

Employment and Quality of Survivorship Among Women With Cancer: Domains Not Captured by Quality of Life Instruments

Linda M. Frazier, MD, MPH, Virginia A. Miller, MS, Douglas V. Horbelt, MD, James E. Delmore, MD, Brigitte E. Miller, MD, and Ellen P. Averett, PhD, MHSA

Background: Many quality of life instruments assess the amount of paid work in combination with role function at home in the same items and do not specifically assess social support in the workplace. The goal of this study was to obtain women's views on the relationship between employment and health-related quality of life.

Methods: A focus group and questionnaire study was conducted among 73 women with gynecologic cancer who were employed at diagnosis and 25 people who provided them with psychosocial support.

Results: The women held a variety of blue collar and white collar jobs at diagnosis. Employment provided a strong sense of accomplishment and a welcome distraction during treatment. The employment experience was described as distinct from role function at home. No one equated working more hours with better quality of life. Social support at work could be poor at the same time that support from family and friends grew stronger.

Conclusions: The contribution to their quality of life that cancer survivors feel they receive from employment may not be linearly related to the quantity of their role function in the workplace. Employment-related items could be useful as an adjunct to standard quality of life measures.

Introduction

As cancer deaths decline, more patients are navigating their treatment and follow-up in the context of their careers. When studying employment outcomes among cancer survivors, typical measures include whether they returned to work, how soon they did so, how many hours they worked per week, and whether their career pathway changed.¹⁻⁴ Quality of life instruments also assess role function, but employment and daily activities outside of work are included within each question, precluding independent evaluation of employment (Table 1).⁵⁻¹³ The widely used

Functional Assessment of Cancer Therapy (FACT) instruments, for example, ask the respondent to rate, on a scale that ranges from "not at all" to "very much," the extent to which he or she is "able to work (include work at home)."⁵

Role functions in the workplace and at home are similar but not identical constructs. It may be more difficult in the face of illness to maintain employment roles than domestic roles. Symptoms may be more limiting at work than at home because job tasks cannot be interrupted and resumed as often as needed. Cancer survivors have reported that they experienced more fatigue at work than at home.¹⁴ Conversely, being able to do some paid work, even if it is not the same amount as previously, may be valued by patients because it helps them retain their personal identity.^{15,16}

A person's perceptions are fundamental to quality of life, according to the World Health Organization's definition of quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns."¹⁷ FACT instruments include a question on personal fulfillment from one's work, but the item includes both employment and role function at home. Other quality of life instruments omit the patient's perceived value of their

From the Department of Obstetrics and Gynecology, University of Kansas School of Medicine, Wichita, Kansas (LMF, VAM, DVH, JED), the Comprehensive Cancer Center at Wake Forest University, Winston-Salem, North Carolina (BEM), and the Department of Health Policy and Management, Kansas University Medical Center, Kansas City, Kansas (EPA)

Submitted May 20, 2008; accepted August 9, 2008.

Address correspondence to Linda Frazier, MD, MPH, Department of Obstetrics and Gynecology, University of Kansas School of Medicine - Wichita, 1010 N. Kansas Avenue, Wichita, KS 67214. E-mail: lfrazier@kumc.edu

Abbreviations used in this paper: FACTG = Functional Assessment of Cancer Therapy - General, EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer's 30-item quality of life questionnaire.

ability to fulfill role functions, focusing instead on the quantity of activities performed (Table 1).

Even when cancer survivors work fewer hours than they did before diagnosis, their quality of life may be enhanced if people at work are a source of social support.^{18,19} On the other hand, lack of social support at work may detract from quality of life when coworkers react negatively or the supervisor stops recommending the cancer survivor for promotion or training to upgrade skills.^{19,21} Such distressing experiences can reduce quality of life even when these individuals have not cut down on the amount of time they work. Cancer survivors may view social relationships at work quite differently from social relationships outside of work, according to research on diagnosis disclosure. In a study of disease-free breast cancer survivors, 96.8%

had told their friends about their illness, but only 51.2% and 41.1% had made this disclosure to coworkers and supervisors, respectively.¹⁹ Quality of life instruments blur potential distinctions between social support in the workplace and in the family or community, but social interactions in the workplace can be assessed using validated instruments for measuring cancer-specific social support, job strain, or workplace productivity (Table 1).^{9-13,22}

The goal of our study was to examine the employment experiences of women diagnosed with gynecologic cancer to obtain their views on the relationship between employment and health-related quality of life. We sought to identify attributes that might be useful to add to the measures of work-related role function on commonly used quality of life instruments.

