

## Palliative Care Opportunities for Women with Advanced Ovarian Cancer Associated with Intraperitoneal Chemotherapy

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### Abstract

Intraperitoneal chemotherapy poses both potential benefits as a cancer treatment and negative consequences on patient and family quality of life.

The profound multi-dimensional quality of life impact of intraperitoneal (IP) chemotherapy upon women with advanced ovarian cancer makes the early integration of palliative care particularly important for this population. Numerous opportunities occur throughout the treatment process to improve the delivery of biopsychosocial-spiritual support to women receiving IP chemotherapy.

### Introduction

**O**VARIAN CANCER (OC) presents a prime example of a critical opportunity to integrate palliative care (PC) with aggressive disease-focused therapy. While OC is responsive to chemotherapy and there have been improvements in available treatments, a significant number of women will either present with or progress to advanced disease.<sup>1</sup> Over 60% of women diagnosed with OC present with advanced disease (Stage III or IV)<sup>2</sup> and even those women diagnosed with early stage disease typically undergo multimodality therapy resulting in elevated distress from significant symptom and quality-of-life (QOL) concerns.<sup>3-8</sup> Recent randomized controlled trials<sup>9,10</sup> have demonstrated clinical benefit from the use of intraperitoneal (IP) chemotherapy for women with advanced OC.<sup>11-14</sup> These findings have generated great interest in this treatment within the oncology community, with many cancer settings increasing their use of IP chemotherapy based on survival data. This intense treatment strategy provides an opportunity to explore the effects on women's QOL and symptom outcomes.

The goal of PC is to prevent and relieve suffering as well as to support the best possible QOL for patients and their families, regardless of the stage of the disease or the need for other therapies.<sup>15</sup> PC is both a philosophy of care and an organized, highly structured system for delivering care.<sup>16,17</sup> PC expands traditional disease-focused medical treatments to include the goals of enhancing QOL for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered

concurrently with life-prolonging treatment such as cancer chemotherapy or as the main focus of care.<sup>18</sup> Unfortunately, PC has too often been reserved for those facing end of life. The Institute of Medicine report on improving end-of-life care has called for models of care that implement PC concurrently with disease-focused care earlier in the course of disease.<sup>19</sup> Given the progressive nature of OC, and the potential symptom burden associated with this disease, these patients are particularly strong candidates for a simultaneous integration of aggressive, disease-focused treatment with PC.<sup>20,21</sup>

Health-related QOL has been compared between intravenous (IV) and IP chemotherapy in the Gynecologic Oncology Group (GOG-172) study by Wenzel and associates.<sup>22</sup> Patients included in this study had optimal stage III epithelial OC. QOL was reported to be significantly worse in the IP arm at the second (before cycle 4) and third (three to six weeks after treatment) time points.<sup>22</sup> The IP chemo arm was associated with significantly more discomfort and QOL disruption in the short term and with more neurotoxicity in the long term, as compared with the IV chemo arm. This was partially attributed to the higher overall dose of chemotherapeutic agents used in the IP arm.

Tumor debulking procedures followed by aggressive IP regimens have also been studied as a possible treatment modality for OC. Their widespread acceptance and implementation have, until recently, been limited by lack of evidence showing clear advantages to this highly specialized treatment regimen that requires not only sophisticated human resources, but also complex technological resources.<sup>9</sup>

Patients with OC frequently suffer from progressive disease, leading to bowel obstructions, pain, cachexia, malignant ascites, and overall poor QOL.<sup>23-25</sup> Ovarian cancer continues to be the leading cause of death from a gynecologic cancer<sup>2</sup> with patients who have advanced OC with peritoneal disease at a heightened risk for recurrent disease. Recurrences frequently occur in the peritoneal cavity, and lead to care focused upon local-regional treatment of peritoneal disease. The aim of this retrospective study was to describe the symptom burden and QOL impact of IP chemotherapy for women who had been treated for advanced ovarian cancer and to identify palliative support opportunities.

