

Information Needs of Wives of Men Following Prostatectomy

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Purpose/Objectives: To identify and evaluate the information needs of wives of men diagnosed with prostate cancer who were treated first with radical prostatectomy and to measure the extent to which their needs were met.

Design: Descriptive.

Setting: Comprehensive cancer center designated by the National Cancer Institute.

Sample: 66 wives of men with prostate cancer.

Methods: On the second day after their husbands underwent prostatectomies, the wives of men with prostate cancer completed the Family Inventory of Needs–Wives and a demographic data form.

Main Research Variables: Information needs and the perceived degree to which they were met.

Findings: All needs were identified as important but were met to varying degrees. Five items were not rated “unmet” by any respondents, whereas four items were considered unmet by at least 30% of respondents. Evidence suggests that the age of the wife influences the percentage of unmet needs, with older wives having more unmet needs. P values for the relationship between needs and the age of the wife, her educational level, and the time between diagnosis and treatment were less than 0.05.

Conclusions: Illness prompts a wife's need for information, which supports findings of earlier research.

Implications for Nursing: Wives have a wide range of information needs. Assessing education needs and the degree to which they are met can guide nurses in restructuring education. Support and guidance regarding more difficult issues, such as fatigue and sexual activity, can decrease barriers to communication. Using a multimodality approach to education, constantly reassessing needs, and encouraging questions are imperative.

Prostate cancer is the most commonly diagnosed cancer in men and has a projected incidence rate of 232,090 (33%) in 2005. Prostate cancer is the second-leading cause of mortality from a malignancy and is estimated to lead to approximately 10% of all cancer deaths in men, or 30,350 cases per year. The probability of developing invasive prostate cancer increases with age. Although African Americans have a higher rate of prostate cancer, they tend to be diagnosed at a later stage and have a poorer survival rate compared to Caucasians. An estimated 90% of all new cases will be diagnosed at local or regional stages, at which the relative five-year survival rate is 100% (Jemal et al., 2005). Options for initial therapy for localized prostate cancer include radical prostatectomy and radiotherapy (National Comprehensive Cancer Network, 2004).

A diagnosis of prostate cancer affects the patient, his wife, and his significant others. Treating the patient as a whole involves including his family members to the degree that he desires. Information needs extend beyond the patient to his wife, particularly when she is the primary caregiver. The wife

Key Points . . .

- Family members of patients with cancer have a need for information.
- Decreased length of hospitalizations and clinical appointments diminishes the time and opportunity available for education.
- A valid and reliable tool identified information needs and the perceived degree to which they were met.
- All needs were considered to be important; however, four needs that were unmet in at least 30% of respondents draw attention to areas for improvement.

of the patient with cancer is a cosufferer of the disease and therefore provides and needs support (Northouse & Peters-Golden, 1993).

Although studies have reported that family members of patients with cancer need information, family members consistently have difficulty in obtaining information about patients (Hilton, 1993; Houts, Rusenas, Simmonds, & Hufford, 1991; Wilson & Morse, 1991; Zahlis & Shands, 1991). When information needs are unmet, the emotional distress of patients increases and adjustment to illness is hampered (Mesters, van den Borne, De Boer, & Pruyn, 2001; Poroch, 1995). Family members' need for information has been overlooked frequently by the healthcare system (Harden et al., 2002; Meissner, Anderson, & Odenkirchen, 1990; Northouse & Peters-Golden, 1993; Rees, Bath, & Lloyd-Williams, 1998; Wilson & Morse).

With the evolution of managed care, patient hospitalizations and clinic appointments have shortened, thus diminishing the time and opportunities to evaluate learning needs and provide education. Wives may not be present, and their information needs may vary from those of the patient. Nurses are challenged to appropriately tailor education that is effective and desirable to both the patient and his wife. Therefore, an adequate description of wives' information needs is necessary to contribute to improved care for these patients.

Recently, several studies of the information needs of family members of patients with cancer have been reported (Echlin & Rees, 2002; Kilpatrick, Kristjanson, Tatarzyn, & Fraser, Tina M. Mason, ARNP, MSN, AOCN®, is an oncology clinical nurse specialist in the H. Lee Moffitt Cancer Center and Research Institute at the University of South Florida in Tampa. (Submitted July 2003. Accepted for publication July 14, 2004.)