Table 1. — Employment-Related Items and Social Support Questions in Selected Instruments

Instrument	Purpose	Example Items	References
FACT-G Version 4 (34 items)	Quality of life	<i>Work-related role function:</i> "I am able to work (include work at home)." <i>Perceived value of work role:</i> "My work (include work at home) is fulfilling." <i>Social interactions:</i> "I get support from my friends and neighbors."	Cella et al ⁵
EORTC QLQ-C30 Version 3 (30 items)	Quality of life	<i>Work-related role function:</i> "During the past week, were you limited in doing either your work or other daily activities?" <i>Perceived value of work role:</i> none. <i>Social interactions:</i> "Has your physical condition or medical treatment interfered with your social activities?"	Aaronson et al ⁶
SF-36 (36 items)	Quality of life	<i>Work-related role function:</i> "Have you cut down on the amount of time spent on work or other activities?" <i>Perceived value of work role:</i> none. <i>Social interactions:</i> "Has your health limited your social activities (like visiting friends or close relatives)?"	Ware and Sherbourne ⁷
SIP (136 items)	Quality of life	<i>Work-related role function:</i> "I am working shorter hours." <i>Perceived value of work role:</i> none. <i>Social interactions:</i> "I am doing fewer social activities with groups of people."	Sullivan ⁸
SFSS (15 items)	Cancer-specific social support	<i>Work-related role function:</i> not applicable. <i>Perceived value of work role:</i> not applicable. <i>Social interactions:</i> "My colleagues gave me helpful advice on coping at work." "My supervisor kept in touch with me during my sick leave."	Lehto-Jarnstedt et al ⁹
JCQ (25 items)	Job strain	<i>Work-related role function:</i> none. <i>Perceived value of work role:</i> none. <i>Social interactions:</i> "How often do you get help and support from your colleagues?"	Bosma et al ¹⁰ De Bacquer et al ¹¹
DCSQ (17 items)	Job strain	<i>Work-related role function:</i> none. <i>Perceived value of work role:</i> none. <i>Social interactions:</i> "My coworkers (colleagues) are there for me (support me)."	Gudbergsson et al ¹²
WLQ (25 items)	Workplace productivity	<i>Work-related role function:</i> "In the past 2 weeks, how much of the time did your physical health or emotional problems make it difficult for you to handle the workload?" <i>Perceived value of work role:</i> none. <i>Social interactions:</i> "In the past 2 weeks, how much of the time did your physical health or emotional problems make it difficult for you to help other people to get work done?"	Lerner et al ¹³

FACT-G = Functional Assessment of Cancer Therapy-General, EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer's 30-item quality of life questionnaire, SF-36 = Medical Outcomes Study Short Form-36, SIP = Sickness Impact Profile, SFSS = Structural-Functional Social Support Scale, JCQ = Job Content Questionnaire, DCSQ = Demand-Control-Support Questionnaire, WLQ = Work Limitations Questionnaire.

Methods

The Institutional Review Boards at the Kansas University School of Medicine (Wichita, Kansas) and Wake Forest University School of Medicine (Winston-Salem, North Carolina) reviewed and approved the ethics and safety of the study (approval numbers 220040745 and BG06-014, respectively). All research participants provided written informed consent. Gynecologic cancer survivors and people who provided them with psychosocial support were recruited. Parallel but separate data collection from support people gave an additional view of the cancer survivor's job experiences.

Participants

We considered individuals to be cancer survivors beginning at diagnosis, which is consistent with the recommendations of the National Cancer Institute, advocacy groups, and others.^{23,24} Study eligibility criteria were having a diagnosis of primary ovarian, invasive cervical, or uterine cancer made at least 3 months previously and having been employed at the time of cancer presentation. We studied women because previous research has documented ways in which they may be a particularly vulnerable group in the workplace.^{3,12,14,25} Although at least two-thirds of employed individuals return to work after cancer diagnosis,^{1,2} women were 70% less likely than men to do so in a study of 1,433 cancer survivors.²⁵ The reduced rate of return to work among women in the study could not be explained by differences in age, cancer type and stage, education, marital status, chronic conditions, or physical demands of the job. In a group of men and women who were tumor-free after primary treatment of a variety of cancers, 17% reported they had made job changes as a result of cancer, and women were more likely than men to do so (21.9% of 219 women compared with 11.3% of 212 men, $P = .003$).³