**Design**

A mixed methods retrospective design using directed content analysis was selected to allow the interdisciplinary research team the ability to explore in depth the “real life contextual” experiences of the sample.<sup>26</sup> The conceptual framework for this study was based on the National Consensus Project’s (NCP) *Clinical Practice Guidelines for Quality Palliative Care*.<sup>15</sup> The mission of the NCP is to provide an evidence-informed blueprint for the structure and provision of PC. These guidelines recognize that multidimensional support of patients and their loved ones is essential in the provision of quality PC and includes integration of PC in the continuum of care. Table 1 presents the multidimensional framework that applies the NCP guidelines (which include the structure and process of care, the four domains of QOL, cultural aspects of care, attention to the needs of the immi-

nently dying, and the ethical and legal aspects of care) to common IP OC symptoms reported in the literature reviewed above.<sup>1,3-8</sup> Following the collection of quantitative reports of symptoms and QOL, each patient participated in an in-depth, semistructured interview. Final selection of tools and study design took into account concerns about overall participant burden for this vulnerable population.<sup>27</sup>

**Setting**

Patients recruited into this study were under the care of the medical oncology department at an urban National Cancer Institute designated comprehensive cancer center in southern California. Approval was received by the institutional review board. Eligible subjects provided written informed consent following recruitment consistent with the institutional policies. The majority of the interviews occurred in the clinic setting following the participants’ appointment with their oncologist. Completion of the packet and interview ranged from 45 minutes to an hour and a half, with most under one hour.

**Sample**

Inclusion criteria included being over 18 years of age, being able to read and write in English, having advanced OC, and having participated in a modified Armstrong protocol<sup>9</sup> for IP chemotherapy during the last year, with a prognosis expected of greater than six months (as determined by the referring physician). The inpatient portion of the protocol consisted of intravenous paclitaxel (135 mg/m<sup>2</sup>) given over 24 hours on

TABLE 1. CONCEPTUAL MODEL

<i>National Consensus Project Guidelines</i>	<i>Application of guidelines to intraperitoneal chemotherapy and ovarian cancer</i>
1. The Structure & Process of Care	Palliative care assessment and intervention will be integrated into the routine practice of the IP chemotherapy protocol.
2. Physical Aspects of Care	Focus on symptom concerns common to IP chemotherapy, i.e., abdominal pain, shortness of breath, catheter care, fatigue, pain, bowel care, insomnia.
3. Psychosocial & Psychiatric Aspects of Care	Focus on issues common in OC such as fear of recurrence, degradation of self-esteem, distress about initial diagnosis, treatment-related distress, and depression.
4. Social Aspects of Care	Address family distress, financial burden associated with IP chemotherapy; genetic concerns of OC; intimacy and sexuality issues, feelings of isolation.
5. Spiritual, Religious, & Existential Aspects of Care	Assess spiritual needs; focus on uncertainty, living with a disease with a poor prognosis while undergoing disease focused treatment.
6. Cultural Aspects of Care	Assess cultural factors in diverse population.
7. Care of the Imminently Dying Patient	While this IP chemotherapy group is not imminently dying, this treatment time provides an opportunity for advance care planning.
8. Ethical & Legal Aspects of Care	Guidance regarding decision making related to continuum of treatment.

IP, intraperitoneal; OC, ovarian cancer.

