Taking Care of Her: A Pilot Feasibility Study of a Caregiver Intervention for Women with Advanced Stage Ovarian Cancer

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Abstract

Keywords

1. Introduction
2. Research Strategy
Medical treatment is extremely difficult and involves extensive surgery (diagnostic and debulking and symptom-inducing chemotherapy). Sadly, despite multiple cycles of chemotherapy, 60%–85% of patients with advanced ovarian cancer will recur and only 25% will survive 5 years after diagnosis. It is extremely difficult to describe the devastation women and their spouse caregivers experience when they are told at initial diagnosis that she has a advanced ovarian cancer. One day the woman is asymptomatic or experiences minimal abdominal discomfort; the next day she is told she needs diagnostic surgery; post-surgery she is told she has advanced disease. Yes, there are other types of advanced cancers that cause distress, but the illness trajectory of a advanced ovarian cancer is arguably among the most rapidly downhill and among the worst prognoses of female cancers. Depressed mood in ovarian cancer patients is significantly elevated compared to population norms; 29%–47% reach or exceed clinical levels of anxiety or depression or both. Women are emotionally devastated by the disease; harbor substantial fears about dying from the cancer; and fear recurrence even at initial time of diagnosis. Spouse caregivers are also devastated by the disease and the magnitude of this distress goes well beyond simple “caregiving burden.” Almost half of the spouses (39.4%) have clinically elevated scores on anxiety or depressed mood or both, both of which are associated with higher distress in cancer patients. Depressed mood can also deleteriously affect the support the spouse is able to offer the patient, strain the marriage and relationship, and negatively impact the ways couples deal with their cancer-related problems and challenges. Spouse caregivers report feeling unprepared for all aspects of caregiving; struggle with what to say or do to support the patient; commonly misjudge how to help her, emphasizing instrumental, not interpersonal support; and feel helpless and a lack of control that, despite best medical treatment, they could lose her to the disease. Social support, when present, significantly predicts the patient’s higher quality of life; it is essential to her healing. But its absence or diminished levels of support set up a cycle of distancing that works against her well-being. In addition to the shock and exacting nature of the woman’s advanced ovarian cancer, elderly spouse caregivers have multiple morbidities that add to their distress. In a recently completed population-based study, the prevalence of multimorbidity (≥2 conditions) increased steeply with older age and reached 77.3% at 65 years and older. Despite the potential vulnerability of spouse caregivers and the magnitude of their distress, they and the diagnosed partner have been seriously underserved in prior intervention studies. The illusion is that there are hundreds of intervention studies involving spouse caregivers or couples that have addressed couples’ and caregivers’ distress, interpersonal support, or communication. The reality is that...
most of these studies have not focused on dyadic adjustment [33][34][35]. Even when intervention studies have included information on the importance of interpersonal support or the quality of marital communication about the cancer, none have focused on advanced stage ovarian cancer; none have trained or coached the caregiver to actually attain the skills or confidence to emotionally support the diagnosed woman with the illness; none have helped the spouse caregivers enact the self-care or supportive communication skills in real time with a nurse coach; none have positioned the spouse caregiver as an active agent to help the diagnosed wife emotionally heal and manage the toll of the cancer; and none have included at-home exercises for the spouse caregiver to carry out with the diagnosed partner in real time.

The most recently completed trials by McLean's [16] and Northouse's [17] teams are highly relevant to this study. Both interventions involved couples dealing with advanced cancer (of mixed types) and both stressed the importance of marital communication and interpersonal support. However, both of these interventions confused discussing communication and support with the caregiver with building those skills. Furthermore, both relied on conjoint delivery, adding to the patients' and caregivers' time burden. With ovarian cancer, such travel or demands are unrealistic, given the patient's surgery and symptom load. Furthermore, Northouse's [17] intervention did not significantly improve marital communication or dyadic support and McLean's [16] intervention did not significantly reduce patients' or spouse caregivers' depressed mood.

What is needed is a paradigm shift in spouse caregiver research in which spouse caregivers are seen as part of the healing team [36]. This is more than being a “coach” for medication management; it is about being an active agent with the potential to positively enhance the Quality of Life (QOL) outcomes for the patient, the caregiver, and their relationship. The Taking Care of Her (TCH) Program is delivered to the spouse caregiver by telephone and includes training and structured exercises with a nurse; exercises designed to help caregivers gain the requisite skills to carry out interpersonal support that the patient experiences as supportive; assists spouses to transfer their acquired competencies to actual interventions and support to the patient in their home; and helps caregivers build and integrate a specific and sustainable self-care plan for themselves so that they can be attentive and responsive to the patient in the long-term, not just during the acute initial phase of treatment. To further reduce burden on the spouse caregiver and to increase accessibility and sustainability, the intervention needed to be delivered through a user-friendly channel that does not require travel or time away from home, the telephone.

