



The effect of a web-based self-care instruction on symptom experience and quality of life in living liver donors: A randomized controlled trial

Li-Chueh Weng^{a,b,*}, Hsiu-Li Huang^c, Yu-Hsia Tsai^{a,d}, Hsiu-Hsin Tsai^{a,e},
Wei-Chen Lee^b, Wann-Yun Shieh^f

^a School of Nursing, College of Medicine, Chang Gung University, Taoyuan, Taiwan

^b Department of General Surgery, Liver Transplantation, Chang Gung Medical Foundation, Linkuo Medical Center, Taoyuan, Taiwan

^c Department of Long-Term Care, College of Health Technology, National Taipei University of Nursing and Health Science, Taipei, Taiwan

^d Department of Cardiovascular Medicine, Chang Gung Medical Foundation, Linkuo Medical Center, Taoyuan, Taiwan

^e Department of Psychiatry, Chang Gung Medical Foundation, Linkuo Medical Center, Taoyuan, Taiwan

^f Department of Computer Science and Information Engineering, Chang Gung University, Taoyuan, Taiwan

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ABSTRACT

Objective: Living liver donors need help to manage symptom distress and improve their quality of life. This study aims to test the effectiveness of a web-based symptom self-care instruction on symptom experience and health-related quality of life of living liver donors.

Methods: This study was a randomized controlled trial. Participants were recruited from January 2019 to August 2020. Participants in the experimental group had access to a web-based symptom self-care instruction, which included text and video. The control group received routine care. The primary outcomes were symptom distress and quality of life.

Results: A total of 90 living liver donors recruited in this study were assigned randomly to the web group (n = 46) and control group (n = 44). The symptom distress was significantly negatively correlated with quality of life at each data collection time. There was an interaction effect with the participants in the web group experiencing more symptom distress at three months after surgery than the control group (B = 3.616, 95% CI: 7.163–3.990, p = 0.046). There was no significant effect on the quality of life.

Conclusion: Patients in the web-based self-care group had higher symptom distress than those in the control group three months after surgery, but there was no difference in quality of life. Future studies could add some interactive elements to the website and include a larger sample size.

Registration: This study was registered at the Chinese Clinical Trial Registry (ChiCTR1900020518).

1. Introduction

Living donor liver transplantation has been an effective treatment for end-stage liver disease [1,2]. There are ethical concerns because living liver donors may risk their health status. Data have shown that the morbidity rate was 10%–78% and the mortality rate

* Corresponding author. School of Nursing, College of Medicine, Chang Gung University, Taoyuan, Taiwan.
E-mail address: ax2488@mail.cgu.edu.tw (L.-C. Weng).

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was 0.3%–0.5% in living liver donors [3]. A recent study reported that living liver donors had a higher all-cause mortality rate than health controls [4]. Reducing the negative impact on physical, psychological, and social functions is an essential goal for liver transplantation teams [5–7]. Systematic reviews pointed out that living liver donors experienced more obvious symptom distress and poorer quality of life within three months after surgery. Nearly 80% of donors return to their pre-surgery status in about six months [8, 9]. The symptom distress and quality of life information of the living liver donor can serve as an essential knowledge base for healthcare professionals to plan long-term care [2,5] and as an information reference for potential donor candidates. However, there is currently insufficient data on the long-term health status of living donors.

Smoothly recovering both physically and mentally after surgery is important for living liver donors. Besides the survival rate and morbidity rate, the outcomes perceived by patients, such as symptom experience and quality of life, are essential indicators of health care effectiveness [10]. In terms of symptoms, living liver donors experience distressing symptoms, including pain, fatigue, wound scarring, diarrhea, and anxiety [11,12]. Untreated symptom distress may negatively affect the quality of life [12,13]. So, managing symptomatic distress and improving quality of life is vital for the care of living liver donors. Liver donors received health care instruction during hospitalization and before being discharged. However, a short hospital stay may result in an insufficient amount of instruction. An additional strategy was needed to enhance the self-care information given to living liver donors.

With the vigorous development of the Internet, it has become the norm to search for helpful information on the Internet. Gathering information before undergoing surgery is recommended for living liver donors [12]. An interview with 13 living liver donors (at least one year after surgery) found that in addition to the information provided by the transplant team, donors would also search the Internet, read relevant research literature, and discuss with other donors to increase their knowledge [14]. Living liver donors suggested that self-care information be provided about surgical wounds, digestive symptoms, pain, and diet [15]. However, a survey of 32 webpages about living liver donation indicated that only 14 webpages clearly described the possible risks and impacts of living liver donation [16]. There is also a lack of information on how to do self-care after donation. Studies have shown the positive effects of web-based learning on symptom management in cancer patients [17,18], chronic headache patients [19], and kidney transplant recipients [20]. Nevertheless, there are no studies on living liver donors.