\*National Consensus Project website: <http://www.nationalconsensusproject.org>

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day one, with IP cisplatin (75–100 mg/m<sup>2</sup>) given over one hour on day two. On day eight, the patient received IP paclitaxel (60 mg/m<sup>2</sup>) as an outpatient in the clinic (typically during a six-hour visit). Although this protocol was designed to be repeated every three weeks for six cycles, none of the eleven participants in this study were able to complete the full treatment regimen. Each of the women experienced significant modifications in the number of cycles (ranging from two to five) that they received and in the total dosing, due to toxicities. The modifications in cycles and dosing were highly variable based upon each individual's symptom burden and are described in more depth in a separate publication.<sup>28</sup>

## Methods

Each eligible participant provided consent and was given information on the study objectives. Participants completed a one-time survey packet that consisted of a demographic form, the City of Hope (COH) QOL-OC tool, and the Functional Assessment of Cancer Therapy-Ovarian (FACT-O). The demographic tool was adapted from a tool used by the investigators in previous studies and includes age, type of tumor, etc.

The COH QOL-OC tool<sup>29</sup> was developed by the investigative team with extensive use in past research, with internal consistency and reliability ranging from .70 to .92 for the disease-specific OC version. Measures of validity of the generic patient version include content validity with the FACT-O instrument ( $r = .78$ ) and factor analysis. The instrument has demonstrated construct validity by discriminating between known groups. This 45-item multidimensional tool encompassing four domains of physical, psychological, social, and spiritual well-being based on the QOL conceptual model developed by the investigators is scored from 0 = worst QOL to 10 = best. Scores for each domain are an overall score and are obtained by summing the items in each section and dividing by the number of items.

The FACT-O<sup>30</sup> is a commonly used, ovarian specific questionnaire that elicits information regarding the QOL impact of OC. This 39-item scale is scored from 0 = worst QOL to 4 = best and allows participants to report physical, social/family, emotional, functional well-being as well as ovarian specific concerns. FACT-O scores are the sum of the five subscale scores (with higher scores indicating better QOL). The possible ranges for each of the FACT-O subscale scores are different, because the number of items within each subscale in the survey varies. The FACT-O total score, and physical, emotional, and functional well-being subscales all demonstrate very good reliability, with Cronbach's alphas and test-retest correlations greater than 0.80. Cronbach's alpha and test-retest correlations for the social well-being and ovarian cancer specific subscales between 0.70 and 0.80 indicate adequate reliability.

Following completion of the quantitative packet, each participant completed one semistructured interview with a clinical oncology social worker (who was also a member of the research team). The researchers developed this interview to reflect the eight domains of the National Palliative Care Guidelines and followed the QOL model as described previously. The interview also integrated the FICA<sup>31</sup> (Faith, Importance, Community, and Address in care) tool as a guide to more thoroughly explore participants' spiritual concerns. FICA is commonly used to assist the health care professional

in obtaining a brief spiritual history and identifying a patient's current spiritual perspective.<sup>32</sup>

During the semistructured interviews, the participants were asked to reflect upon their experience with IP chemotherapy and to indicate if they had noticed any symptoms or concerns within each domain of QOL. Additionally, they were asked about their perceptions of the care that they had received during treatment and if they had any suggestions for future women who may be undergoing IP chemotherapy, to aid us in better preparing women for this treatment regimen. The participants eagerly offered tips and strategies regarding additional palliative support opportunities based upon the lessons that they had learned from this experience.

## Data analysis

Quantitative data were entered into a database and audited for accuracy. Frequency distributions were computed on all variables, and means, medians, ranges, and standard deviations were computed on all continuous variables. The COH QOL-OC subscores and total scores were calculated. Using SPSS 15.0 (SPSS Inc., Chicago, IL), summary statistics were computed on the Demographic and Treatment Data tool.

Qualitative data obtained from the interviews were transcribed verbatim. Transcripts were then coded and analyzed (not using a computer software program). Themes were identified using directed content analysis, using a framework that was identified a priori.<sup>33–35</sup> The investigative team read each transcript and then met together to identify key themes and concepts organized within the four COH QOL domains. Tables were created highlighting these themes. Representative examples of each theme were extracted from the transcripts and compiled. These items were reviewed by the entire research team individually and as a group during the monthly research meetings to reach consensus and to ensure saturation of theme content.

## Results

Eleven patients were accrued, consented, and completed the packet of questionnaires and interview. There were no refusals.