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1998; Rees et al., 1998; Rees, Sheard, & Echlin, 2003). However, limited research exists that specifically addresses the information needs of wives of men with prostate cancer in the United States. The purpose of this study was to examine the perceived information needs of wives of men who have undergone radical prostatectomy and the degree to which their needs were met.

Literature Review

Information Needs of Families

Kristjanson, Atwood, and Degner (1995) noted that families have many needs during the cancer illness of a member, some of which may not be met. The families' needs remain constant over a period of time, and their efforts to address these needs are largely through trial and error (Kristjanson et al.). Since the early 1990s, researchers have shown a growing interest in the information needs of family members (i.e., partners, parents, children) of patients with cancer (Davison et al., 2002; Hardwick & Lawson, 1995; Houts et al., 1991; Kilpatrick, Kristjanson, & Tataryn, 1998; Meissner et al., 1990; Pyke-Grimm, Degner, Small, & Mueller, 1999; Rees et al., 1998, 2003; Stetz, McDonald, & Compton, 1996; Yates & Stetz, 1999).

Meissner et al. (1990) examined the information needs of patients with cancer, their significant others, and the general public as reflected by telephone calls to the Cancer Information Services, a national toll-free telephone inquiry service. Patients with cancer and their significant others were found to have similar needs regarding information about cancer sites, treatments, and referrals for second opinions. However, the needs for requests for counseling services and clinical trials differed. Venn et al. (1996) found that of those who called a national telephone hot line managed by the British Association of Cancer United Patients (BACUP), patients most often asked for advice and information about their disease and their relatives usually wanted support and reassurance. BACUP reported more female than male callers to the helpline (Boudioni et al., 1999), and more women than men accessed the Internet at least once a week for health information, according to Eysenbach, Sa, and Diepgen (1999). O'Rourke and Germino (1998) studied 12 spouses and 6 of their partners in a prostate cancer support group. They found that participants did not use national cancer resources effectively and suggested that nurses must assess informal information sources and work toward a more comprehensive presentation of treatment options.

Stetz et al. (1996) studied 19 adult family members of patients who had undergone bone marrow transplantation. They found that the family members and patients experienced a unique set of information needs that could be diminished with appropriate educational tactics. Five themes of information needs emerged: preparing for caregiving, managing care, facing challenges, developing supportive strategies, and discovering unanticipated rewards and benefits. Although caregiver needs varied, difficulty communicating with healthcare professionals was emphasized, and family caregivers noted the need to be listened to, acknowledged, and treated with respect.

Information Needs of Spouses

Although an abundance of literature exists regarding family information needs, fewer studies specifically address the

needs of spouses. Kilpatrick, Kristjanson, Tataryn, and Fraser (1998) conducted a study using the Family Inventory of Needs–Husbands (FIN-H) tool to identify and measure the information needs of the husbands of women newly diagnosed with breast cancer and to determine the extent to which their needs were being met. Care and communication needs were identified as the most important. Among the husbands whose wives had undergone surgery, family relationships, changes in family responsibility, and the husbands' practical involvement in care were reported as least important. Whether the husband's needs were met depended somewhat on whether the wife had undergone surgery before. Husbands were at greater risk of not having their needs met if their wives had undergone only one surgery for breast cancer. In addition, husbands who were retired or laborers, lived in rural areas, were 60 years of age or older, or had less than a high school education were at greatest risk of not having their needs met.

Using a modified version of the FIN-H, Rees et al. (2003) found a significant correlation between information-seeking behavior and the information needs of men with prostate cancer and their partners. Results suggested that the need for information increased as tendencies to seek information rose, thereby stressing the necessity of considering the information-seeking behaviors of patients and their family members. The partners had high information needs regardless of their information-seeking behavior. Internal consistency of the modified tool, Family Inventory of Needs–Partners, was found to be 0.97.

Rees et al. (1998) studied information concerns of women with breast cancer and their spouses. Both the women and their spouses agreed that the spouses had important information needs that frequently were overlooked by healthcare professionals. As a result, the patient often was the most important and primary source of information for the spouse. In addition, many spouses felt uncomfortable approaching healthcare professionals for information. Rees et al. (1998) noted similar and different information needs of the spouses compared to the women with breast cancer.