Based on the above, this study addresses two issues worthy of attention in the care of living liver donors. One is to prospectively follow-up the donor's self-reported outcome indicators, such as symptom experience and quality of life. The second is to provide self-care information, especially information related to the symptoms after surgery. A website that includes electronic questionnaires and symptom self-care information might overcome these two issues. Living liver donors can answer the electronic questionnaires on the web platform prospectively, and at the same time they can obtain symptom self-care information. Therefore, this study aims to analyze the effect of a web-based self-care instruction on symptom distress and quality of life in living liver donors. The hypothesis was that participants who received the web-based symptom self-care instruction would report lower symptom distress and higher quality of life than those who did not.

2. Methods

2.1. Design

This study was a prospective two-armed randomized clinical trial to test the research hypothesis that a web-based self-care instruction would improve the symptom distress and quality of life among living liver donors. The trial was registered at the Chinese Clinical Trial Registry (ChiCTR1900020518).

2.2. Participants

Data were collected from living liver donors who underwent surgery at Chang Gung Memorial Hospital in Northern Taiwan. The sample was recruited from January 2019 to August 2020. Using the convenient sampling method, we formed the following sample inclusion criteria: over the age of 20, underwent living liver donation surgery, and have experience using 3C devices such as smartphones, tablet computers, and personal computers. The exclusion criterion was postoperative complications requiring repeated hospitalization (such as biliary problems).

2.3. Sample size estimation

There are currently no randomized trials of living liver donors to refer to for sample size estimation. For other web-based studies, the effect size varied from 0.16 to 0.62 [18,19]. Thus, this study used G power software's defaults of effect size = 0.25, power = 80%, and $\alpha = 0.05$ to estimate the sample size. A required sample size was 76 living liver donors. After incorporating a 20% lost-to-follow-up rate, the sample size was 96. If the sample size was not achieved, we would conduct a post-hoc power analysis.

2.4. Randomization and allocation

We used simple random allocation to divide the sample into an experimental group and a control group. First, a research assistant used a random number generator (<https://www.random.org/>) to create a table of random integers and associated the even numbers with the experimental group and the odd numbers with the control group. The research assistant prepared 96 opaque and sealed envelopes that contained website account passwords. After a participant's written consent was obtained, the participant was asked to

complete the basic demographic questionnaire, symptom distress scale, and quality of life questionnaire (baseline data, T0) on a tablet computer. After the T0 data had been collected, the research assistant asked the participant to draw and open a sealed envelope. Within the envelope, there was a website account password to use when logging into the website.

2.5. Usual care

The participants in the web group and control group received the routine post-donation care provided by the nurses of the transplantation ward, including wound care, diet instruction, medication, and clinical follow-up. The usual care was provided in an unstructured manner through the entire hospitalization period. Before discharge from hospital, the nurses would ask donors whether they had any concerns that needed to be addressed.

2.6. Intervention

Participants in the web group received web-based self-care symptom instruction with specific information in text and video. The process of establishing the website included webpage design, program syntax setting, correction, and testing. The website's Uniform Resource Locator is www.ldltcare.com.tw. The main components of this website are the electronic questionnaire and self-care information. Besides, the website also had additional information, including an introduction of the study, a list of research team members, links to other relevant websites, and how to contact the research team.

The characteristics and possible causes of symptoms, methods of management and monitoring, and self-care methods in symptom management were the core content of the self-care instruction. To create the text concerning self-care of a symptom, the researchers searched databases such as PubMed, Cochrane library, and UpToDate. An example of the educational content was shown in Table 1. The information on each symptom was limited to no more than 1 page for easy reading. After completing the first draft, seven transplant experts in the field of transplantation care (one nurse, three nursing specialists, two transplant coordinators, and one nutritionist) were invited to conduct an expert review. Each symptom was reviewed 2–3 times for correction and confirmation of the text. The final version of the text was then uploaded to the website. This study gathered information on wound pain, menstrual period changes, insomnia, itchy skin, scarring problems, loss of appetite, diarrhea, tiredness, weight problems, dizziness, headaches, difficulty concentrating, infections, joint pain, vision problems, abdominal pain, and emotional problems. We created a total of 17 text files and three audiovisual files (introduction of living liver donation, acupuncture to reduce fatigue, and relaxation skills).

