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RESEARCH

Social media-based bibliotherapy for improving the mental health of informal caregivers of people with dementia: a randomized controlled trial

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Abstract

Background Despite their own experience of mental health issues, informal caregivers of individuals with dementia are often overlooked, and there is a limited availability of community services tailored specifically for them. A self-help intervention, bibliotherapy, shows promise as an intervention to enhance the mental well-being of caregivers in resource-constrained settings, and social media has demonstrated its efficacy as a user-friendly platform for delivering health interventions. However, the efficacy of social media-based bibliotherapy remains untested.

Aim This study aims to test the efficacy of social media-based bibliotherapy on improving the mental health of informal caregivers of people with dementia through a randomized controlled trial.

Methods A total of 60 informal caregivers were enrolled in this randomized controlled trial. Participants were randomly assigned to either the social media-based bibliotherapy group, which received eight weekly sessions of bibliotherapy, or the usual care group, which only received routine services from community centers. Outcomes were assessed at baseline and immediately after the intervention. Post-intervention interviews were conducted to explore participants' experiences with this intervention. Descriptive statistics, t-tests, Mann-Whitney U tests, χ^2 tests, and generalized estimating equations were used for quantitative data analysis. Content analysis was employed for qualitative data analysis.

Results The average age of caregivers was 57.41 (SD, 13.63), with a majority being female (79.3%). Baseline characteristics were similar between groups. Both quantitative and qualitative data demonstrated that social media-based bibliotherapy was acceptable for informal caregivers, with WhatsApp being the preferred medium in this study. The recruitment rate, retention rate, and completion rate of weekly tasks all met satisfactory levels. Caregivers found the intervention useful and flexible while experiencing changes in their perceptions towards caregiving responsibilities. The efficacy on mental health (Wald $\chi^2 = 8.918$, $p = .003$) and all the subscales of stress (Wald $\chi^2 = 4.198$, $p = .040$), anxiety (Wald $\chi^2 = 7.667$, $p = .006$), depression (Wald $\chi^2 = 9.127$, $p = .003$) was statistically significant. The

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efficacy on caregiving appraisal was only significant on the perceived caregiving burden subscale (Wald $\chi^2=4.954$, $p=.026$). However, caregivers expressed changes in caregiving appraisal in qualitative interviews. The efficacy on the mental component scale of health-related quality of life approached significance (Wald $\chi^2=3.634$, $p=.057$). However, the efficacy on the positive psychological well-being remains insignificant.

Conclusions To the best of our knowledge, this is the first attempt to use social media-based bibliotherapy among informal caregivers of individuals with dementia. The utilization of WhatsApp was well received among caregivers, and the positive effects on their mental health was demonstrated.

Trial registration The trial has been registered on ClinicalTrial.gov (Ref: NCT06327022).

Keywords Dementia, Informal caregiver, Bibliotherapy, Social media, Intervention, Randomized controlled trial

Background

Recognized as a global public health priority by the World Health Organization, dementia poses a significant challenge for families and societies worldwide. With the aging population, there is an anticipated surge in dementia prevalence and an increased demand for caregivers [1]. The provision of care for individuals with dementia entails a multitude of logistical tasks, including personal care, housekeeping, medication administration, financial transactions processing, and other activities [2]. Moreover, as the disease progresses, caregiving assumes even greater significance for ensuring the well-being of patients [2].

The caregiving journey often spans over a decade, transforming informal caregivers into hidden secondary patients burdened with mental health issues. According to the World Alzheimer's Report, more than 92% of caregivers experience stress due to their caregiving role [3]. Survey findings revealed that Chinese informal caregivers of people with dementia exhibit poor mental health, with 64.7% suffering from probable depression [4]. Furthermore, it has been identified that their psychological well-being needs improvement [5]. Another study reported that 80% of working dementia caregivers experience feelings of sadness, depression or hopelessness, while 60.8% perceive their health status as poor or fair [6]. Therefore, urgent support is needed to assist informal caregivers.