Eighty couples (i.e., patients with prostate cancer and their partners) recruited from the Prostate Centre in Vancouver, Canada, identified prognosis, stage of disease, treatment options, and side effects as their primary information needs at the time the men were diagnosed (Davison et al., 2002). The men preferred to have an active or collaborative role in decision making with their physicians and partners, and the majority of partners wanted to play a collaborative role. Men ranked information on sexuality as more important than did their partners, whereas partners ranked information on home self-care higher than the men.

Gray, Fitch, Phillips, Labrecque, and Klotz (1999) examined the presurgery experiences of patients with prostate cancer and their spouses. Six themes were prominent: the shock of diagnosis, connecting with each other, obtaining information and making decisions, communicating with others, carrying on as usual, and dealing with anxiety. Some couples took quite a while to investigate options and make decisions, and the men and their spouses often had difficulty assessing the usefulness of the specifics of the information they gathered. Each couple also went through a process of deciding who to tell and how to tell them about the prostate cancer diagnosis. Sources of anxiety included the process and outcome of surgery, being in the hospital, the possibility

of impotence or incontinence, and the long-term impact of the disease and treatment on the marital relationship.

Phillips et al. (2000) studied patients with prostate cancer and their spouses 8–10 weeks after surgery. Five themes emerged: Hearing news about the extent of the cancer after surgery influenced patients' recovery, men placed greater emphasis on recovering physical capacity quickly, couples connected through working out care routines and managing irritability, a range of responses to surgery side effects and complications was described, and the meaning of the cancer varied for couples, with most seeing it as a temporary disruption.

Fukui (2002), who studied family caregivers of newly diagnosed patients with cancer, noted that more than 90% of Japanese caregivers (N = 66) wanted disease-related information and 83% wanted treatment-related information. In addition, 72%, 45%, 36%, and 33% of the caregivers wanted information about the prognosis, patient physical care, psychological care, and family care, respectively.

Lavery and Clarke (1999) assessed coping and marital adjustments of 12 patients with prostate cancer and their spouses after treatment. Nine of the 12 men underwent surgery for their prostate cancer, of which 4 also received radiotherapy and 3 received monthly hormone injections. One subject had radiotherapy only, and 2 only received hormone injections. Spouses were engaged more actively than their partners in meeting the demands of the illness and sought out information about prostate cancer in addition to that provided by doctors, whereas patients employed more buffering than their spouses by avoiding discussions about their cancer or denying their anxieties and concerns. Wives also employed more active coping strategies than their husbands. A few men reported negative changes in their marital relationships. Of those who had been sexually active before their diagnosis, all men reported negative changes related to impotence secondary to treatment.

Harden et al. (2002) conducted focus group research of couples' experiences with prostate cancer. Focus group participants had an overwhelming need for information regarding each of four themes: enduring uncertainty, living with treatment side effects, coping with changes, and needing help. Enduring uncertainty was related to participants' need for information to make informed decisions. In addition, many couples felt unprepared to recognize and manage treatment side effects. Harden et al. concluded that (a) current methods for support and information are limited in effectiveness, (b) information given at the time of diagnosis often is absorbed poorly, (c) full disclosure of potential treatment side effects is needed, and (d) all participants reported distress, suggesting the possible need for emotional assessment and referrals.

In general, wives of men with prostate cancer report a need for information and difficulty in obtaining it. Strategies for helping spouses of patients with cancer to manage the stressful effects of the disease include providing information and offering support (Northouse & Peters-Golden, 1993). Information can help spouses anticipate side effects during recovery that are considered typical, rather than problematic or signs of advancing disease. Spouses need to learn more about the emotional aspects of the illness and recovery throughout the course of the disease. Furthermore, information must be relevant to spouses' concerns (Northouse & Peters-Golden).

Harden et al. (2002) noted that all focus group participants agreed that a great need existed for information that varied from other sources. Research is limited but necessary to address the information needs of spouses.

Methods

Sample and Setting

This descriptive study identified and measured the perceived information needs of wives of men diagnosed with prostate cancer who had undergone radical prostatectomy. The extent to which their needs were met also was examined. The convenience sample consisted of wives of men diagnosed with prostate cancer at the time of their hospitalization for radical prostatectomy and who had not undergone previous treatment. The study took place at a university-affiliated, National Cancer Institute-designated comprehensive cancer center in west central Florida. Sixty-six wives were recruited from the genitourinary program at the cancer center two days after their husbands' surgeries.