The participants of the web group and control group used their accounts and passwords to log into the website. The web group could browse the self-care information on symptom management anytime and anywhere, and the website's interface recorded and saved the number of views of the self-care information. The webpages for the control group only had questionnaires and did not have self-care information. Because this study involved web-based self-learning, the double-blind design could not be achieved. Data collection was completed through electronic questionnaires on the web, which can reduce possible bias from the data collector.

2.7. Data collection

This study used electronic questionnaires. The T0 data were collected via a tablet computer because at T0 participants had not been assigned a group yet and did not have a password to log into the website. T1 to T3 data were collected by the website. An electronic version of the questionnaire was first built as a data collection tool before the formal study. From January 1, 2018, to May 14, 2018,

Table 1

The educational content for symptom management.

<p>Development of self-care instruction for a specific symptom (using fatigue as an example).</p> <p>The researchers searched PubMed by title and keyword, limiting it to clinical trials, publication year within one year, and English writing. There were 150 articles obtained. After reading the titles and abstracts, the researchers eliminated the articles that focused on sports injuries, medication clinical trials, and fatigue related to neurological trauma. In the end, 36 articles were reviewed. A summary of the methods mentioned in the literature that can improve fatigue includes dietary adjustment and supplementation, exercise and recreation (walking, yoga, and relaxation exercises), proper sleep, and lifestyle adjustment. This material was organized into a text containing a brief description of the problem and principles of self-care.</p> <p>The content of fatigue symptom self-care (as an example)</p> <p><i>Introduction</i></p> <p>After the operation, one may experience declining physical fitness and the tendency to feel tired quickly, mainly due to the removal of part of the liver. Fatigue and weakness should improve when the liver function index gradually stabilizes one to two weeks after the operation. Gradual improvement will occur, of course, by moderately increasing physical activity, sleeping well, and using proper nutrition.</p> <p><i>Ways to Boost Physical Performance and Prevent Fatigue</i></p> <ol style="list-style-type: none"> 1. Moderate exercise: Exercise sessions should occur regularly and gradually increase in intensity. Exercise can strengthen physical fitness and improve cardiovascular system efficiency. Moreover, avoid excessive exercise within three months after the operation to avoid injury. 2. Sufficient daily water intake: Water intake can maintain metabolic function and allow the cardiovascular system to operate stably. When kidney function is OK, the daily water intake, in milliliters, should be about "body weight (in kilograms) x 30". 3. Balanced nutrition: Intake of high-protein foods such as fish, beef, beans, tofu, eggs, green vegetables, and nuts can help the regeneration of liver cells. 4. The diet principle is to eat light (less oil and less salt) and avoid alcohol and spicy foods. 5. When eating out, pay attention to the menu choices and avoid foods with high fat and insufficient fiber (avoid fast food). 6. Sufficient sleep and good sleep quality. 7. Keep a balance between work and rest.

twenty living liver donors were recruited for assessing the equivalence between the paper versions and electronic versions of the questionnaires. The results showed that the value of the intraclass correlation coefficient (ICC) ranged from 0.544 to 0.971 (perfect agreement); kappa agreement values ranged from 0.221 to 1 (fair agreement to perfect agreement) in items of symptom distress and from 0.500 to 1 (moderate agreement to perfect agreement) for the quality of life scale. The scales used in this study are described in the next section. The 20 cases included at this stage were not included in the randomized trial (the formal study).

The formal research was conducted from January 2019 to August 2020. In addition to the baseline data collection (T0), data were collected 1 (T1), 3 (T2), and 6 (T3) months after surgery. Before each data collection time, the researcher reminded the participant by text message to enter the website and complete the questionnaires. Trained research assistant reviewed the functions and status of the web platform every day. Suppose participants had questions about the website self-care instruction or other relative issues. They can ask questions via the website's "Q & A" or "Connect us". The research assistant checked the website daily and communicate with the participants to solve their concerns or problems.

2.8. Outcome measures

The primary outcomes analyzed in this study were symptom distress and quality of life.

2.8.1. Symptom distress

The "Symptom Distress Scale after Liver Donation Surgery", which was developed by the first author, was used to measure the symptom distress. The author had invited eight experts (2 transplant coordinators, 3 clinical nurse specialists, 1 nurse supervisor and 2 scholars) to examine the content validity. The content validity index of this scale was 0.99. There were 20 symptoms rated on a Likert scale of 0–3 points, where 0, 1, 2, and 3 points indicated no symptom distress, mild symptom distress, moderate symptom distress, and severe symptom distress, respectively. Scores could range from 0 to 60, and a higher score represented more severe symptom distress. The Cronbach's α for internal consistency reliability was 0.88 in this study.