Despite the articulated demands for health and social services from informal caregivers, there continues to be a scarcity of community-based dementia caregiver-specific services, and a low utilization rate of existing services [7]. Various factors could account for this phenomenon, such as the existing caregiver services offered by community centers primarily encompass counseling and emotional support, inadequately tailored to address caregivers' specific needs [8]. Consequently, access to appropriate support for dementia caregivers remains restricted [9]. Although caregivers could get some respite from older adult services, service quotas are consistently constrained leading to extensive waiting lists [8]. In addition, relying solely on external services is insufficient in addressing the inherent complexities of health issues associated with caregiving, as caring for individuals with dementia entails significant burdens and emotional involvement. Chinese dementia caregivers exhibit a high level of tolerance and prefer to independently tackle challenges rather than seeking assistance [10]. They tend to prioritize the care recipient, feeling guilty about diverting attention towards their own well-being due to filial piety [11, 12]. Consequently, it is unsurprising that these caregivers are reluctant to seek help even when they acknowledge their own health problems.

To address the aforementioned issues, self-help interventions may serve as a viable approach to enhance caregiver well-being. Bibliotherapy, a non-pharmacological intervention employing therapeutic reading materials, has shown promise in improving psychological health [13]. Yet, all the published studies are based on western culture. Given that caregiving experiences are influenced by cultural and sociological factors, further investigation is warranted within the Chinese population. In response to this need, we have developed a bibliotherapy manual (i.e., caregiver workbook) and demonstrated its feasibility and preliminary efficacy among informal caregivers in China [11, 14]. Moreover, participants expressed the need for incorporating the caregiver workbook with explanatory videos, i.e., expanding the traditional reading material-based bibliotherapy to an electronic mode, in order to enhance accessibility and usability of the intervention.

Our systematic review also revealed that electronic bibliotherapy can effectively lead to significant improvements in caregiver mental health [13]. The delivery mode of electronic bibliotherapy included webpage or videos. However, the number of published studies on this topic remains limited, with only six available. Given the widespread use of smartphones, digital social media platforms such as WhatsApp, Facebook, Twitter, and WeChat, have demonstrated their effectiveness in delivering health interventions [15]. However, it is important to note that these platforms have predominantly been utilized for disseminating health promotion messages [16, 17]. The effect of employing social media as a platform for delivering bibliotherapy remains untested. Therefore, this proposed study will transform bibliotherapy into a format delivered through social media by developing video materials and utilizing social media as a platform for intervention delivery. The efficacy of bibliotherapy delivered via social media will be assessed through a randomized controlled trial.

To the best of our knowledge, this is the first study to employ social media-based bibliotherapy among informal caregivers of people with dementia. If proven to be effective, this study will serve as a steppingstone towards a larger research project that utilizes technology-based bibliotherapy to enhance holistic health for diverse caregiver populations. Given its potential cost-effectiveness and minimal professional involvement required, bibliotherapy can be accessed by caregivers at their convenience and location, hence, strong generalizability is expected in the future.

Objectives

This study aims to investigate the efficacy of social media-based bibliotherapy in enhancing mental health for informal caregivers of people with dementia.

Methods

Trial design

A randomized controlled trial. This trial has been registered at ClinicalTrials.gov (ref No.: NCT06327022). The reporting of this clinical trial adheres to CONSORT guideline.

Participants

Eligibility criteria: The inclusion criteria include (1) caregivers providing regular care to individuals with mild to moderately severe dementia (Global Deterioration Scale = 4 ~ 6 [18] of any type, requiring at least five hours per week for a minimum duration of six months; (2) aged 18 or above; (3) not receiving payment for caregiving services rendered; (4) assisting with at least one daily activity of the care recipient; (5) possessing reading ability; and (6) having utilized social media platforms such as WhatsApp/Facebook/Twitter/Instagram/WeChat for more than six months. Exclusion criteria encompassed the following: (1) caregivers with unstable physical or mental conditions; (2) caregivers unable to communicate logically; and (3) involvement in another interventional study.

Sample size calculation: In order to achieve a statistical power of 90% and a two-sided significance level of 5%, assuming a moderate effect size (f = 0.25) for time and group interaction effects, a sample size of 23 per group will be needed. Considering an anticipated attrition rate of 20% in our pilot study [14], the estimated sample size in each group amounts to 28. Consequently, we targeted at recruiting 60 participants in this study.