### Quantitative findings

**Demographic tool.** The participants' time since initial diagnosis ranged from 1 year to over 18 years at the time of the interview. The majority were diagnosed less than 5 years prior to the interview, and all were 6 to 12 months post-IP treatment. Table 2 describes the sample of women (N = 11), who ranged in age from 50–72 years, with a mean age of 58. Eighty percent had at least some college education. Ninety percent were married. Nearly one third of the women were ethnic minorities, reflecting the population served at this cancer center.

**COH QOL-OC tool.** Table 3 describes the overall QOL scores as measured by the COH-QOL tool at the time of the interview. Study participants indicated a wide range of QOL concerns across all QOL domains, but psychological distress was ranked the worst. Specific item scores at 6.0 or below are indicated in Table 4 and provide evidence for areas to explore in future intervention studies.

TABLE 2. DEMOGRAPHICS

<i>patients (N=11)</i>			
Age			
Mean = 58 Range = 52-72	N	(%) <sup>a</sup>	
Ethnicity			
Caucasian	8	73	
American Indian	1	9	
Hispanic/Latina	1	9	
Asian	1	9	
Highest level of education			
College or more	9	82	
High school or less	2	18	
Religious preference			
Protestant	6	55	
Catholic	3	27	
Buddhist	1	9	
Other	1	9	
Marital status			
Married	10	91	
Widowed	1	9	
Employment status			
Homemaker	4	36	
Retired	3	27	
Full-time	2	18	
Disabled	2	18	

<sup>a</sup>Percentages may not equal 100% due to rounding.

**FACT-O tool.** The QOL scores from the FACT-O were similar to the overall and subscale scores reported for the COH QOL-OC tool. The overall FACT-O score was moderate. The Ovarian Specific subscale had a score of 37.4. Table 5 describes these findings and of note, is the emotional well-being subscale, which had the lowest score across all of the QOL domains. The FACT-O findings are consistent with those reported on the COH QOL-OC tool. Both reveal that emotional and psychological well-being are the predominant areas of concern for these IP OV patients. Participant ratings below a 3 are described in Table 6, with the lowest scores including treatment side effects, worry that conditions will worsen, and sexuality and appearance concerns.

**Qualitative findings from the interview data**

**Physical domain.** Participants reported experiencing a wide variety of symptom concerns that included constipation; diarrhea; menopausal symptoms; lowered blood pressure;

TABLE 3. CITY OF HOPE QUALITY OF LIFE SCALE: OVARIAN CANCER PATIENT SUMMARY OF SUBSCALES AND TOTAL QOL SCORE

<i>Quality of life dimension</i>	<i>Mean</i>	<i>Standard deviation</i>
Physical	8.5	1.2
Psychological	6.3	1.7
Social	6.7	1.3
Spiritual	6.7	2.4
Total QOL	7.1	1.2

QOL, quality of life.  
\*0-10 Likert scale; higher score=better QOL.

TABLE 4. CITY OF HOPE QUALITY OF LIFE SCALE: OVARIAN CANCER (ITEMS SCORED 6.0 AND BELOW)

<i>Variable</i>	<i>Mean</i>	<i>Standard deviation</i>
Physical well-being		
Neuropathy	5.7	3.0
Psychological well-being		
Changes in appearance	4.7	3.6
Distress from initial diagnosis	2.4	2.3
Distress from treatments	3.2	2.3
Distress from time between treatments	4.7	2.9
Fear of future diagnostic tests	5.7	3.4
Fear of second cancer	5.7	3.5
Fear of recurrence	5.4	3.7
Social well-being		
Family distress	3.1	1.6
Sexuality	5.6	3.8
Concerns with one's relative's risk of a subsequent cancer	3.7	2.7
Spiritual well-being		
Spiritual activities (meditation)	5.7	3.8
Uncertainty	5.2	3.5

(0-10 Likert scale; higher score=better QOL)

hearing changes; neuropathy; "chemo brain;" sleeping problems; IP port problems (including catheter leakage, placement discomforts, increased site sensitivity); complications resulting in delays of treatment (fistulas, cellulitis, colitis, blood clots); fatigue; pain; bloating; nausea; dehydration; concerns about body image (scars, weight changes, hair loss). They provided detailed accounts of the impact of these events upon their QOL.