Table 1. Demographic Data

Characteristics	Wives (n = 66)		Patients (n = 66)	
	n	%	n	%
Age (years)				
40–49	12	18	3	5
50–59	36	55	31	47
60–69	14	21	29	44
70 or older	4	6	3	5
Stage				
I	–	–	3	5
II	–	–	61	92
III	–	–	2	3
Education level				
Less than high school	17	26	–	–
High school, some college	47	71	–	–
Graduate school or higher	2	3	–	–
Ethnicity				
Caucasian	56	85	55	83
African American	4	6	5	8
Hispanic	3	5	4	6
Other	3	5	2	3
Occupation				
Clerical	20	30	–	–
Professional	13	20	–	–
Homemaker	11	17	–	–
Service	8	12	–	–
Sales	5	8	–	–
Manager, administrator	4	6	–	–
Skilled crafts, repairer	1	2	–	–
Other	4	6	–	–
Time between diagnosis and surgery (months)				
1	–	–	7	11
2	–	–	19	29
3	–	–	18	27
4	–	–	12	18
5	–	–	6	9
7	–	–	2	3
14	–	–	1	2
15	–	–	1	2

Note. Because of rounding, not all percentages total 100.

Instruments

The **Family Inventory of Needs–Wives (FIN-W)** is a 30-item instrument consisting of two subscales: the importance of the wife's needs and the extent to which these needs are met. The importance of the specific needs of the wives of men with prostate cancer was measured on a five-point scale (i.e., 1 = not important to 5 = extremely important). If a need was ranked 2 or higher, the respondent was asked to report whether the need had been met (i.e., 1 = met, 2 = partly met, 3 = unmet).

The FIN-W is a modified version of the FIN-H, which was developed by Kristjanson et al. (1995) and designed to survey husbands of women newly diagnosed with breast cancer. Internal consistency estimates were 0.91 and 0.93 as measured by Cronbach's standardized alpha coefficients. Test-retest correlations were acceptably high ($r = 0.76-0.82$). Exploratory factor analysis suggests validity with five factors: pre- and postoperative care needs, communication with healthcare professionals, family relationship issues, disease and treatment specifics, and the husband's practical involvement (Kilpatrick, Kristjanson, & Tataryn, 1998). The

only modification made from the FIN-H to the FIN-W was that "husband" was changed to "wife," which was approved by the developer of the FIN-H. Because of the revisions, Cronbach's alpha coefficients were computed using the data from this study. The researcher did not feel that restudying validity was necessary.

A **demographic data form** was used to collect information about the sample, including the age of the patient and his wife, their educational levels, their ethnic backgrounds, the wife's occupation, the stage of prostate cancer, and the date of diagnosis.

Procedures

After institutional and review board approval, potential subjects were approached regarding participation in the study. The researcher asked only the person identified by the patient as his spouse to participate. Interested participants completed a consent form, a demographic data form, and the FIN-W in writing at the patient's bedside on postoperative day 2. The investigator collected data over a two-year period.

