

Understanding the Effectiveness of an Online Support Group in Enhancing Recovery
Identity and Health-Related Quality of Life of Middle-aged and Older Ovarian Cancer
Patients: A Randomized Controlled Trial

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Ovarian cancer poses challenges for middle-aged and older patients, impacting physical and self-conceptual aspects. A research gap exists on the impact of online support groups (SPs) on identity synthesis and Health-Related Quality of Life (HRQOL) for these patients. This research aims to understand the effect of a mobile online support group in developing a recovery identity and enhancing HRQOL among middle-aged and older ovarian cancer patients. Additionally, the research seeks to discern and compare the intervention effects between the online support group and a traditional offline support group.

Intervention

Inspired by SIMIC, we developed the theoretical framework of both the online support group and the offline support group which is illustrated in Figure 2. The intervention is designed with aim to prevent identity loss and foster a new identity for ovarian cancer patients to enhance health outcomes. Both interventions incorporate core features of education and peer support, with an added function for recording symptoms and emotions. With those core features will appear in offline support group in form of segment of the workshop, and will appear in online support group in form of function of a mobile health product. To ensure the usability of the online support group solution, the prototype designed carefully by following the Universal Design Mobile Interface Guideline Version 2 (UDMIG v2.0) for design tailored to the aging demographic (Ruzic et al., 2016).

The experiment group (the mobile online support group)

In the experiment group, participants studied the patient education materials that provided in both word content and video format by themselves. Weekly reminder was sent to remind patients to study one of the education materials. The video format education materials were presented and video recorded by the healthcare professionals

which each last around 10 minutes. Inspired by the Group 4 Health workshop rooted in Social Identity Theory (Haslam et al., 2019), the educational materials of both online and offline support group, comprise four mandatory courses derived from scientific research on physical, emotional, and role management knowledge relevant to the rehabilitation of ovarian cancer patients (Graziani & Tsakos, 2020). These materials underwent a comprehensive review process involving researchers and healthcare professionals, including a head nurse, an attending physician from the in-hospital ovarian cancer department, and a registered psychological therapist specializing in geriatric psychology. This thorough review aimed to ensure the content's reliability and readability. The first class introduced the management of physical and mental symptoms, and the importance of role management. The second class facilitated the identification of existing group memberships. In the third and fourth classes, participants explored ways to enhance existing meaningful group memberships and acquire new ones, respectively.

To nurture a sense of belonging and enhance peer support between patients, the online support group provided online community function to enable patients to share their daily feelings, activities, or questions. Patient interaction included replies, "likes," and private communication through the online chat room. System-generated invitations for posting was sent twice weekly to encourage regular engagement.

The symptom recording feature aligned with the health-related quality of life questionnaire for ovarian cancer patients (QLQ-OV28) and assessed symptoms such as abdominal pain, loss of appetite, heartburn, hair loss, tingling or numbness in limbs, fatigue, gastrointestinal issues, constipation or diarrhea, night sweats, and skin problems. Patients recorded symptoms on a three-point scale ranging from "no symptoms" to "severe symptoms." Emotional status was recorded on a five-point scale, ranging from "depression" to "happy." Notifications prompt participants to complete symptom recording twice a week.

The control group (the offline support group)

The offline support group shared similar functionalities with its mobile online counterpart. Weekly group interventions were conducted, each lasting for 1 to 1.5 hours. Participants in the control group were divided into two subgroups, each comprising 17 participants. Patient education sessions were conducted during the initial 10 minutes of the workshop. Subsequently, participants were allotted approximately 4 minutes each to express their thoughts and concerns to health professionals and fellow participants. A hard-copy form was distributed to participants during the first session, where they were instructed to document their daily emotions and symptoms. Peers who delivered offline support group were healthcare workers who had completed deception in nursing or psychology

Measure

Identity synthesis (primary outcome)

The measure of recovery identity included the assessment of patients' acceptance of their illness identity and their self-esteem derived from their social identities. The acceptance of illness identity was measured using the Illness Identity Questionnaire's acceptance sub-scale, consisting of 6 items (Oris et al., 2016). The maintenance of former social identities was measured using the Maintenance of Group Memberships sub-scale of Exeter Identity Transition Scales (Haslam et al., 2008), encompassing 4 items. The new meaningful social identity was measured using the New Group Memberships sub-scale of the Exeter Identity Transition Scales, which includes 4 questions. Responses were rated on a scale from 1 to 5, with higher scores indicating a higher level of acceptance of the identity. The recovery identity is calculated as the sum of each average score of acceptance of illness identity, maintenance of former identity and new identity.

Health-related quality of life (secondary outcome)

HRQOL was measured using the Short Form Health Survey 12 (SF-12) (Jakobsson, 2007), which includes twelve questions. Each item is transformed into a scale ranging from 0 to 100 according to a specific scoring algorithm. These scores are then aggregated to generate two summary scores: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The resulting scores are norm-based, comparing an individual's health status to population norms. HRQOL is calculated as the summary of PCS and MCS. Higher scores indicate better HRQOL, with scores around 50 representing the average.

Participant Engagement

In the experimental group, the peer support was calculated based on system-recorded time spent on relevant pages, while health record and patient education involvement were gauged by the frequency of actions, encompassing symptom recording and engagement with educational materials. Conversely, in the control group, participant engagement was evaluated by calculating peer support based on session duration. Health record involvement was quantified by the number of symptom and emotion record entries, and patient education engagement was measured by the number of attended lessons.

Data collection and analysis

Data collection occurred at three time points: before the intervention, immediately after the intervention, and at a three-month follow-up. Questionnaires were administered through a website link hosted on Sojump, and data were stored in Excel and analyzed using SPSS 26.0. The determination of the sample size involved a statistical power analysis, considering a two-sided test with a significance level ($\alpha = 0.05$) and a desired statistical power of 80% ($1-\beta$). A minimum of 34 individuals per intervention arm was deemed necessary.

Participant engagement was assessed through comparing the number of courses undertaken, average time spent on peer communication, and instances of health recording behaviors. The assessment of the intervention's impact on shaping participants' recovery identity and improving HRQOL involved comparing scores for identity synthesis and HRQOL before and after the experiment.

T-tests or non-parametric test were employed to ascertain the significance of the observed changes, and for assessing the differences in intervention effects between groups. Additionally, Cohen's d effect size representing the mean-level difference in scores between groups was calculated as the mean difference between interventions on each outcome divided by the pooled standard deviation. Regression coefficients and 95% confidence interval were measured through regression analysis to understand the difference in treatment effects. Associations between recovery identity and HRQOL were examined through Pearson correlation coefficients. Hierarchical regression analyses were conducted to evaluate the predictive value of demographic factors and recovery identity for HRQOL.