2.8.2. Quality of life

The Medical Outcome Study SF-12 (MOS SF-12) measures health-related quality of life. It was developed by Ware et al. from the original MOS SF-36. It is commonly used in measuring quality of life and has shown good reliability and validity [21–23]. The scale contains 12 questions and 8 domains, including physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health [21]. Each domain contains various items, and the item scores are summarized and transformed to a scale of 0–100. A higher score represents better quality of life. The SF-12 scale can also be integrated into two constructs: the physical component summary (PCS) score and the mental component summary (MCS) score. In this study, the Cronbach's α for internal consistency reliability was 0.82 in the PCS and 0.87 in the MCS.

2.8.3. Potential covariates

We also collected some variables that may influence the effect of intervention as confounding variables. These potential covariates included age, sex, education level, marital status, relationship with recipient, and employment status. In addition, donated liver lobe (right or left lobe), recipient's status (alive or deceased), surgical complication (yes or no), length of hospital stay (days), donated liver weight (gm), graft-to-recipient weight ratio (GRWR), and number of clinic visits within 6 months after surgery were also collected through the audit of medical records.

2.9. Ethical consideration

The study followed the Declaration of Helsinki. In terms of the principle of autonomy, researchers and trained research assistants explained to the research participants the purpose of the research and the time and method of data collection. The participants were also informed that participating in the research would not affect their care and that they had the right to withdraw from the research anytime during the research process. To protect privacy and confidentiality, we used research codes to represent the identity of the participants. The participants' identity data were stored in a computer with a password. The website utilized the https protocol to ensure the security of data transmission, and each participant had an account and password. Additionally, all input data fields were encrypted to avoid plain text; only internal links were allowed in the database or document file. This study was approved by the institutional review board of the Chang Gung Medical Foundation (approval number 201701285B0C601). All participants provided written informed consent before participating in the study.

2.10. Statistical analysis

IBM's Statistical Package for the Social Sciences, version 24, was used to analyze data. The variables were analyzed using descriptive statistics such as mean, standard deviation, frequency, percentage, etc. Independent samples t-tests and the Mann-Whitney test (if a normal distribution was not assumed) were used to compare the potential covariates, symptom distress and health-rated quality of life between groups. We used Pearson correlation and Spearman correlation (if a normal distribution was not assumed) to analyze the relationship between symptom distress and quality of life. The normality of data was checked by using the Kolmogorov-Smirnov test. This study used a generalized estimating equation (GEE) model with a first-order autoregressive correlation (AR1) structure to analyze the effect of time (different time points), intervention (usual care or web-based instruction), and the interaction

effect of intervention and time. The model can be expressed as $Y_i = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \beta_3 (X_1 X_2) + \text{CORR} + e_i$, where X_1 represents the intervention, X_2 represents time, and CORR is the working correlation matrix. The first-order autoregressive correlation (AR1) structure was used because there were three waves of data collection (not including the baseline), the data were dependent, and the correlation among data may not be the same. The GEE method is currently widely used in longitudinal research data analysis [24,25]. We used the intent-to-treat principle to analyze the collected data based on the assigned groups [26].

3. Results

There were 106 consecutive living liver donors who underwent living liver donation surgery during the data collection period (January 2019 to August 2020). Among them, 8 were not enrolled because they were less than 20 years old. Of the 98 eligible donors, 3 donors did not agree to participate due to reading difficulties and no interest, and 5 donors were not accessible due to the COVID-19 pandemic. A total of 90 donors were included in this study. The participants were not significantly different from the non-participants in terms of age, gender, and the relationships with their recipients.

After a study participant's written consent was obtained, baseline data were collected and the participant was randomly assigned into either the web group ($n = 46$) or the control group ($n = 44$). The data collection flow was shown in Fig. 1. The numbers on participant responses at each time point are as follows: 90 participants (46 in the web group, 44 in the control group) at baseline (T0), 73 participants (35 in the web group, 38 in the control group) at T1, 67 participants (34 in the web group, 33 in the control group) at T2, and 61 participants (33 in the web group, 28 in the control group) at T3. The overall attrition rate was 28.3% and 36.3% in the web group and control group, respectively. Attrition resulted from loss of contact and the participants declining to answer the questionnaires. The reasons for loss of contact included going abroad. The reasons for declining to answer a questionnaire included not enough time and no more interest. The basic and clinical data for the two groups were shown in Table 2. There was no statistically significant difference between the web group and control group in demographic and clinical data.

Symptom distress, PCS score, and MCS score were presented in Figs. 2–4. There was no statistically significant difference between the two groups in symptom distress, PCS and MCS at baseline, T1, T2, and T3.