Table 2. Rank Order of Needs and Degree of Being Met

Need	\bar{X}	Degree Met					
		Met		Partly Met		Unmet	
		n	%	n	%	n	%
Be assured that best possible care is being given	4.97	54	82	12	18	–	–
Know the probable outcome of husband's illness	4.92	31	47	26	39	9	14
Feel there is hope	4.91	56	85	9	14	1	2
Have questions answered honestly	4.88	54	82	11	17	1	2
Know what treatment husband is receiving	4.88	53	80	13	20	–	–
Informed of changes in husbands' condition	4.86	47	71	17	26	2	3
Know specific facts concerning husband's future	4.85	28	42	30	46	8	12
Know side effects caused by treatment	4.85	30	46	26	40	9	14
Feel healthcare professionals care about husband	4.83	55	83	11	17	–	–
Explanations given in understandable terms	4.83	58	89	7	11	–	–
Have information about what to do for husband at home	4.83	25	38	20	30	21	32
Know specific facts concerning husband's treatment	4.82	39	60	22	34	4	6
Know how to provide physical care to husband	4.80	25	39	23	35	17	26
Know exactly what is being done for husband	4.74	50	76	16	24	–	–
Know specific facts concerning husband's disease	4.74	41	63	18	28	6	9
Know why things are being done for husband	4.70	47	71	18	27	1	2
Know how to provide emotional support to husband	4.67	26	41	20	32	17	27
Know when to expect symptoms to occur	4.65	31	47	23	35	12	18
Know what symptoms are caused by the illness	4.64	38	58	20	30	8	12
Feel included by healthcare professionals	4.61	43	66	20	31	2	3
Be told about changes in treatment plans while they are being made	4.59	44	69	17	27	3	5
Know names of healthcare professionals involved in husband's care	4.47	52	80	12	19	1	2
Know what to expect of husband's energies	4.47	22	35	19	30	22	35
Know how to talk to husband about illness	4.40	32	53	12	20	16	27
Help with husband's care while he is in hospital	4.35	52	83	10	16	1	2
Know how to touch husband	4.33	29	48	13	22	18	30
Know how to approach changes related to sexuality	4.15	28	48	16	27	15	25
Know what to say to children	3.77	30	59	9	18	12	24
Be told about people who could help with problems (i.e., financial, household)	3.41	20	37	12	22	22	41
Have someone be concerned about my health	3.26	23	46	15	30	12	24

N = 66

Note. Items were rated on a scale from 1 = not important to 5 = extremely important.

Note. All participants did not answer every question.

Data Analysis

Demographic data and item scores were analyzed using means, standard deviations, frequencies, and percentages. Reliability was calculated using Cronbach’s alpha.

Mean scores with standard deviations were obtained for the demographic variables of age of the patient and his wife and the time between diagnosis and treatment. Totals and percentages were obtained for age ranges, stages of cancer, educational levels, ethnicities, occupations, and the time between diagnosis and treatment.

The mean scores for the 30 needs on the FIN-W were ranked from highest to lowest. Further delineated was the degree to which each need was met (i.e., not met, partly met, met) by total score and percentage.

Results

Demographics

Table 1 describes the demographic characteristics of the patients and their wives. The patients’ mean age was 59.7 years (SD ± 6.17), and the majority was Caucasian, was diagnosed at stage II, and had undergone surgery within four months of diagnosis. The average length of time between diagnosis and surgery was 3.3 months (SD ± 2.4). Ninety-seven percent of patients were diagnosed at stage I or stage II. The mean age of the wives was 55.6 years (SD ± 7.97), and the majority was Caucasian, had some college education, and held clerical jobs.

Reliability

Reliability of the modified tool, the FIN-W, was estimated using Cronbach’s alpha. Alpha coefficients were 0.94 for the Importance of Needs subscale and 0.87 for the Degree of Being Met subscale.

Importance of Needs

Table 2 lists the highest-to-lowest ranked order of means for the 30 needs. Further delineated is the degree to which each need was met. All needs were identified as important, with the lowest mean score (3.26) calculated for the need to “have someone be concerned about my health” and the highest mean score (4.97) for the need to “be assured that best possible care is being given.”

Met and Unmet Needs

Five items were not rated “unmet” by any respondents. These needs were to “be assured that best possible care is being given,” “know what treatment [my] husband is receiving,” “feel healthcare professionals care about my husband,” “explanations given in understandable terms,” and “know exactly what is being done for [my] husband.” Four items were considered unmet by at least 30% of respondents, drawing attention to areas for improvement. These needs were to “have information about what to do for [my] husband at home,” “know what to expect of [my] husband’s energies,” “know how to touch [my] husband,” and “be told about people who could help with problems (e.g., financial, household).”

Relationships Among Variables

Table 3 shows logistic regression analysis used to determine whether a relationship existed between the proportion of unmet needs and the age and educational level of the wife. Evidence

Table 3. Wives’ Total Needs and Unmet Needs According to Demographic Variables

Variable	n	\bar{X} Total Needs	Unmet Needs		
			\bar{X}	%	p
Age (years)					
Younger than 60	48	29.31	2.65	9	0.0019
60 or older	18	29.06	6.28	22	
Education level					
Less than high school	17	28.70	3.94	14	0.9601
High school, some college	47	29.40	3.53	12	
Graduate school or higher	2	30.00	3.50	12	

suggests that the age of the wife influenced the percentage of unmet needs (p = 0.0019). As the age of the wife increased, the odds of needs being met decreased. No relationship was found between total scores and educational levels; however, a significant relationship was found between the educational level of the wife and one item (i.e., “have someone be concerned about my health”). Additional logistical regression analysis of the age of the wife, the educational level of the wife, and the time between diagnosis and treatment, as well as estimates of the likelihood of specific needs being met or unmet, are listed in Table 4. Seven needs were noted with a p value of less than 0.05 in relation to the age of the wife. Two needs, “know specific facts concerning husband’s treatment” and “know side effects caused by treatment,” also were significant with regard to the time between diagnosis and treatment.