We chose a larger sample size than that in other focus group studies²⁶⁻²⁹ for three reasons. First, we wanted to represent a relatively broad spectrum of women's cancer-related role function limitations by including women with endometrial, ovarian, and cervical cancer.^{27,28,30-32} Physical limitations are short-lived in early-stage endometrial cancer but are typically chronic and recurrent among women with ovarian cancer because it presents at later stages and is often refractory to treatment. Older age at diagnosis may make retirement a viable option among women with cancers of the ovary or endometrium, whereas cervical cancer is more likely to occur among younger women for whom retirement may not be an option. Their need to remain wage earners may be complicated by the fact that cervical cancer is more common among minority women of low socioeconomic status; the jobs available to them may have greater physical demands and fewer benefits such as paid medical leave.²⁷ Women with gynecologic cancers have also been underrepresented in previous research

on employment outcomes.^{1,2,4,19,26} The second reason for recruiting a large sample was to include a wide variety of jobs. Because women's employment experiences are likely to differ by job type, we estimated that thematic saturation would occur at a larger than usual sample size.²⁹ The third reason for the large sample size was that we wanted to collect quotes to use when developing educational materials about employment issues during cancer survivorship. Quotes, vignettes, and narratives from peers may increase self-efficacy for adopting health behaviors and can make educational materials more interesting.³³⁻³⁵ At the usual point of thematic saturation in focus group research, the collection of quotes on an important topic may not include any that are concise enough for patient education purposes.

Cancer survivors were recruited primarily through two gynecologic oncology practices. The Kansas oncology practice is a community-based clinic affiliated with a satellite campus of a medical school; it is the only gynecologic oncology practice within a 150-mile radius. The North Carolina oncology practice is the gynecologic oncology section of a comprehensive cancer center at the main campus of a medical school. Recruitment was also accomplished by public advertising and word of mouth. A referral form allowed participating cancer survivors to recommend their husbands or another support person for possible study participation.

Data Collection

Each focus group was led by a moderator of the same gender as the participants. Focus groups were offered at a variety of times, including evenings and weekends. Participants could select either a face-to-face or telephone focus group format. Conferencing was used to link multiple participants by telephone. Dynametric Call Saver Pro, version 1.05 (Monrovia, CA), was used to record calls directly to a computer. Focus group moderators used a set of interview guide questions (Table 2) while allowing the discussion to flow freely. Before beginning this study, an initial set of questions was used in preliminary focus groups. We used some questions that addressed risk factors for poor work outcomes after cancer diagnosis.^{2,19} We modeled other questions on those used in prior qualitative studies of employment and quality of life among cancer patients, such as "Did you discuss your illness with the people you worked with?"²⁶ and "Should doctors ask their cancer patients whether they want help dealing with...?"²⁸ Based on the field tests, a smaller set of questions with more open-ended phrasing was developed for the present study (Table 2).

Characteristics of the study population were collected by questionnaire and medical record review. Work history items were modeled on those used in previous studies among cancer patients and among individuals with occupational injuries.^{2,36,37} Satisfaction

with the main job held at cancer presentation was assessed for “How things went overall at your job,” using a 10-point scale ranging from 1 (“not satisfied at all”) to 10 (“very satisfied”). The wording “How things went” has been used in validated instruments assessing functional limitations at work¹³ and physician satisfaction with patient encounters.³⁸

Current quality of life was assessed using the Functional Assessment of Cancer Therapy-General (FACT-G), version 3, which has a maximum score total score of 104, comprised of four subscale scores: physical well-being (7 items), social and family well-being (7 items), emotional well-being (5 items) and functional well-being (7 items).⁵ Each item is scored on a scale from 0 (“not at all”) to 4 (“very much”), with higher scores representing better quality of life. The instrument is reliable (Cronbach’s alpha values > 0.88) and has excellent test-retest results (correlation coefficients > 0.90).^{5,39,40} The functional well-being subscale contains 2 items regarding work — one that addresses ability to work (including work at home) is fulfilling (Table 1). In the general population (without cancer), the FACT-G physical well-being and functional well-being subscale scores (mean ± standard deviation) are 22.7 ± 5.4 and 18.5 ± 6.8, respectively, and a change of 2 to 3 points is considered clinically significant.³⁹

Data Analyses

Descriptive data from questionnaires and medical records were managed using the Statistical Package for the Social Sciences, version 14.0 (SPSS Inc, Chicago, IL). Focus group recordings were transcribed and categorized using NVivo7 (QSR International Pty Ltd, Cambridge, MA). Two observers coded each transcript independently. Open coding was first used to generate broad descriptive categories centering on the topics in the focus group moderator guides and then according to additional topics that participants raised. Keywords,

Table 2. — Focus Group Moderator Guide Prompts About Employment and Quality of Life

Gynecologic Cancer Survivors
Tell me what quality of life means to you.
Describe your feelings about having a job or having a career.
What tips about work situations would you give to newly diagnosed women?
To whom did you turn for advice about your job?
How are your feelings about your job influenced by whether a person at work helped you with a job issue related to a health problem you were having?
Support Persons
What does quality of life mean to you?
Describe your experience about the cancer survivor’s work.
What advice did you provide her about her job?
Talk about how people at work affected her health.

ideas, and themes were identified and ordered logically. Categories were combined and collapsed to organize the qualitative data. Quotes that best exemplified key themes were then selected.²⁹