The structure and form of the TCH Program were designed to be easily delivered by telephone by Masters prepared patient educators (nurses, social workers, certified health educators, psychologists, or mental health counselors) and not require clinic space or a doctorally prepared therapist. A telephone-delivered program also has the potential to reach spouse caregivers distant from the clinic and for whom travel, access, funds, and availability pose a burden. Longer range,
the form of the TCH as a fully scripted intervention has the potential for training health-related personnel in diverse settings with diverse credentials. The intervention tightly, not broadly, articulates with both the Relational Model of Adjustment to Cancer [5, 11, 12, 29, 37, 39] and Bandura's Social Cognitive Theory [40, 41, 42]. Social Cognitive Theory provides the structure and organization for each intervention session, including the mechanisms in the theory that are known to change spouse caregivers' skills and self-efficacy.

The specially designed exercises were developed to add to the caregiver's skills to interact with the patient under exceptionally challenging situations caused by the ovarian cancer, including when the patient says things like: “I don’t think I will survive this.” Or, “We need to plan for my not being alive by this time next year.” Each skill exercise is broken into its component parts and is systematically worked by the patient educator with the caregiver in each session.

There is no focus in Taking Care of Her on teaching about the biology, treatment of, or symptom management of the cancer. Instead, the total focus is on creating communication and support competencies in the caregiver that have the potential to relieve the patient’s distress and feel supported as well as add to the caregiver’s own self-care.

The intervention was delivered through the simple telephone (land line or cell phone) to accommodate the realities of both younger and older patients and caregivers. Seniors continue to lag behind younger Americans when it comes to technical adoption and many seniors remain largely unattached from online and mobile life—41% do not use the internet at all, 53% do not have broadband access at home, and 23% do not use cell phones. Furthermore, internet use and broadband adoption each drop off dramatically around age 75 [43]. Recent completed research also shows that the simple telephone can attain or exceed the benefits of using more complex telehealth methods to enhance the quality of life of patients with a different type of female cancer and their caregivers [44]. Rather than add web-based or other telehealth technologies, which we initially considered, the intervention uses a method of reteaching and intervening with both younger and elderly caregivers for whom travel is costly or time prohibitive, including those who would likely have multimorbidities.

Longer range, the reach and saturation of the telephone has exceptionally high potential for national dissemination and integration into provider settings.

2.1. Study Design/Protocol/Study Measures
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were unable to read or write in English, had early stage ovarian cancer, were initially diagnosed with early stage disease that then became advanced stage disease; were single women with no intimate partner; had no access to a telephone; or were diagnosed with additional types of cancer.

After approval of the Human Subjects Committee, participants were recruited from medical practices of physicians in the Pacific NW through a site intermediary. When diagnosed patients verbally agreed to participate, their spouse caregivers were contacted. Pending verbal approval to enroll, they were mailed a study packet containing separate consent forms, baseline and post-intervention questionnaires, and program materials [each intervention session was sealed in a separate envelope]. The patient educator contacted the diagnosed wife and spouse caregiver after receipt of the packet to assist in interpreting the consent form and to answer questions about study questionnaires. Once signed consent forms and baseline questionnaires were received, the patient educator scheduled the first telephone intervention session with the spouse caregiver.

Five intervention sessions (lasting 30-60 minutes each) were scheduled at 2-week intervals. At immediate completion of the 5th session, the caregiver was asked to complete and return the post-intervention questionnaires in a provided stamped, addressed envelope.

Study Measures

Diagnosis, demographic and treatment-related variables were obtained through medical record and self-report. Data on standardized measures of adjustment were obtained separately from spouse caregivers and diagnosed wives.

2.2. Self-Efficacy Scale

Spouses' self-efficacy was measured by the Cancer Self-Efficacy Scale (CASE), a 19-item self-report measure of the degree of self-confidence spouses had in supporting their wife and carrying out their own self-care[17][30][39]. The questionnaire consists of two subscales: a Wife-focused subscale and a Self-care focused subscale. Structured response options range from "Not at all confident" (1) to "Very confident" (10).

The Wife-focused subscale (14 items) measures spouse caregivers' confidence in being able to talk with the patient about her cancer-related concerns and ways to be supportive to her, e.g., "I know what to do to be supportive to my wife/partner about the ovarian cancer" and "I know how to help my wife/partner express her worries and concerns about the ovarian cancer."

The Self-care focused subscale (5 items) measures spouse caregivers' confidence in helping them deal with their own demands and challenges from the ovarian cancer, e.g., "I know what resources to use to help me personally cope with my wife's ovarian cancer."

The internal consistency reliability for the Total scale was 0.95 and 0.95 for the Wife-focused and 0.81 for the Self-care focused subscales.

2.3. Depressed Mood

Depressed mood was measured by the Center for Epidemiologic Studies Depression Scale.