Discussion

This study found that illness prompts a need for information. The top five needs of husbands of women with breast cancer reported by Kilpatrick, Kristjanson, Tataryn, and Fraser (1998) also were found among the top seven needs identified in this study. In addition, the five lowest-ranked needs found in this study were identical to those reported by Kilpatrick, Kristjanson, Tataryn, and Fraser.

Husbands who were relatively young, Caucasian, and diagnosed at an early stage were reflective of those who would be candidates for surgery. Similarly, their wives also were young and Caucasian. As mentioned, a relationship existed between the age of the wife and the odds of her needs being met. The majority of the wives had little or no education beyond high school. According to demographics of the catchment area, minorities were under-represented at the institution where the data were collected.

All items on the tool were identified as important, with varying degrees of being met. Ten needs were scored as unmet by more than 23% of respondents, with four rated unmet by more than 30%. Data regarding the item “have information about what to do for [my] husband at home” may be inaccurate or misleading because data collection occurred before discharge, when the majority of that information would have been provided. Another limitation of the study was that no data were collected regarding any comorbid conditions of the patients that would have helped to establish couples’ coping strategies or their need for information. Two informational needs, “know what to expect of [my] husband’s energies”

Table 4. Likelihood Estimates: Factors Affecting Whether a Need Is Met

Need	p	Odds Ratio	95% Confidence Interval
Age of wife			
Know what symptoms are caused by the illness	0.016	0.871	0.778–0.975
Know when to expect symptoms to occur	0.001	0.835	0.747–0.933
Know the probable outcome of husband's illness	0.003	0.835	0.742–0.941
Have information about what to do for husband at home	0.010	0.903	0.835–0.976
Be told about people who could help with problems (e.g., financial, household)	0.035	0.918	0.848–0.994
Know how to provide physical care to husband	0.007	0.889	0.816–0.969
Know how to provide emotional support to husband	0.049	0.926	0.857–1.000
Educational level of wife			
Have someone be concerned about my health	0.009	0.919	0.832–1.016
Time between diagnosis and treatment			
Know specific facts concerning husband's treatment	0.022	0.894	0.757–1.055
Know side effects caused by treatment	0.046	0.946	0.853–1.050

and “know how to touch [my] husband,” scored high as being unmet, possibly reflecting nurses’ uneasiness about addressing issues such as fatigue and sexual activity. After the questionnaire was administered and reviewed with subjects, very few who rated “be told about people who could help with problems (e.g., financial, household)” as unmet stated that they did not have a need for this information. They scored this item as unmet because staff did not ask them if they needed this support. The patients were screened by social workers and would have been approached if this need was identified.

Clinical Implications

A wide range of information needs exists for patients who undergo prostatectomies and their wives. Assessing educational needs and the degree to which they are being met can guide nurses in restructuring education by focusing on partly met and unmet needs in a process of quality improvement. The needs of patients and their wives are equally important because wives can play a pivotal role in patients’ recovery and quality of life. Including patients’ wives remains vital as the nursing shortage increases and the hospital length of stay and time available to

spend with patients decrease. Oncology clinical nurse specialists can provide support and guidance for staff on harder-to-address issues, such as fatigue and sexual activity, as a way to help decrease barriers to communication. Providing literature for patients and their loved ones, as well as staff, on these educational needs is important to complement verbal discussion. Constantly reassessing needs and encouraging questions remain imperative responsibilities of nurses.

Future research is recommended to address the needs of family caregivers other than wives in relation to patients. Addressing needs over time, as well as reevaluating needs after interventions are implemented, is indicated. A more descriptive, qualitative assessment may provide a more comprehensive portrayal of needs.

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