The symptom distress was statistically significantly negatively correlated with PCS and MCS at baseline, T1, T2, and T3 (data not

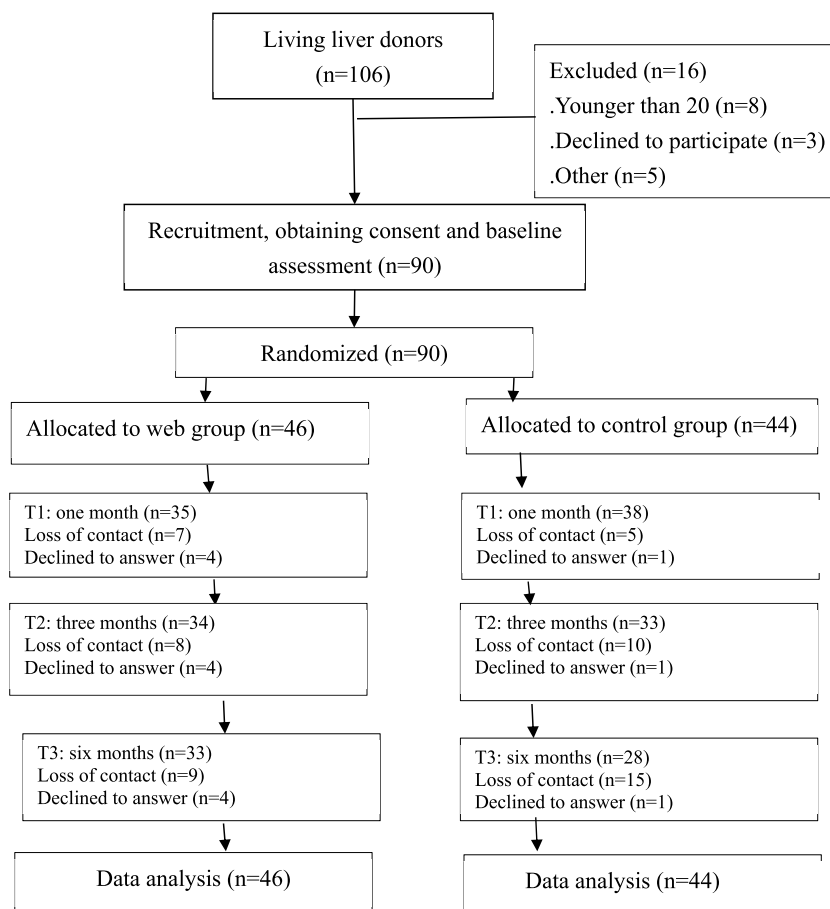


Fig. 1. Flowchart of data collection.

shown in the tables).

There was an interaction effect (intervention x time) on symptom distress at T2 ($B = 3.616$, $p = 0.046$). This indicated that the increase in symptom distress was significantly different between the web group and control group. The web group's symptom distress score was 3.616 higher than the control group's at T2. There was a significant time effect on symptom distress at T1 as well. The symptom distress was higher than baseline ($B = 12.704$), and then it significantly reduced from T2 to T3 ($p < 0.05$) (Table 3).

There was no significant interaction effect of the PCS between the two groups. There was a significant time effect on the PCS score, as the PCS score decreased obviously at T1 ($B = -22.846$) and then showed improvement over time (T2, $B = -13.350$; T3, $B = -5.000$) ($p < 0.05$) (Table 4). There was no significant interaction effect of the MCS between the two groups. The time effect on the MCS score just only happened at T1 as the MCS score was statistically significantly poorer than the baseline ($B = -6.488$, $p < 0.05$) and then was similar with the baseline ($p > 0.05$) (Table 5).

The post hoc power analysis showed that the powers for symptom distress, PCS, and MCS were 0.297, 0.614, and 0.557, respectively.

We now consider differences between completed participants and non-completed participants. For the total sample and the control group, there was no significant difference in demographic data, clinical data, symptom distress, PCS, or MCS between completed and non-completed participants. In the web group, the non-completed participants donated more liver by weight (702.7 g m vs. 604.9 g m, $p = 0.014$), had lower symptom distress at T0 (1.70 vs. 0.62, $p = 0.023$), and a higher MCS score at T1 (44.36 vs. 59.55, $p = 0.027$) than the completed participants.

