

Review

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Quality of life and psychosocial adjustment in gynecologic cancer survivors

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Abstract

Gynecologic malignancies occur in approximately 1 in 20 women in the United States. Until recently, clinical management of these cancers has focused almost exclusively on prolonging the survival of patients. A recent literature search using MEDLINE revealed relatively few research studies that reported data on quality of life (QOL) in a gynecologic cancer population. Reports in the literature have been conflicting, with some studies finding deterioration in QOL and some finding stability or improvement in QOL over time. Until recently, the impact of various treatments (surgery, radiation, chemotherapy) on QOL in this population was unknown. Recently, the QOL of women with gynecologic cancer has been compared to that of women with other types of cancer. Also, risk factors for poor adjustment in gynecologic cancer are beginning to be investigated. This presentation will attempt to 1) summarize the relevant literature on QOL in a gynecologic cancer population, 2) compare QOL in this population to other types of cancer, 3) examine risk factors for poor adjustment and 4) describe the limitations of the literature and future research directions.

Overall, it appears that QOL is most negatively affected from time of diagnosis through completion of treatment. Following treatment, QOL appears to improve over the course of 6–12 months, but then appears to remain stable from that time through two years post-treatment. Compared to breast cancer patients, it appears that gynecologic cancer patients experience poorer QOL on several domains during active treatment, but that after completion of treatment, overall QOL is similar between groups. Risk factors for maladjustment include treatment with radiotherapy or multi-modality treatment, increased length of treatment, younger age, and coping using a disengaged style. Other risk factors include lower education, poor social support and lower levels of religious belief. The significance of these findings and future research directions will be discussed.

Review of Literature

Until recently, treatment for gynecologic malignancies has focused almost exclusively on prolongation of life, and few research studies have adequately addressed issues related to quality of life [1]. Quality of life (QOL) typically involves the assessment of several dimensions: physical well-being, emotional well-being, social well-being, and

functional well-being. As recently as 1993, Andersen published an article acknowledging a grave lack of research on quality of life and challenging "institutions and study groups to support quality of life research for women with gynecologic cancer" [2]. To date, few studies have utilized QOL as a primary endpoint.

Numerous challenges exist in treating gynecologic malignancies. Often, there are few, if any, symptoms until the tumor is in an advanced stage. Further, these symptoms are often non-specific and may consist of things like abdominal distention, vaginal bleeding, abdominal or low back pain, often leading treating professionals to misinterpret early signs or defer further work-up. Treatment for gynecologic malignancies is often quite morbid and may involve multiple modalities (surgery, radiation and chemotherapy). Changes in bowel, bladder, hormonal, sexual and reproductive function are common. In addition, palliation is often difficult in the terminal stage, and death from a slow, obstructive, intra-abdominal process is not unusual.

Women frequently must adjust to physical changes after treatment including loss of ovarian function, hot flashes, vaginal dryness, hair and skin changes, and mood changes. Surgical scarring may be another hurdle to adjustment, as are the need for urostomy or colostomy. Sexual functioning may be impaired, and difficulties with desire and sexual response are common. Dyspareunia is also frequently experienced. Infertility is an issue for many young women diagnosed with gynecologic cancer, and concerns may include adoption, egg donation, and surrogacy.

The goals of the present article are to summarize what is known about QOL in women treated for gynecologic malignancies, compare QOL in women with gynecologic versus other malignancies, attempt to draw tentative conclusions about variables affecting quality of life and risk factors for maladjustment, and suggest directions for future research.

Quality of life in women with gynecologic cancer

Bodurka-Bevers and colleagues [3] assessed the prevalence of depression and anxiety in 246 women diagnosed with ovarian cancer. These patients were at all stages of disease, and also were in various phases of active treatment or surveillance. Results suggested that 21% met criteria for depression and 29% scored above the 75th percentile for anxiety. Performance status was related to depression and anxiety. The authors conclude that the prevalence of depression and anxiety may be higher than expected in an ovarian cancer population, and this clearly highlights the need for further assessment of QOL in this group of patients.

Miller, Pittman and Strong [4] also highlighted the need for assessment of quality of life and emotional functioning. These researchers administered questionnaires to 95 patients with gynecologic cancer at least 6 months after completion of treatment. The questionnaires asked patients to retrospectively rate any emotional symptoms

experienced during active treatment. 57% of patients reported needing help dealing with emotional problems. A majority of patients wanted their physicians to ask questions dealing with spirituality, death and dying, and emotional problems.

Capelli et al. [5] studied 115 women between the ages of 21 and 83 years who were referred to a university hospital for ovarian, endometrial and cervical cancer. Women completed the SF-36 questionnaire, a widely used and well-validated QOL instrument. The authors then compared these scores with age-specific expected mean values in published data from a healthy population of women.