Results

A total of 73 gynecologic cancer survivors and 25 support people participated in the study. Most of the cancer survivors (83.6%) were referred from the two gynecologic oncology practices. Characteristics of the cancer survivors are provided in Table 3. At the time of

Table 3. — Characteristics of Gynecologic Cancer Survivors Who Participated in the Study (N = 73)

Characteristic	Mean ± SD (range)
Age at diagnosis, yrs	49.8 ± 9.0 (25–70)
Months since diagnosis	34.9 ± 35.2 (3–216)
	n (%)
Cancer type	
Ovarian	28 (38.4)
Cervical	21 (28.8)
Endometrial	19 (26.0)
More than one gynecologic primary	5 (6.8)
Residence in rural area or small town	34 (47.2)
Type of work at cancer presentation	
Service industries	20 (27.8)
Health care	17 (23.6)
Education	13 (18.1)
Sales	8 (11.1)
Other white collar industries	8 (11.1)
Manufacturing	6 (8.3)
Business size at cancer presentation	
< 50 employees	34 (48.6)
≥ 50 employees	36 (51.4)
Employment hours at cancer presentation	
Full-time	56 (80.0)
Part-time	14 (20.2)
Business ownership at cancer presentation	
Self-employed or business owner	6 (8.4)
Worked for a company	66 (91.7)
Sick leave†	
Received paid short- or long-term disability benefits	43 (59.7)
Used unpaid time off	31 (43.1)
Status within the first year of survivorship of job held at cancer presentation	
Kept working same job	48 (66.7)
Left job due to illness	13 (18.1)
Fired, quit to avoid being fired, or forced out after cancer diagnosis	5 (6.9)
Left job because of new opportunities or priorities	3 (4.2)
Business closed	2 (2.8)
Left job because moved	1 (1.4)
Satisfied with how things went with job after cancer diagnosis‡	58 (84.1)

* Denominators vary due to questionnaire items left blank. Percentages may not add up to 100 due to rounding.
† Categories are not mutually exclusive.
‡ Response of 7–10 on a 10-point scale.

study participation, their FACT-G scores (mean \pm standard deviation, range) were physical well-being, 22.3 \pm 7.3, range 0-28; social and family well-being, 22.4 \pm 5.4, range 8-28; emotional well-being, 16.0 \pm 4.0, range 0-20; functional well-being, 21.8 \pm 6.1, range 7-28; total score, 83.4 \pm 18.3, range 26-104. Among the 73 cancer survivors, 41 (56.2%) referred a support person for possible study participation. Among the 18 husbands and 23 female friends or relatives referred, 13 (72.2%) and 12 (52.2%), respectively, chose to participate in the study.

The Meaning of Quality of Life

During the focus groups, quality of life was described by the women living with cancer as being able to participate in activities that were important to them:

Quality of life means everything. It means being able to see the sun come up in the morning. It means complaining about the hot weather down here if I want to. It means being able to get out on my new John Deere mower and mow the front yard and wave at all the neighbors.

Caring interpersonal relationships and fulfillment of one's responsibilities were important contributors to quality of life. One husband said:

I think quality of life is having a healthy, caring, loving family and being able to take care of them and everybody being, you know, being able to do what they want to do.

Employment and Quality of Life

Cancer survivors viewed their jobs as important to their quality of life, as exemplified by the following quote from a teacher:

[Getting back to work] was something I was always working towards. Actually during my treatments, I'd have teachers call me. I kept saying I was bored... The teachers brought me things that I could do like bulletin boards... I would cut out and I would color and it made me think that I was there. Even though it was not my work — it was somebody else's — it was just my incentive... It uplifted me and kept me motivated then. Not sit at home and wait around and do nothing.

Another woman felt left out when she could not work at her job:

There were times I felt so bad that just getting through the treatment seemed like an

ordeal. But then when you are at that time when you are not really, really bad — that is totally depressing. To feel like everybody else has this life and it is just going by you... You are just kind of hanging out on the outside looking in. You are going to treatments and coming back home.

Social relationships at work were important to quality of life. A cancer survivor's husband said:

I think that the relationship that they have at work brings out a lot of qualities of life. The people she worked with were so critical to her quality of life.

A cancer survivor's daughter revealed the following, which had not been mentioned by the cancer survivor herself:

For my mother, her job is a big part of her life because she does not have any grandchildren. She is not married, so her job and her cats and her dogs and me are her life... I mean, I don't know what she would do without her job.

Devoting too much time to work, however, detracted from quality of life, as noted by women who said that cancer helped them review their priorities:

Quality of life, it changed after this for me. It was more, I mean I was really sometimes so involved in career that I would put my family off. The most important things to me now are my kids and spending time with them. Just getting a balance with my job and my family.