**Psychological domain.** Participants reported a range of emotional concerns, which included endorsement of QOL items on "depression" and "anxiety" regarding the ambiguities inherent in coping with the possibility of facing recurrent disease. Most of the participants focused their comments toward their efforts to contextualize the cancer experience and to create meaning from the lessons they have learned from this ordeal. Women voiced concern about attempting to maintain a "positive attitude" despite awareness of their serious prognosis and reported attention to "living life fully" as long as they can.

TABLE 5. FACT-O OVARIAN CANCER-SPECIFIC DATA: SUMMARY OF SUBSCALES AND TOTAL QOL SCORE

<i>Subscale name</i>	<i>Possible range</i>	<i>Mean</i>	<i>Standard deviation</i>
Emotional well-being	0-24	18.5	5.1
Functional well-being	0-28	20.5	6.1
Physical well-being	0-28	20.9	7.6
Social/family well-being	0-28	24.7	3.0
Ovarian-specific subscale	0-44	37.4	6.8
TOTAL FACT-O SCORE	0-152	122.0	24.2

QOL, quality of life.  
<sup>a</sup>The higher the mean score the better the quality of life (fewer symptoms and concerns).

TABLE 6. FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY: OVARIAN CANCER (ITEMS SCORES BELOW 3.0)

Variable	Mean	Standard deviation
<i>Physical well-being</i>		
Lack of energy	2.4	1.6
Treatment side effects	2.4	1.5
<i>Social/family well-being</i>		
Sexuality	2.4	1.6
<i>Emotional well-being</i>		
Worry about dying	2.7	1.5
Worry that condition will worsen	2.4	1.4
<i>Functional well-being</i>		
Work is fulfilling	2.8	1.4
Sleeping well	2.6	0.9
Enjoying things I do for fun	2.9	1.1
Content with QOL	2.7	1.3
<i>Ovarian cancer specific additional concerns</i>		
Bowel control	2.8	1.5
Appearance	2.4	1.2
Interest in sex	1.7	1.4

0–4 Likert scale; higher score = better QOL.

**Social domain.** Participants provided information regarding the impact that cancer and its treatment have had upon their social networks (including family, friendship networks, and employment and leisure activities). Women were particularly troubled by the possibility that other family members might be genetically susceptible to cancer and voiced worry that their daughters may be at heightened risk for OC.<sup>36</sup> Participants were also asked to reflect upon how well the treatment team had met their cultural concerns. The costs of treatment and difficulties in managing multiple medications were also important themes that emerged.

**Spiritual domain.** Information for this domain was derived from a combination of open-ended questions from the interview as well as from responses from the FICA interview guide. For this study, spirituality was characterized as distinct from religion,<sup>37</sup> with prompts that explored women's beliefs regarding their meaning and purpose in life. Participants reported that their spiritual beliefs were important in sustaining them as they coped with illness and treatment. The majority reported that faith was very important to them (consistent with their reports on their quantitative tools), though few identified specific ways in which they would want their health care team to be involved in this aspect of their lives.

Women were asked directly if their health care team had discussed with them the seriousness of their illness, and responded candidly about their attempts to reconcile an awareness of their prognosis with a desire to be hopeful about their future. Women were also asked about complementary methods of care that they might have used during treatment. Prayer was the most common strategy reported. Several women indicated a desire to use various complementary strategies "once they began to feel better," but found that they had no extra energy to pursue these plans during treatment.