Turning to relationships in the web group among the number of views, symptom distress, PCS, and MCS, the web group took 284 views of webpage information. Page views ranged from 1 to 50, and the mean was 9.16 (Std Dev = 13.26, median 3). Topics that had ten or more views were the introduction on liver transplantation (video), acupuncture for reducing fatigue (video), pain, menstrual period changes, scarring, body weight gain, itching, sleep problems, dizziness, and depressive mood. The number of views positively correlated with symptom distress at T1 ($r = 0.443$, $p = 0.034$) and T2 ($r = 0.433$, $p = 0.039$) but did not statistically significantly correlate with PCS or MCS. There was no significant difference in number of views between completed and non-completed participants in the web group.

4. Discussion

This study showed no significant difference in symptom distress or quality of life between the web and control groups. This study

Table 2

Comparison of basic and clinical data between experimental and control groups by using independent *t*-test and Chi-square test ($N = 90$).

Variables	Control (N = 44)		Experimental (N = 46)		$t/\chi^2/z^b$	p
	Mean (n)	Std Dev (%)	Mean (n)	Std Dev (%)		
Age ^a	32.8	8.88	33.3	9.27	-0.15	0.884
Sex						
Female	21	47.7	25	54.3	0.17	0.677
Male	23	52.3	21	45.7		
Education level						
High school and below	21	47.7	22	47.8	0.01	0.993
College and above	23	52.3	24	52.2		
Marital status						
Single	28	63.6	31	67.4	0.02	0.879
Married	16	36.4	15	32.6		
Relationship with recipient						
Spouse	5	11.4	6	13	0.39	0.821
Child	34	77.3	33	71.7		
Other	5	11.4	7	15.2		
Employment status						
Unemployed	13	29.5	12	26.1	0.13	0.714
Employed	31	70.5	34	73.9		
Liver lobe						
Right lobe	43	97.7	40	97.6	0.001	0.975
Left lobe	1	2.3	1	2.4		
Recipient's status						
Alive	34	77.3	38	82.6	0.14	0.712
Deceased	10	22.7	8	17.4		
Complication						
No	44	100	46	100	-	-
Yes	0	0	0	0		
LOS (days) ^a	9	1.85	8.9	1.78	-0.15	0.884
Donated weight (gm)	632.7	116.5	632.5	123.9	0.01	0.993
GRWR (%)	0.97	0.19	0.96	0.25	0.19	0.847
Clinic visits ^a	4.05	0.88	4.15	1.38	-0.36	0.713

Note: LOS length of stay; GRWR graft-to-recipient weight ratio; ^a Mann-Whitney test; ^b statistic from an independent samples *t*-test, chi-squared test, or Mann-Whitney test.

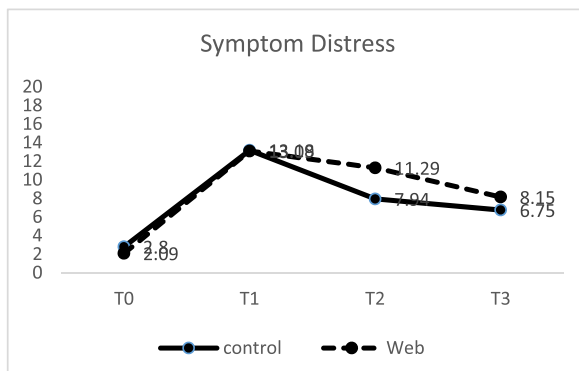


Fig. 2. Symptom distress from T0 to T3.

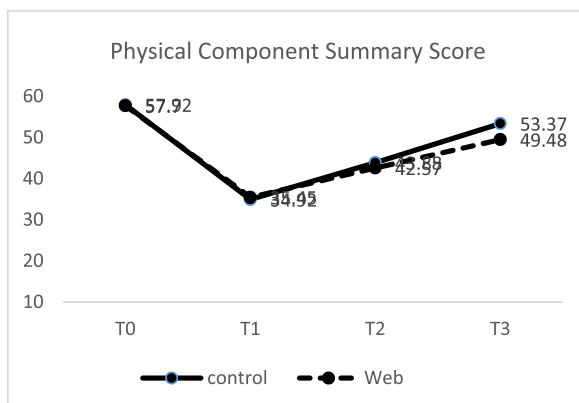


Fig. 3. Physical Component Summary score from T0 to T3.