In mine, my quality of life, I take more time now to do things that I want to do. I listen to my body. I take time for myself. I think it is bad in nursing... A lot of time we put things in front of our personal needs.

Other women said:

[My doctor] observed me and said, "You need to stop doing so much"... He was just concerned that I was working too much and that I needed to slow down a little bit. Take care of myself first, is what the doctor told me.

Quality of life, I think as I, like, if I was to recur... If I was to recur I would be really angry that I have spent all this time working.

Impact of Morbidity on Employment

Symptoms and treatment complications were major reasons why women's jobs were disrupted by cancer:

The night before I was supposed to go back to work, I ended up in the hospital... I did my first infection.

I would take the day off for chemotherapy and then return to work a few days later.

When I was working when I was having chemo, I could tell I was not as sharp as I usually was.

I felt like I did not have the strength that I needed, you know. I mean before this cancer, I had a lot more strength. You know, my job is very physically demanding. There is a lot of lifting and pushing and pulling and bending, you know, and a lot of walking.

When women could not perform all the functions of their jobs because of their cancer, coworkers were sometimes unsympathetic:

I tried to do all the work I could. There was a little lifting and I could not do that. I had to ask one girl. When you work in quality control, people don't like you. You have to be the tough guy. And so I said, "Can you help me lift these out of the box?" "I'm busy," she turns her head... I just kept to myself. I had people stare at me, watch me.

When coworkers reacted negatively, social support at work could be negative at the same time that social support among friends and family was positive. For instance, one woman described becoming closer with her husband after diagnosis and receiving support from friends, but her supervisor became less supportive:

[With my husband] all the little things that might have irritated before just become unimportant. And the fact that we can be together, and that is much more important right now than it might have been before... You know, you have friends who will do things for you... I had a supervisor who just was not there for me... He just could not see what I was going through and could not relate to me.

Women who could no longer do any paid work were able to fulfill some of their role functions at home if they took their time:

I had 48 chemo and radiation treatments in the last year... I can't work. I have applied for disability and I was approved the first time... The grandchildren want to come over... they cannot stay over too long, because it is hard on me. I love them to death. There are times when I just have to go lay down... You do laundry one day and something else the next day.

Lack of Medical Leave Time

Many women said that lack of medical leave was a hardship. For example, one of the cancer survivors had used most of her sick time during the 2 years before her cancer diagnosis to care for her dying mother and mother-in-law. Rapid return to work was necessary after her surgery, and this was not a positive experience. She soon quit her job to avoid being fired:

I was naive about how bad it could be (laughs), how bad it could be with one's workplace. Totally naive, having seen other things with people that had gone well. I was in a very bad situation by the time I got a diagnosis. I think I had a total of one week of sick leave left after five years of being there... I pretty much had to pick up and go on as quickly as I could... Colleagues offered to management to give me some of their sick leave or vacation and that was denied... It was almost like an opportunity to get rid of me... I made a decision to leave my job.

Her support person provided an additional view, describing the emotions the survivor felt at the time:

Coming back after her surgery, she was not 100%, and yet she had to give more than 100% at our workplace. Because at our job, just giving 100% is not enough. She had to give it 120%. She could not and she knew she was going to fail. She was anxious. I think she felt like a drowning woman. 'No matter what I do, I am not going to survive this work, nor this situation...' So a lot of us listened to her anxieties and tried to be there for her... If they had not put the squeeze on her so soon after her surgery, she might have made it.

Income Loss

Suddenly reduced wages or unemployment combined with new medical bills were serious blows to the family budget:

The money wasn't good. My short-term dis-

ability only sent home 60%... The money was very limited.

We always had two pretty good incomes coming in and then all of sudden to not have the income... it was, well, you know... I found out that I could not work.

I didn't want to give up working because I needed the money, needed to pay those medical bills. I haven't thought much about a lifelong unfulfilled dream, but I sure would like to win the lottery.

Fears About Work

Cancer symptoms were a source of fear, especially when women thought they might lose their jobs or income:

I am scared to call in sick... You gotta work to eat.

Women who were initially fearful sometimes discovered that their workplace was a caring environment:

I was so scared that they were going to throw me out the door. Because I needed the company. I had only been there for a couple of years. I thought they would be angry that my work was piling up on them. Or regretful that I got time off more than they did. They did not take vacation time while I was gone. Things like that. They absolutely were in solidarity with me. They haven't ever shown any resentment.

Role of Employment in Recovery

Coworkers helped the women deal with their treatment side effects:

Our [supervisor] two years earlier had had a bout with cancer and chemotherapy. It was breast cancer and she is getting over her second round of chemo now because it came back... The day that I got my diagnosis, she and another one of my supervisors... came down here to my office. She talked to me and she told me I was going to be okay... I called her the day I was doing the prep for surgery and she was telling me the things I could have. "Now you get you some bouillon or some chicken soup. You know that you can have Jell-O," she said. So she was just a huge help.