### Summary of interview narratives

Although a wide variety of QOL concerns emerged during the interviews, the participants were careful to contextualize their experiences and reported overall satisfaction with their treatment and positive regard toward their health care team. The women provided rich narratives regarding their concerns during diagnosis and their subsequent decision making regarding treatment choices (and how they came to receive IP chemotherapy) and focused upon lessons learned. Key themes that emerged from the interviews focused upon establishing goals of care and coping with the frustration of treatment delays (with suggestions offered for strategies to streamline the delivery of care). Communication concerns and system problems (including prescription challenges and problems with clinic logistics) were noted.

Each woman was queried regarding recommendations that she might offer to future women who would be considering IP chemotherapy as a treatment option. Participants were overwhelmingly grateful for the opportunity to have intensive treatment that might prolong their survival and voiced sincere appreciation for access to a supportive interdisciplinary team, although each identified that in retrospect they realized that there were multiple opportunities for additional biopsychosocial-spiritual support that would have been valuable. Table 7 provides a selection of quotes from the interviews representing each QOL domain.

Patients in this study had a mean age of 58 and reported concerns related to the need to juggle employment and family obligations while coping with this rigorous treatment regimen. In an attempt to accommodate these competing priorities, treatments were often scheduled for inpatient infusions over the weekend followed by IP chemotherapy as an outpatient. This resulted in the unintended side-effect of there being fewer hospital support staff (social workers, chaplains, physical therapists, etc.) on weekends or in the outpatient clinics<sup>38,39</sup> who were available to see these patients. Thus, despite a wide range of symptom concerns, few participants reported contact with social work, chaplaincy, pain management, PC, or other supportive services.

The participants acknowledged that they understood the serious nature of their illness and were attempting to reconcile themselves with their limited prognosis (Figure 1). They wanted to be sure the interviewer understood that they didn't regret their choice of treatment and that they remained committed to "doing everything possible" to control their disease.

### Discussion

This mixed methods descriptive retrospective study provides information on how women with OC were impacted by their experience undergoing IP chemotherapy. As more women are exposed to IP chemotherapy, increased understanding of how supportive interventions can be used to improve the QOL in OC patients undergoing IP chemotherapy becomes increasingly urgent.<sup>40</sup> The progressive nature of OC coupled with the serious multidimensional side effects of IP chemotherapy creates many opportunities to integrate PC principles with this intervention. The results from the participant interviews and the quantitative measures highlight numerous opportunities to provide information and support to better coordinate

TABLE 7. SELECTED QOL QUOTES FROM SEMISTRUCTURED INTERVIEWS AND THE FICA TOOL

*Physical*

## Nausea

- But I think probably the worst thing was the nausea—just a constant sick feeling, although I never vomited. It's a dreadful feeling to cope with. It's just a constant feeling of being nauseated.

## Neuropathy

- But, I've been told it's cumulative and I can tell that now. I've had some of that numbness in my fingers and toes, which progressed....It's kind of disturbing, but that's probably my biggest complaint...I can't put it out of my mind any more.

## IP Port Concerns

- You're always aware that this port was in your side. I did not wear a bra for a long time because that band was sitting right on top of it. The actual needle going into the port, which I had the port sewn in my side that was really uncomfortable. It was pretty severe pain when I went home. But having that in my side for all those months was uncomfortable. But it was bearable. It was saving my life.

*Psychological*

## Perspective on the cancer experience

- At first, I guess you wonder a lot of things—why, and what's going to happen, kind of the unfairness of the whole thing—and then I had to resolve myself to my situation. Plus, I tended to try to remain focused in a positive way. But as you get toward the end, I think you start to wonder, "Is this really going to work?"
- My philosophy the last time I had cancer was "cancer is going to come back for me." Mentally, that prepares me. I'm not a worrier. I'm a doer. Cancer never leaves you, even if you go in remission or you're cancer-free the rest of your life you still are a cancer patient. It changes how you look at life. In my situation the decision that I have made is that I am going to do anything humanly possible in order to prevent this cancer from continuing and if I have to suffer numb hands and feet, in order to outwit it, the cancer, that's what I would do. It's a decision that the cancer is more insidious and you want to kill the cancer and then you just have to suffer the consequences of the side effects.