Results of this research suggested that women with primary (as opposed to recurrent) gynecologic cancer had QOL scores that were similar overall to healthy women. However, patients with recurrent disease scored an average of 10 points lower on each scale of the SF-36. Also notable was the fact that women with primary gynecologic cancer scored lower than healthy women on scales measuring emotional and physical role functioning. Patients undergoing palliative chemotherapy treatment had the lowest scores overall, as would be expected.

The authors also used linear regression to adjust for age and primary vs. progressive/recurrent disease status. Results of this analysis showed that the poorest QOL scores were reported by the youngest women with cervical cancer. This was especially true in young women with recurrent disease. This was in opposition to women with ovarian and endometrial cancer where age was negatively correlated with QOL.

Wenzel et al. [6] studied the QOL of long-term (over 5 years) survivors of ovarian cancer. 49 women were assessed and the results indicated that this disease-free sample enjoyed a good QOL compared to other cancer survivors and non-cancer cohorts. However, approximately 20% of survivors reported significant long-term treatment related side effects, including abdominal, gynecologic and neurologic toxicity. Furthermore, greater than half of the women surveyed indicated that they would have attended a support group if one were available to them at the time of diagnosis and treatment.

Quality of life in women with gynecologic cancer compared to other populations

Greimel and colleagues [7] prospectively assessed 248 women with gynecologic or breast cancer. QOL data (EORTC-30, Spitzer QL-I) was collected at six points from pre- to post-treatment. The first assessment of QOL was conducted at one day prior to initiation of treatment. The final assessment was performed at one year post-treatment. The mean age of patients was 55 years. Of the

subjects, 26.2% were diagnosed with breast cancer, 31.9% with cervical cancer, 25.8% with ovarian cancer, and 16.1% with endometrial cancer.

At pre-treatment, there were no statistically significant differences between breast cancer and gynecologic cancer patients on any QOL domain. During active treatment, breast cancer patients had significantly higher QOL scores, particularly in the areas of physical functioning and role functioning. At completion of treatment, breast cancer patients scored significantly lower on emotional functioning compared to patients with ovarian cancer. At six-month and one year post-treatment follow-up visits, there were no significant differences between breast cancer and gynecologic cancer patients on any of the QOL domains assessed.

Overall, the researchers conclude that during active treatment patients with gynecologic cancer are significantly more physically impaired compared to breast cancer patients. However, QOL is comparable between groups at one-year follow-up, suggesting that gynecologic cancer survivors experience significant improvement in QOL following treatment. Predictors of long-term QOL included pre-treatment performance status and severity of surgery. Not predictive was family support, number of treatments, age, stage or site of disease.

Miller, Pittman, Case & McQuellon [8] compared QOL in disease-free gynecologic cancer patients (N = 85) to that of 42 unmatched healthy women seen for standard gynecologic screening exams. Their data showed no overall difference in FACT-G scores between gynecologic cancer patients and normal women. In fact, cancer survivors scored slightly higher on the emotional well-being subscale. Within the cancer survivors, QOL appears poorest in women diagnosed with ovarian cancer.

Patients who had treatment over a longer period of time reported decreased functional well being and total FACT-G scores. It should be noted that these patients tended to have an ovarian cancer diagnosis and most had been treated with surgery and approximately 6 months of combination chemotherapy. Patients treated with surgery only had better overall QOL, probably due to short treatment time and less advanced disease. The authors note that prior research has shown that acute treatment effects are resolved after 6 months, and there is only little change expected thereafter.

Also related to lower QOL scores was lower education level. The authors propose that lower levels of education may be predictive of a less supportive social environment, limited knowledge of health issues and poor general

health. Lack of help at home was also predictive of poor QOL.

Predictors of quality of life in women with gynecologic cancer

Eisemann & Lalos [9] assessed well-being in women with endometrial and cervical cancer at pre-treatment and also at 6 month and 1 year post-treatment. Subjects completed a clinical interview and also brief, non-standardized questionnaires. Results showed that cervical cancer patients reported significantly more symptoms at all time points. Furthermore, well-being before treatment was significantly predictive of post-treatment well-being.

Chan and colleagues [10] performed a prospective, longitudinal study of 74 newly diagnosed gynecologic cancer patients. QOL was measured at 4 points from pre-treatment to 18 months post-treatment. A structured interview was used to measure self-esteem, outlook on life, self-role and femininity. It should be noted that this study only included individuals who had no recurrence of their disease, so this may not be indicative of all patients diagnosed with gynecologic malignancies. Also notable is the fact that all psychosocial variables were assessed at pre-treatment primarily by clinical interview (as opposed to more standardized assessment tools).