I went bald immediately in the shower, which was a traumatic shock. I went back to work and sent an e-mail to all the people

that I work with that I am going to be wearing hats because of the fact that I lost my hair... [My coworkers] that were bald told me that I was welcomed to the club, except for the fact that I would have to leave when my hair grew back (laughter).

Survivors noted that work kept their mind occupied and helped make them feel less depressed:

Working is the best thing I can do to keep my mind away from the image and depression.

If I didn't work, I would be in the nut house somewhere. The work, I have to work, I have to be busy. I don't leave myself any time to think about this.

I felt good about myself as long as I was able to walk out the door and go to work.

Discussion

Items about role function on commonly used quality of life instruments such as the Medical Outcomes Study Short Form-36 (SF-36), the FACT-G, and the European Organization for Research and Treatment of Cancer's 30-item quality of life questionnaire (EORTC QLQ-C30) do not distinguish between employment and roles at home (Table 1). In our study, the employment experience was described as distinct from role function at home. The women cancer survivors in our study described many positive influences of workplace experiences on their quality of life. They often felt a sense of accomplishment when they were well enough to work, even when they had to reduce their hours or if were not able to perform certain tasks. Work provided normalcy at a time when cancer threatened to take control of their lives, a finding that has been noted by other investigators.⁴¹

Workplace experiences also had a negative impact on quality of life. Involuntary job loss was a real risk after cancer diagnosis (18.1% left due to illness and 6.9% were fired or forced out or quit to avoid being fired) (Table 3); loss of income could be a significant hardship. Most women received social support at work, but when postoperative limitations and treatment side effects affected their ability to be productive, some coworkers resented this. One woman kept working the same amount despite not feeling well, saying, "You gotta work to eat," but she was in constant fear that she would be fired if she did not do so. Another woman was afraid that her coworkers would be upset because she had to reduce her working hours. However, her medical limitations in the workplace indirectly improved her quality of life by giving coworkers a chance to step in and do the tasks she could not perform, showing that they cared about her.

Our quality of life findings add to previous studies in the literature that linked unsupportive workplace environments with lower rates of return to work after cancer diagnosis.^{19,21} The cancer survivors in our study said that social support from coworkers and the quality of the relationship with the supervisor were highly important to their quality of life. Social support received at work could be poor, while at home or in the community, social support could be good. It is not clear how this would affect the net amount of social support that cancer survivors report on quality of life items that do not specifically address positive and negative interactions with people in the workplace (Table 1).

No cancer survivor or support person equated working more hours with greater quality of life. Rather, many women said that just being able to work was important to them. Cancer made some women pause to rethink their priorities and realize that working too much before diagnosis had detracted from their quality of life. Rapidly returning to work and working a full schedule of hours despite symptoms and treatment complications were stressful for some women. These findings suggest that a domain not captured by existing quality of life instrument is the value that cancer survivors place on their work-related role function and that the intangible value provided by employment may not be linearly related to quantity of role function in the workplace.

This study has several limitations. The sample size did not provide enough statistical power to compare employment outcomes according to cancer type and stage among the cancer survivors, and only 25 support people participated. However, the sample size was sufficient for gathering many perspectives and experiences for qualitative data analysis. The retrospective design may have led to recall bias, and selection bias could have occurred if research participants with certain characteristics were more likely to participate. These potential biases did not invalidate this study because women with both good and poor employment outcomes participated, and participants described both happy and painful workplace events.

A strength of this study was the variety in the sample, which provided a rich collection of employment experiences from women in two geographically-distant states. The study population represented many kinds of jobs at diagnosis — blue collar and white collar occupations, self-employment and employment by a company, large and small companies, and urban and rural employers. Conducting focus groups in the evening and on weekends allowed women to participate regardless of current employment status. Offering focus groups by telephone allowed women to participate if they were currently ill or lived far from the study center.

Another strength of this study was that the women living with cancer, their husbands, and women support

persons provided complementary perspectives. This was illustrated by the narrative from a woman with little sick time who returned to work too soon and then quit because she feared being fired. The coworker confirmed these events and added to the cancer survivor's story by telling how people at work reacted to her predicament and tried to help her. A daughter described reasons why work was such an important part of a cancer survivor's life. These details would not have come to light through use of standard quality of life instruments or if only the women with cancer had been invited to participate in the research.