*Social*

## Impact upon supportive network

- The thing that I notice more is with my daughter. She was in sophomore year in high school when I was diagnosed the first time. It has made her more anxious when I'm not feeling well. For my husband, it's changed everything because he has had to help take care of me. His work schedule had to change. Those are things that have changed how the family dynamics work. Everything that you do changed—having company over, going out to eat. You can't do those things any longer.

*Spiritual*

## Importance of spirituality

- I love nature...and every night I look out and I can see the stars before I go to bed. And in the morning the sun comes in and every day I appreciate that so much....It just touched me so deeply that there was such a peace and serenity.
- I think it's quite important because it does give me that centered feeling that there is more to life than just me, especially when you have cancer you tend to focus on yourself. It takes me outside of myself and lets me focus on other people and other things.

FICA, Faith, Importance, Community, and Address in care; IP, intraperitoneal; QOL, quality of life.

biopsychosocial-spiritual care services for this vulnerable patient population.

Because there are relatively few women with OC, and fewer still who have received IP chemotherapy, it is not surprising that many report feeling isolated.<sup>41</sup> Our results underscore the importance of systematically ensuring that these women have access to education, support, and resources.

General QOL indicators may mask marked distress in psychosocial-spiritual domains. The aggressive nature of this treatment protocol precipitates a cumulative increase in distress and depression with high levels of fatigue. Because OC has a high recurrence/relapse rate, women typically experience OC as a chronic illness.<sup>42</sup> Even with the most aggressive treatments, durable remissions are rare. Not uncommonly, women experience periodic cycles of treatment interspersed with only short periods of reprieve, reinforcing the impor-

tance of systematic integration of PC services for these at-risk patients and families.<sup>43</sup>

**Clinical recommendations**

Although the findings from this study are from only 11 patients, they are consistent with a growing literature that reports the benefits of early integration of PC into aggressive treatment.<sup>44</sup> The relatively small number of women who receive IP chemotherapy has implications for institutions and highlights the need to provide robust staff and patient education and support.<sup>45</sup> To implement this complex and demanding protocol, a dedicated infrastructure is needed to support a range of skilled staff (physicians, nurses, social workers, spiritual care providers, and others) with sufficient experience to develop comfort and confidence delivering this labor-intensive intervention.

Clinical caregivers for those with advanced illness facing rigorous treatment regimens may find it especially useful to provide routine early referrals to PC teams for family-centered biopsychosocial-spiritual support. Conversations regarding goals of care and advance directives are especially important for this population. Because of the cumulative impact of this treatment, periodic assessments of patient and family functioning are vital. Due to the high morbidity and mortality associated with advanced OC, we recommend consideration of a simultaneous referral to a PC team to proactively address the QOL concerns of patients receiving IP chemotherapy.

### **Study strengths and limitations**

Although generalizations from this retrospective study are impossible due to the small convenience sample, the quantitative and qualitative data collected from each patient is in depth and covers a period of 12 months from the initiation of IP treatment. The findings are consistent with previously reported studies of OC survivors and highlight the urgency of integrating PC early into treatment to better address the multitude of QOL and symptom concerns facing IP chemotherapy patients. A retrospective approach is also a potential limitation, but its strength is that it provides an opportunity for women to reflect upon their experience when they are not in the acute distress associated with this intense treatment.