2.2. Self-Efficacy Scale

2.3. Depressed Mood
2.4. Anxiety

2.5. Marital Communication

2.6. Spouse’s Skills
2.7. Wife’s Appraisal of Spouse’s Support

3. Study Sample
4. Study Results
4.1. Study Aim 1 - Feasibility

4.2. Study Aim 2 - Short-Term Impact
Table 1. Summary of study sample for diagnosed wives and spouse caregivers.

<table>
<thead>
<tr>
<th>CODE</th>
<th>NUMBER</th>
<th>Age</th>
<th>Education</th>
<th>Ethnicity</th>
<th>Treatment in last 6 Months</th>
<th>Months since diagnosis</th>
<th>Stage</th>
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Spouse Caregivers’ Demographics

<table>
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<tr>
<th>CODE</th>
<th>NUMBER</th>
<th>Age</th>
<th>Gender</th>
<th>Education</th>
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<th>Years in relationship</th>
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<td>Male</td>
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<td>College graduate</td>
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<td>Male</td>
<td>Doctoral degree</td>
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</table>

Table 2. Study outcomes comparing baseline and post-intervention scores on standardized measures of depressed mood and anxiety for diagnosed wives and spouse caregivers.

<table>
<thead>
<tr>
<th>Patient Depressed Mood</th>
<th>Spouse Depressed Mood</th>
<th>Patient Anxiety</th>
<th>Spouse Anxiety</th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Pre-Test</th>
<th>Post-Test</th>
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<th>Post-Test</th>
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<td>15</td>
<td>4</td>
<td>23</td>
<td>25</td>
<td>22</td>
<td>30</td>
</tr>
</tbody>
</table>

Mean 20.00 14.17 12.83 9.00 34.50 32.17 33.17 29.00
SD 4.4 5.2 5.0 10.8 11.6 15.2 8.1 7.7
Median 18.5 12.5 11 5 36.5 24 34.5 27
Possible range 0-60 0-60 20-80 20-80
Cutoffs ≥16 ≥16 >39 >39
Wilcoxon b 0.116 0.248 0.500 0.400

a Participant is 65 years of age or older
b Values comparing pre-test with post-test scores.
Table 3. Study outcomes comparing baseline and post-intervention scores on standardized measures of diagnosed wives’ appraisal of spouse support and spouse caregivers’ report of spouse support.

<table>
<thead>
<tr>
<th>CODE NUMBER</th>
<th>What He Does for Me</th>
<th>What I Do for Her</th>
<th>Spouse Skills</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-Test</td>
<td>Post-Test</td>
<td>Pre-Test</td>
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<tr>
<td>8001</td>
<td>a 81 81</td>
<td>91 106</td>
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<td>56 74</td>
<td>84 97</td>
<td></td>
</tr>
<tr>
<td>8004</td>
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<td>77 89</td>
<td></td>
</tr>
<tr>
<td>8005</td>
<td>a 40 59</td>
<td>94 93</td>
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<tr>
<td>8006</td>
<td>a 60 69</td>
<td>82 96</td>
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<tr>
<td>8010</td>
<td>73 85</td>
<td>89 98</td>
<td></td>
</tr>
</tbody>
</table>

Mean 61.83 73.00 86.17 96.50
SD 14.2 9.3 6.3 5.7
Median 60.5 72 86.5 96.5
Possible range 18-90 26-130

Wilcoxon 0.066 0.028

a Participant is 65 years of age or older,
b Values comparing pre-test with post-test scores.

Table 4. Study outcomes comparing baseline and post-intervention scores for diagnosed wives on the quality of marital communication about the cancer.

<table>
<thead>
<tr>
<th>CODE NUMBER</th>
<th>Wife MIS Total</th>
<th>Wife MIS Expressing Sad Thoughts</th>
<th>Wife MIS Open Communication</th>
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</thead>
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<td>Pre-Test</td>
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<td>a 115 45</td>
<td>112 45</td>
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<td>24 28</td>
</tr>
<tr>
<td>8010</td>
<td>114 45</td>
<td>111 43</td>
<td>45 43</td>
</tr>
</tbody>
</table>

Mean 88.00 97.33 32.33 36.50 36.33 40.17
SD 23.7 14.4 10.5 7.1 8.0 5.7
Median 84.5 99 29.5 36.5 36.5 42.5
Possible range 23-115 9-45 9-45

Wilcoxon 0.115 0.080 0.078

a Participant is 65 years of age or older,
b Values comparing pre-test with post-test scores.

on communicating their sad though ts and feelings to their spouse caused by the ovarian cancer (MIS Expressing Sad Thoughts subscale). Even when improvements failed to reach statistical significance, likely due to the small sample size, wives and caregivers had reduced scores on depressed mood and anxiety at post-test compared to baseline scores.
4.3. Gains Attributed by Patients and Spouse Caregivers to TCH Program
5. Discussion of Results

6. Study Limitations
Acknowledgements

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Cancer - 164.

Englewood Cliffs

McNair D. (1996) Self-Rating Scale

C. (1990) Self-Rating Scale


Agentic - 231. - 164.

C. - 43. - 5.

T. P. - 12.


Hammond S. (2010) Older Adults and Technology Use


Cancer - 164.

Englewood Cliffs

McNair D. (1996) Self-Rating Scale

C. (1990) Self-Rating Scale


Agentic - 231. - 164.

T. P. - 12.


Hammond S. (2010) Older Adults and Technology Use


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