Conclusions

Established quality of life instruments such as the FACT-G and the EORTC QLQ-C30 reliably detect differences in quality of life associated with disease stage and treatment effects when used in clinical trials of antineoplastic therapy.^{5-8,39} Because these instruments do not distinguish between role function and social relationships at work and at home, they may be used with anyone, regardless of employment status (Table 1). Improved antineoplastic therapy is increasing patient longevity and decreasing morbidity for many cancers, making it possible for survivors to participate in the workforce in greater numbers than in the past.^{24,42} More precise measurement of employment-related role function may be desirable to help evaluate the impact of survivorship services such as psychosocial assistance, exercise, and rehabilitation.^{24,43-45}

Our study participants described work as an experience distinct from experiences at home. The lack of precision for assessing employment factors in general quality of life instruments may be remedied by asking employed individuals to complete one or more additional instruments that measure role function in the workplace and social support received from coworkers and supervisors (Table 1). The domains captured by such supplementary instruments would address important topics raised by the participants in our study, but respondent burden would be increased because of the combined length of all instruments administered. Future research may be warranted to determine if a reduced set of employment-related items could be validated for use as an adjunct to standard quality of life measures.

Appreciation is expressed to the women cancer survivors and support people who participated in this study. We appreciate their courage in telling their stories. The study could not have been accomplished without the able assistance of Liesa Hopper.

Disclosures

No significant relationship exists between the authors and the companies/organizations whose products or services may be referenced in this article.