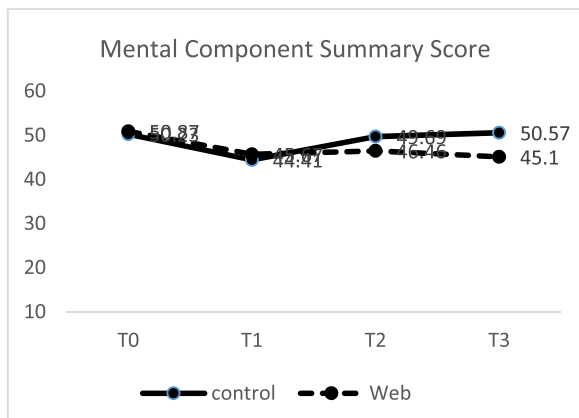


Fig. 4. Mental Component Summary score from T0 to T3.

fails to confirm that a web-based self-care instruction could reduce symptom distress and increase the quality of life. It may be because the web information of this research is still in Web 1.0 (mostly presented in text). Although participants think it is practical, future research may extend the design to Web 2.0 or 3.0 to increase user interaction. The higher attrition rate than expected in this study lowers the power. In addition, in the web group, participants with lower symptom distress and a better MCS score tended to drop from the study. These reasons may explain why a significant effect was not achieved and the research hypothesis was rejected.

In organ donation and clinical transplantation care, experimental research on providing self-care guidance on the web or via any information technology (IT) is still in its infancy. There are few relevant research results and most of them were related to kidney donor or kidney transplantation. A study using guided and tailored internet-based cognitive-behavioral intervention provided to living

Table 3

General estimating equation analysis for the effects of the intervention on symptom distress (N = 90).

	B	CI (lower bound)	CI (upper bound)	Wald χ^2	p
Intercept	1.559	0.882	2.236	20.383	.000
Web	-0.303	-1.245	0.640	.396	.529
Control	0				
T3	5.194	3.107	7.281	23.797	.000
T2	6.141	4.748	7.536	74.601	.000
T1	12.704	9.734	15.674	70.281	.000
T0	0				
T3 x web	1.881	-1.538	5.299	1.163	.281
T2 x web	3.616	0.068	7.163	3.990	.046
T1 x web	-0.487	-4.770	3.796	.050	.824

Note: T0 is baseline; T1 is 1 month after surgery; T2 is 3 months after surgery; T3 is 6 months after surgery.

Table 4

General estimating equation analysis for the effects of the intervention on Physical Component Summary score (N = 90).

	B	CI (lower bound)	CI (upper bound)	Wald χ^2	p
Intercept	57.92	55.689	59.896	2899.448	.000
Web	-0.199	-2.777	2.378	.023	.880
Control	0				
T3	-5.000	-7.980	-2.020	10.816	.001
T2	-13.350	-16.475	-10.225	70.103	.000
T1	-22.846	-26.105	-19.587	188.753	.000
T0	0				
T3 x web	-3.047	-7.17	1.077	2.097	.148
T2 x web	-1.125	-5.875	3.625	.216	.642
T1 x web	0.665	-4.015	5.344	.078	.791

Note: T0 is baseline; T1 is 1 month after surgery; T2 is 3 months after surgery; T3 is 6 months after surgery.

Table 5

General estimating equation analysis for the effects of the intervention on Mental Component Summary score (N = 90).

	B	CI (lower bound)	CI (upper bound)	Wald χ^2	p
Intercept	50.033	47.250	52.815	1241.949	.000
Web	0.803	-3.307	4.914	.147	.702
Control	0				
T3	-0.557	-3.692	2.578	.121	.728
T2	-1.085	-4.094	1.925	.499	.480
T1	-6.488	-9.978	-2.998	13.275	.000
T0	0	0			
T3 x web	-4.374	-9.217	0.470	3.132	.071
T2 x web	-1.907	-6.369	2.556	.701	.402
T1 x web	1.244	-3.379	5.868	.278	.598

Note: T0 is baseline; T1 is 1 month after surgery; T2 is 3 months after surgery; T3 is 6 months after surgery.

kidney donors with adjustment problems before and after donation had preliminary results indicating that the donors felt their problems had improved [27]. A meta-analysis study on the use of IT-based postoperative care interventions for kidney transplant patients analyzed eight studies. Of the three studies that used web-based methods, two of them pointed out that web-based instruction can increase the knowledge of kidney transplant candidates. However, another study showed no significant difference in self-efficacy and skills between the control group and the experimental group, which received post-organ transplant care provided by a virtual nurse on a webpage [20]. Using web-based intervention to provide care instruction is sustainable and not limited by space. It has potential for development. Future research needs to consider more convenient and interactive methods of providing content (chatbot, mobile app), effectiveness evaluation, and follow-up methods in research design.