The study found that self-esteem and depression remained constant over time. The incidence of depression in this sample was twice that seen in a healthy population. Subjects reported no change in relationship with spouse and sexual activity (though this may have been under-reported due to the fact that this variable was assessed by clinical interview). The authors found three high-risk groups for maladjustment; those with low religious belief, those who had received surgical treatment, and those with low educational level.

Lutendorf and colleagues [11] assessed 98 women with early stage or regionally advanced gynecologic cancer. Prospective assessments were done measuring QOL (FACT-G), coping style (COPE) and mood (POMS) at pre-treatment and one year post-diagnosis. Sleep disturbance was common throughout the study, and occurred in approximately 40% of the sample. Lack of energy and sexual satisfaction were the other two most common complaints.

Surprisingly, medical factors such as disease extent and treatment intensity did not significantly predict physical well being at one year. However, coping strategies contributed significantly to the variance of physical well being, even when medical factors were controlled. Over the course of the first year following diagnosis, emotional and functional well being improved significantly for both

early stage and advanced patients. The authors note that this improvement occurred even in the absence of significant increases in physical well being, suggesting possible adaptation to residual physical limitations. Decreases in anxiety, depression and confusion were seen in both groups, but regionally advanced patients had poorer QOL and mood compared to early stage patients.

Interestingly, coping strategies appeared to be very predictive of QOL at one year post-treatment. Specifically, positive reframing was associated with increases in functional and physical well being. Greater disengagement (avoiding problems, giving up attempts to cope) was associated with poorer relationship with physician, poorer functional and physical well being, and greater mood distress.

Another study by Chan and colleagues [12] assessed 144 women with newly diagnosed gynecologic cancer. These subjects were assessed at pre-treatment, immediately post-treatment, 6 month, 12 month and 24 month post-treatment. They assessed the impact of age, symptoms, disease parameters, and treatment type on QOL using the EORTC-30. In this study as well, women with recurrent disease were dropped from final analysis, so this likely represents a sample of the most medically healthy patients. This is important, as this study may not accurately represent the QOL of all newly diagnosed women, but may represent the QOL of newly diagnosed women with the most favorable prognosis.

In contrast to their earlier study, the results suggested that patients treated with surgery alone reported the best QOL (compared to those treated with multi-modality treatment). Younger patients reported poorer physical health compared to older patients. Site and stage of disease had no significant effect on QOL after treatment, and QOL remained stable between 6–24 months following treatment. Furthermore, overall QOL appeared to improve after treatment, and this improvement was seen in global health status, functional scales and symptom report scales. There was a strong correlation between pre-treatment QOL and that at 24 months post-treatment.

In another compelling study, Lutgendorf and colleagues [13] assessed 48 women on QOL (FACT-G), mood (POMS) and coping style (COPE). 24 women had received one year of extensive chemotherapy, and 24 women had received no chemotherapy. QOL was measured at one year post-diagnosis.

Overall, extensively treated women reported substantial, lasting decrements in physical, functional and emotional well being. There were no differences between groups in depressed or anxious mood. Avoidant coping again seemed to predict poorer QOL, specifically in domains of

physical and emotional well being. Social well being appeared unimpaired in both groups. Surprisingly, social support was not associated with any of the outcome variables, and the authors suggest that perhaps social support is not as important in maintaining QOL post-treatment as it is during pre- and active treatment.

Conclusion

Gynecologic malignancies pose special risks for quality of life. Despite the fact that gynecologic malignancies occur in approximately 1 in 20 women in the United States, QOL has not been widely researched, with the bulk of research devoted to prolongation of life. Reports in the literature have been conflicting, with some finding deterioration in QOL and some finding stability or improvement over time. Little has been known about the impact of various treatments, diagnoses, stages of illness, and other risk factors on QOL in these patients.

Given the challenges and changes that women must face after a diagnosis of gynecologic cancer, QOL is an especially pertinent issue on which to focus. Before concluding anything regarding QOL, however, several caveats are important to note. First, it is important to utilize a well-validated measure of QOL in order to compare QOL in patients with gynecologic malignancies to any other group of patients or healthy subjects. The studies reviewed in the current paper have generally done so, with the exception of three [6,9,10].

Second, due to the relatively small number of gynecologic cancer patients seen at any one cancer center, most of the research studies above have grouped gynecologic cancer patients into one group, as opposed to separating out by diagnosis. Because of this, any interpretation of the impact of diagnosis on QOL must be tentative. Related to this is the fact that type of treatment may be reflective of stage of disease (i.e. patients with advanced disease will be more likely to have multi-modality treatment, while patients with early stage disease may have surgery alone). As such, any interpretation of the impact of treatment type on QOL must also be done cautiously and in the context of disease stage.