References

- Bradley CJ, Bednarek HL. Employment patterns of long-term cancer survivors. *Psychooncology*. 2002;11(3):188-198.
- Spelten ER, Sprangers MA, Verbeek JH. Factors reported to influence the return to work of cancer survivors: a literature review. *Psychooncology*. 2002;11(2):124-131.
- Gudbergsson SB, Fosså SD, Dahl AA. A study of work changes due to cancer in tumor-free primary-treated patients: a NOCWO study. *Support Care Cancer*. 2008;16(10):1163-1171. Epub 2008 Feb 7.
- Steiner JF, Cavender TA, Nowels CT, et al. The impact of physical and psychosocial factors on work characteristics after cancer. *Psychooncology*. 2008;17(2):138-147.
- Cella DF, Tulskey DS, Gray G, et al. The functional assessment of cancer therapy-BRM (FACT-BRM): a new tool for the assessment of quality of life in patients treated with biologic response modifiers. *Qual Life Res*. 2004;13(1):137-154.
- Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst*. 1993;85(5):365-376.
- Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I: conceptual framework and item selection. *Med Care*. 1992;30(6):473-483.
- Sullivan M. The Sickness Impact Profile (SIP). An instrument for overall health assessment: a basic evaluation. *J Drug Ther Res*. 1988;13:167-169.
- Lehto-Jarnstedt US, Ojanen M, Kellokumpu-Lehtinen P. Cancer-specific social support received by newly diagnosed cancer patients: validating the new Structural-Functional Social Support Scale (SFSS) measurement tool. *Support Care Cancer*. 2004;12(5):326-337. Epub 2004 Apr 3.
- Bosma H, Marmot MG, Hemmingway H, et al. Low job control and risk of coronary heart disease in Whitehall II (prospective cohort) study. *BMJ*. 1997;314(7080):558-565.
- De Bacquer D, Pelfrene E, Clays E, et al. Perceived job stress and incidence of coronary events: 3-year follow-up of the Belgian Job Stress Project cohort. *Am J Epidemiol*. 2005;161(5):434-441.
- Gudbergsson SB, Fosså SD, Sanne B, et al. A controlled study of job strain in primary-treated cancer patients without metastases. *Acta Oncol*. 2007;46(4):534-544.
- Lerner D, Amick BC III, Rogers WH, et al. The Work Limitations Questionnaire. *Med Care*. 2001;39(1):72-85.
- Lee MK, Lee KM, Bae JM, et al. Employment status and work-related difficulties in stomach cancer survivors compared with the general population. *Br J Cancer*. 2008;98(14):708-715. Epub 2008 Feb 19.
- Ferrell BR, Smith SL, Ervin KS, et al. A quantitative analysis of social concerns of women with ovarian cancer. *Psychooncology*. 2003;12(7):647-663.
- Gillies B, Johnston G. Identity loss and maintenance: commonality of experience in cancer and dementia. *Eur J Cancer Care (Engl)*. 2004;13(5):436-442.
- Fitzpatrick R, Davey C, Buxton MJ, et al. Evaluating patient-based outcome measures for use in clinical trials. *Health Technol Assess*. 1998;2(14):i-iv, 1-74.
- Taskila T, Lindbohm ML, Martikainen R, et al. Cancer survivors' received and needed social support from their work place and the occupational health services. *Support Care Cancer*. 2006;14(5):427-435. Epub 2006 Jan 10.
- Stewart DE, Cheung AM, Duff S, et al. Long-term breast cancer survivors: confidentiality, disclosure, effects on work and insurance. *Psychooncology*. 2001;10(3):259-263.
- Pryce J, Munir F, Haslam C. Cancer survivorship and work: symptoms, supervisor response, co-worker disclosure and work adjustment. *J Occup Rehabil*. 2007;17(1):83-92.
- Bouknight RR, Bradley CJ, Luo Z. Correlates of return to work for breast cancer survivors. *J Clin Oncol*. 2006;24(3):345-353.
- Feuerstein M, Hansen JA, Calvio LC, et al. Work productivity in brain tumor survivors. *J Occup Environ Med*. 2007;49(7):803-811.
- Twombly R. What's in a name: who is a cancer survivor? *J Natl Cancer Inst*. 2004;96(19):1414-1415.
- Hewitt M, Greenfield S, Stovall E, eds. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academies Press; 2006.
- Short PF, Vasey JJ, Tunceli K. Employment pathways in a large cohort of adult cancer survivors. *Cancer*. 2005;103(6):1292-1301.
- Maunsell E, Brisson C, Dubois L, et al. Work problems after breast cancer: an exploratory qualitative study. *Psychooncology*. 1999;8(6):467-473.
- Ashing-Giwa KT, Padilla GV, Bohórquez DE, et al. Survivorship: a qualitative investigation of Latinas diagnosed with cervical cancer. *J Psychosoc Oncol*. 2006;24(4):53-88.
- Dey I. *Qualitative Data Analysis: A User-Friendly Guide for Social Scientists*. London: Routledge; 1993.
- Vistad I, Fosså SD, Dahl AA. A critical review of patient-rated quality of life studies of long-term survivors of cervical cancer. *Gynecol Oncol*. 2006;102(3):563-572. Epub 2006 May 22.
- von Gruenigen VE, Frasore HE, Jenison EL, et al. Longitudinal assessment of quality of life and lifestyle in newly diagnosed ovarian cancer patients: the roles of surgery and chemotherapy. *Gynecol Oncol*. 2006;103(1):120-126. Epub 2006 Mar 23.
- Miller BE, Pittman B, Case D, et al. Quality of life after treatment for gynecologic malignancies: a pilot study in an outpatient clinic. *Gynecol Oncol*. 2002;87(2):178-184.
- Chan YM, Ngan HY, Li BY, et al. A longitudinal study on quality of life after gynecologic cancer treatment. *Gynecol Oncol*. 2001;83(1):10-19.
- Mancuso CA, Sayles W, Robbins L, et al. Novel use of patient-derived vignettes to foster self-efficacy in an asthma self-management workbook. *Health Promot Prac*. 2008 April 10. [Epub ahead of print]
- Swift TL, Dieppe PA. Using expert patients' narratives as an educational resource. *Patient Educ Couns*. 2005;57(1):115-121.
- Kennedy A, Robinson A, Rogers A. Incorporating patients' views and experiences of life with IBS in the development of an evidence-based self-help guidebook. *Patient Educ Couns*. 2003;50(3):303-310.
- McLellan RK, Pransky G, Shaw WS. Disability management training for supervisors: a pilot intervention program. *J Occup Rehabil*. 2001;11(1):33-41.
- Gillen M, Baltz D, Gassel M, et al. Perceived safety climate, job demands, and coworker support among union and nonunion injured construction workers. *J Safety Res*. 2002;33(1):33-51.
- Shore BE, Franks P. Physician satisfaction with patient encounters: reliability and validity of an encounter-specific questionnaire. *Med Care*. 1986;24(7):580-589.
- Webster K, Cella D, Yost K. The Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System: properties, applications, and interpretation. *Health Qual Life Outcomes*. 2003;1:79.
- Smith AB, Wright P, Selby PJ, et al. A Rasch and factor analysis of the Functional Assessment of Cancer Therapy-General (FACT-G). *Health Qual Life Outcomes*. 2007;5:19.
- Kennedy F, Haslam C, Munir F, et al. Returning to work following cancer: a qualitative exploratory study into the experience of returning to work following cancer. *Eur J Cancer Care (Engl)*. 2007;16(1):17-25.
- Hoffman B. Cancer survivors at work: a generation of progress. *CA Cancer J Clin*. 2005;55(5):271-280.
- Johansen C. Rehabilitation of cancer patients: research perspectives. *Acta Oncol*. 2007;46(4):441-445.
- Franklin DJ. Cancer Rehabilitation: challenges, approaches, and new directions. *Phys Med Rehabil Clin N Am*. 2007;18(4):899-924, viii.
- Dirmaier J, Zaun S, Koch U, et al. Psychometric properties of the EORTC Quality of Life Questionnaire in inpatient cancer rehabilitation in Germany. *Palliat Support Care*. 2004;2(2):115-124.