Overall, symptom distress worsened one month after surgery but improved over time, which was similar with previous studies [11, 28]. Participants still experienced symptom distress six months after the operation, indicating the need for long-term follow-up [29]. Judging from the data, most of the symptoms were associated with mild distress. The causes of discomfort experienced by living liver donors may be related to surgical incisions, gastrointestinal symptoms, and the loss of a large liver area. The assessment, monitoring, medical management, and self-care were also critical. Menstrual discomfort was one of the frequently viewed symptoms in the self-care instruction; it has seldom been reported as a symptom of concern. Half of the web group's participants were women, and the study's sample was young. Thus, there would be concerns about fertility after liver donation [30]. This has brought attention to explore whether instant liver dysfunction may interfere with the gonadotropin hormone regulation or some unknown mechanism [30]. The

subjective experiences and concerns of menstrual period change in female living liver donors need to be explored more deeply.

The PCS domain of quality of life declined after surgery and did not recover to baseline six months after surgery. It seems understandable that the subjective quality of life at the physical level will decline after surgery because during this period (about one month after surgery) the surgical wound needs to heal, pain may affect rest and sleep, gastrointestinal symptoms lead to reduced nutritional intake, and a significant decline in liver function leads to fatigue, which may further affect daily life functions and require assistance from others [28,29]. As the liver cells gradually regenerate and restore their functions and the physical symptoms gradually improve, the quality of life at the physical level also improves, which takes about 3–6 months [31–34]. In long-term follow-up, the donors are similar to nondonors in terms of quality of life but lower in physical-related quality of life [35].

The MCS of living liver donors did not change as obviously as the PCS. These results are also similar with previous studies [33,34]. Overall, the MCS score is lower than the PCS score (except one month after the operation). However, there is no dramatic change due to liver donation surgery. As living liver donors make the decision to become a donor, they may experience emotional pressure when facing important relatives suffering from end-stage diseases [36]. However, after the operation, the focus of worry may be on the recovery status of relatives and themselves. If a donor's health condition can recover as scheduled, it is possible that the donor's quality of life at the psychological level will not deteriorate [36].

The total number of page views was positively correlated with the degree of symptom distress after surgery. The web-based self-care instruction in this study was not similar to in-class or group instruction. The latter usually involves collecting outcome indicators after health education has finished. Participants in the web group watch online information independently and may watch it again whenever they feel symptoms and at any other time. However, the association between the number of views (the intervention dose) and outcome indicators seems unclear because the calculation of the number of views in this study was just at the end of the study. Future research needs to collect the number of views according to the time course to make it more accurate for analysis.

Living liver donors are healthy people undergoing surgery whose physical and mental health and quality of life are the highest priorities. Therefore, the strength of this study was that it used the Internet to provide follow-up prospectively and continuous self-care instruction. Although this study did not achieve significant effectiveness, the research design can be used as a reference for future research. Some limitations should be noted. The attrition rate of this study led to low power. Only six months of post-donation data were collected, so it is impossible to infer long-term benefits from these results. In addition, when using the results of this study, it must be noted that part of the study period overlapped with the COVID-19 pandemic, and the effectiveness of web-based instruction must be interpreted carefully.

5. Conclusion and implication

This study showed that a web-based self-care instruction did not have a superior effect on symptom distress and quality of life compared to usual care. The advantage of web-based self-care information is that it could help living liver donors access information anytime. It is suggested that the website be upgraded with more interaction and attraction. The study was conducted partially during the COVID-19 pandemic. Although the website was not affected by warnings or city closures during the pandemic, living donors may have worked from home, diverted their Internet use to pandemic-related activities, or had their motivation affected by the epidemic. Future studies could increase the lost to follow-up rate in the sample estimation and use various reminding strategies to overcome any attrition problems.

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Author contribution statement

Li Chueh Weng: conceived and designed the experiments; performed the experiments; analyzed and interpreted the data; contributed reagents, materials, analysis tools or data; wrote the paper.

Hsiu Li Huang: conceived and designed the experiments; analyzed and interpreted the data; wrote the paper.

Yu Hsia Tsai: conceived and designed the experiments; performed the experiments; analyzed and interpreted the data; wrote the paper.

Hsiu Hisn Tsai: analyzed and interpreted the data; contributed reagents, materials, analysis tools or data; wrote the paper.

Wei Chen Lee: conceived and designed the experiments; analyzed and interpreted the data; contributed reagents, materials, analysis tools or data; wrote the paper.

Wann Yun Shieh: conceived and designed the experiments; analyzed and interpreted the data; contributed reagents, materials, analysis tools or data; wrote the paper.

Data availability statement

Data will be made available on request.

Declaration of interest's statement:

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Clinical trial

This study was registered at the Chinese Clinical Trial Registry (ChiCTR1900020518).

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2023.e17333>.

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