### **Conclusions**

The specific aim of this study was to describe the PC concerns of OC patients treated with IP chemotherapy focusing on QOL and symptom management and to identify opportunities for increased palliative support. The intense nature of this treatment regimen results in multifaceted impact on patients and their families (communication concerns, transportation issues, dramatic role shifts, economic implications, changes in functional status, spiritual and existential concerns, body image issues effecting sexuality and intimacy, etc.) and underscores the importance of ensuring concurrent palliative services for this vulnerable population. A collaborative interdisciplinary approach such as provided in PC offers women undergoing IP chemotherapy the opportunity to have their multidimensional concerns addressed in a more timely manner.

With improved survival demonstrated by several studies with the use of IP chemotherapy for ovarian and colorectal malignancies with peritoneal disease,<sup>46</sup> this treatment modality is increasingly being incorporated into clinical practice.<sup>47</sup> However, there is still further work needed to determine the most effective strategy to provide support for patients who receive IP chemotherapy. Further studies are needed combining improved methods of IP chemotherapy with methods to improve QOL during treatment.

This study identifies opportunities to improve care for women with advanced OC receiving IP chemotherapy. Findings from this study provide evidence that is consistent with

M.R. is a 61 year old Caucasian female with a history of endometriosis which led to a hysterectomy and bilateral salpingo-oophorectomy 10 years ago. Seven years later, she developed a vaginal discharge and a pelvic mass which was diagnosed as ovarian cancer. She had chemotherapy and did well for another two and a half years. As part of her follow up care she had a CT scan which showed thickening in the sigmoid area. She had surgery and placement of an intraperitoneal port. She received one cycle of intravenous paclitaxel and IP cisplatin. Unfortunately, the cisplatin caused her to have renal failure and a lengthy hospitalization. M.R.'s treatment regimen was changed for the remaining five cycles with adjustments made following each treatment cycle to accommodate her symptoms and side-effects from the medications. She experienced dehydration, loss of appetite, fatigue, pain, and electrolyte imbalances. M.R. found strength from her spouse, friends and spiritual beliefs to cope with the challenges of her treatment regimen. M.R. gave permission to the research team to use portions of the journal that she kept during treatment that highlighted her struggles to face her mortality.

Throughout the trajectory of her illness, M.R. had many complex physical, emotional, and spiritual needs. M.R.'s multidimensional needs were best met with ongoing comprehensive assessments and an interdisciplinary team of care providers.

FIG. 1. Patient narrative.

**Facing Mortality**

- *I am now faced with a direct assault on my own mortality. It's not that death is imminent but that it is sure. It is not sure that the cancer will kill me but right now it is at the top of the possibilities.*
- *When we left (after getting CT results following treatment) my husband, the greatest of optimists, was joyfully elated but questioned my quietness. I simply said I wasn't ready to believe yet. He had desired the return of my joy for so long. I was sorry that I could not show that to him. Cancer is not an acute illness. Unless God does something miraculous, it is chronic and often fatal. I have lived with that and so has my husband for a long time.*
- *It seems like I have a need to be reflective when the chemotherapy sessions are about to happen. I guess they remind me that I have cancer. I don't often feel like I have it until I pass a mirror and see this little bald head. Then I remember.*
- *Both of my doctors asked me to start drinking Ensure to supplement my diet because I couldn't eat enough to keep my weight up. Reasonable request. I immediately thought of my husband's mom and that she lived on Ensure for the last part of her life and then she died. Then someone told me about a relative that drank Ensure, he died. My conclusion, drink Ensure and you die.*
- *God does know the days of our lives and he has set in motion the plan for each of us. Where the rubber meets the road is in the realization that we do not know the time or how of our return to the creator. I've been pondering this a lot lately. Since God knows when I'm going to die then he also knows how. He knows whether this cancer will kill me, or whether, like my Mom, I will survive cancer only to die of heart disease.*
- *I don't really think Cancer is about surviving. I think it's about living the best that you can.*

FIG. 1. (Continued).

increasing recommendations<sup>48</sup> for the integration of concurrent PC to proactively address needs for biopsychosocial-spiritual supportive services into standard oncology care for all of those with advanced cancer.

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