack of control may limit his interest in social outings and change his selfperception. If his symptoms are severe enough and his coping skills and social support network are marginal, he may experience distress, anxiety, or even depression. Although perhaps an outlier example, most surgeons who perform a large number of cystectomy and urinary diversion surgeries will recognize this story. Urinary diversion can give a person their life back, or it can change life in profound and deleterious ways.

Given these potential changes, there is considerable interest in how urinary diversion impacts

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quality of life, both among cystectomy patients and patients managed with diversion for purely reconstructive purposes. 9,10 Indeed, development of continent urinary diversion was driven primarily to avoid the need for an external stoma and urostomy appliance and restore anatomic and volitional voiding with the objective of preserving quality of life in patients who require urinary diversion. 11,12 This presumption was in part supported by several early studies comparing ileal conduit to continent urinary diversions that reported better physical, social and functional outcomes in patients who received continent diversion. 13,14 Clearly, preserving and even improving HRQOL are highly relevant to urinary diversion. This review is structured to examine how and in what areas urinary diversion may impact patient quality of life and selectively reviews research findings from recent HRQOL studies performed in the urinary diversion patient population.

HEALTH-RELATED QUALITY-OF-LIFE DEFINITIONS, FRAMEWORK, AND DOMAINS

Several definitions of HRQOL have been proposed, but most focus on several common themes. For example, both the World Health Organization and Centers for Disease Control and Prevention definitions include language linking HRQOL to perceived physical and emotional function and health within the context of a person's standards, and concerns for their health. 15,16 Stated more explicitly by Health People 2020, HRQOL "is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning... [and] goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life."17 Inherent in almost all definitions, HRQOL is perceived by the individual. It is the subjective reaction to health, wellness, and disease that positively or negatively affects physical function, emotional well-being, and an individual's ability maintain social interactions connections. 18-20

Wilson and Cleary²¹ proposed a framework for HRQOL that encapsulates many of the concepts mentioned in the above definitions.²² In the Wilson-Cleary model, biology, physiology, patient symptoms, physical functioning, health perception, and HRQOL interconnect and interact across a causal pathway. This model suggests that individuals' personal perception of their health, coping skills, and support they receive from their social network interact with the severity of their health problem, symptoms, and resulting functional

status to mediate how they experience and perceive their quality of life.²¹ Consider the following example: Metabolic changes associated with urinary diversion, such as metabolic acidosis and electrolyte abnormalities (biology/physiology), may result in fatigue and lethargy (symptoms) that limit an individual's energy and impair day-to-day activities (physical and social functioning), ultimately resulting in a negative self-perception of health. In this example, as in others, the overall affect of health problems and symptoms on HRQOL varies according to the extent of the problem, how an individual experiences and copes with the problem, and external supporting factors and resources that assist them in managing the problem. Consider bowel dysfunction associated with urinary diversion as another example. One individual may have a more exaggerated response to minor changes in bowel function, such as bloating, more frequent bowel movements, and occasional diarrhea, whereas another may adapt to even moderate bowel dysfunction because they have an adaptive coping style, have greater access to resources to manage their symptoms, and are less bothered by the change in physical function and its associated consequences. The first individual is more bothered by the symptoms, experiences a greater degree of stress that may negatively impact social function, and perceives a decline in their quality of life. The experience and perception are different for the second individual even though their symptoms could be considered more severe, and as a result, their quality of life is not deflected as significantly.

As noted in the above examples, urinary diversion is associated with a range of experiences, symptoms, functional changes, and health problems that combined make up HRQOL after diversion surgery. Concerns and problem areas, also referred to as domains, that are specific to urinary diversion include bowel, sexual, and urinary function, body image, and psychosocial function, including anxiety, depression, and strain in social situations, function, or interactions. General problems and concerns experienced after surgery, such as pain, fatigue, and sleep disturbances, may also influence HRQOL among urinary diversion patients.²³

URINARY DIVERSION-SPECIFIC HEALTH-RELATED QUALITY-OF-LIFE MEASURES

Several measures, or questionnaires, can be used to assess HRQOL after urinary diversion. In general, HRQOL measures can be divided into generic questionnaires that assess general symptoms, concerns, and problems, and condition-specific

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