Finally, recommendations are difficult to make based on the research. There have been no prospective studies in which gynecologic cancer patients have been randomly assigned to any psychological or psychiatric treatment before, during or after treatment. The author of this review is currently planning such a study to investigate how a structured, psychological support group will impact levels of a growth factor (VEGF) which has been linked to cancer progression in women with ovarian cancer.

Table 1: Quality of life in gynecologic cancer research studies

Authors	Date	QOL assessment	Other assessments	Major findings
Bodurka – Bevers et al.	2000	SF-36	CES-D, STAI	-higher than expected prevalence of depression, anxiety
Miller et al	2003	FACT-G	self-report questionnaires	57% of patients reported needing help with needing help with
Capelli et al	2002	SF-36	None	Women with primary GYN CA had similar QOL to healthy women -Women with recurrent disease had significantly poorer QOL compared to healthy women
Wenzel et al.	2002	telephone interview	physical exam	-long term survivors of ovarian CA report good QOL compared to other cancer cohorts and healthy individuals -20% of individuals had significant long term treatment-related side effects
Greimel et al.	2002	EORTC, QL-I	KPS	-GYN CA pts have poorer QOL compared to breast CA pts during treatment -Both groups have comparable QOL at one year follow-up -predictors of QOL included pre-tx KPS, severity of surgery
Miller et al.	2002	FACT-G	None	no differences in QOL between disease-free GYN CA pts and healthy women -poorest QOL in pts with ovarian CA, longer treatment -risk factors for poor QOL included lack of education, lack of help at home
Eisemann et al	1999	clinical interview	non-standardized questionnaires	pts with cervical CA have more physical symptoms than pts with endometrial CA-pre-tx well-being predicted post-tx well-being
Chan et al.	2001	clinical interview	HAMAS, interview	-incidence of depression in disease-free sample twice that of normal population -risk factors for poor QOL included lack of education, low religious belief, surgical treatment
Lutgendorf et al	2002	FACT-G	COPE, POMS	-sleep disturbance, anergia sexual problems most common problems -coping style predicted QOL (even when medical variables controlled) -disease extent and treatment intensity did NOT predict physical well-being -QOL improved over 1 year period, even in the absence of physical improvement
Chan et al.	2002	EORTC-30	None	site and stage of disease had no impact on QOL -younger pts reported poorer physical health -QOL improved after treatment ended
Lutgendorf et al.	2000	FACT-G	COPE, POMS	-strong correlation between pre- and post-tx QOL -extensive treatment led to poor QOL (physical, functional, and emotional) -avoidant coping predicted poor QOL

Despite the limitations of the current research, we can draw some tentative conclusions regarding QOL in this population. In sum, there appears to be a higher than expected incidence of depression and anxiety in patients undergoing treatment for gynecologic malignancies. This is likely related to the high treatment toxicity and often poor prognosis of many of these illnesses. It appears that QOL is most negatively affected from the time of diagnosis through the completion of treatment. It also appears

that QOL is more substantially impaired during treatment of gynecologic malignancies than during treatment of other cancers. QOL typically improves after treatment for 6–12 months, then stabilizes. 1–2 years after treatment, disease free patients report QOL that is generally equivalent to other cancer survivors and healthy women.

Further, emotional and functional well-being increase over the first year following treatment, even in the absence

of corresponding increases in physical well-being, suggesting adaptation to residual physical limitations. Despite these positive results, a significant minority of patients continue to report lasting emotional problems and treatment related toxicities.

Risk factors for maladjustment include treatment with radiotherapy or multi-modality treatment, increased length of treatment, younger age, and coping using a disengaged style. Lower levels of education and spiritual/religious belief, as well as lack of help at home, are also risk factors for poor QOL. Surprisingly, site and stage of disease have not reliably been correlated with QOL.

Future research should include large, multicenter studies, which would allow comparative analysis of QOL by diagnosis. Also, studies measuring the impact of various chemotherapeutic agents on QOL should be undertaken, as there appear to be long-lasting toxicities from many of the chemotherapeutic regimens, which are only beginning to be understood. Due to the difficulty in palliating terminal illness, any studies focusing on improvement of QOL in end-stage disease patients would be welcome and clinically relevant.

Finally, prospective studies of the impact of psychological treatments on QOL and prognostic factors should be undertaken. Future studies will hopefully assist women in coping with the challenges and rigors of treatment and post-treatment toxicities. Ideally, these studies would determine risk factors not only for psychological morbidity, but also medical mortality and morbidity, and attempt to modify psychosocial variables to improve survival time and quality of life.

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