Intervention and control conditions

The intervention group received eight weekly e-bibliotherapy sessions while continuing to receive the usual service provided by community centers (Supplementary Table S1). Each week, participants were required to read a chapter of the caregiver workbook, watch an explanatory mini video prepared by our research team (limited to 5 min in length), and complete the corresponding assignment. The caregiver workbook was developed and pilot tested in our previous study conducted by our team [14]. The explanatory mini videos were exclusively for this project and uploaded to YouTube on our private channel accessible only to participants with a project ID (Supplementary Fig. S1). The assignments included post-session exercises and weekly task completion checkup questions that were set up using Qualtrics, a web-based software for creating surveys.

In the pre-program briefing session, caregivers in the intervention group were given the opportunity to select their preferred medium for receiving e-bibliotherapy, and ultimately all caregivers opted for WhatsApp as their chosen platform. Furthermore, 20 caregivers requested hardcopy versions of the caregiver workbook to facilitate convenient reading and note-taking, while 10 others requested softcopies to be sent directly to their email addresses. The intervention materials were distributed to participants every Wednesday, along with a release reminder by WhatsApp, and a Qualtrics online survey link. The survey included weekly task completion check-up questions tailored to the content of each chapter. These questions comprised a general inquiry about task completion and detailed questions specific to the chapter's content. If caregivers provided correct answers, they received feedback such as "Well done, you are right!"; otherwise, they were given encouraging messages like "Sorry, that's incorrect. Please refer to page * of the caregiver workbook for the correct answer." If it was observed that the weekly task remained unfinished by the following Tuesday, a gentle reminder would be sent to them. In the event that participants encounter any difficulties during the weekly session, telephone coaching will be arranged for them.

The control group participants exclusively received routine care from community services, such as respite services, emotional support and counseling [19]. Subsequently, the control group was provided with the same caregiver workbook and videos upon project completion.

Implementation

Participant recruitment

Participants were consecutively recruited using convenience sampling from September 2022 to November 2023 in Hong Kong. Due to social distancing policies during COVID-19, it was impossible to rely solely on community centers for participant recruitment. Hence, participants were recruited through diverse methods, including community and elderly service center staff referrals, caregiver responses to designated Facebook page posters, and university bulletin boards. Interested caregivers underwent telephone or on-site screening for eligibility assessment.

Data collection

Quantitative data collection Eligible caregivers were assessed at baseline (T0) and immediately after the intervention (T1). Written informed consent was obtained from each participant prior to random group assignment, and T0 data were collected using Qualtrics, an online survey software. The survey links were distributed via WhatsApp for participant self-administration. To ensure confidentiality, a subject ID number unrelated to personal information was assigned to each participant. T1 data were collected within two weeks of completing the intervention, using Qualtrics online survey.

Randomization Simple randomization was employed, wherein a statistician utilized R software to generate a set of random numbers. The intervention group was designated as "group A", while the control group was labeled as "group B".

Group allocation and allocation concealment The random numbers were securely stored in an encrypted hard disk and managed by the statistician. Following the acquisition of informed consent and completion of baseline assessment, the participant was assigned to their respective group based on their subject ID.

Blinding The research assistant and community health care professionals were blinded to the group label of "group A" and "group B". However, due to the nature of the intervention, it was unfeasible to implement a double-blind procedure for the participants and the interventionist.

Intervention fidelity A comprehensive set of intervention fidelity strategies encompassing five key aspects, namely intervention design, provider training, intervention delivery, receipt of intervention, and enactment of treatment skills were implemented. The development of the intervention design was informed by a series of rigorous systematic reviews [13, 20, 21], while the effectiveness and feasibility of the intervention manual were evaluated through a pilot study [14]. The structured manuals and instructional videos were utilized for delivering the intervention. To ensure fidelity to the protocol, research assistants assessed participants' adherence to the assigned tasks and proficiency in acquiring treatment skills through regular monitoring, i.e., the post-session exercises and weekly task completion checkup questions.

Qualitative data collection Qualitative data were collected at T1 through individual interviews to explore their experiences participating in this study. Following the acquisition of informed consent, a research coordinator scheduled a 30-minute to 1-hour interview via Zoom video conferencing, a secure online communication platform. Participants from the intervention group were purposefully selected based on their completion status so that caregivers with different weekly task completion rates could be recruited, thereby avoiding biased data collection. To ensure focus during the interviews while allowing for exploration of relevant ideas, a semi-structured interview guide was employed. The questions aimed to investigate caregivers' perceptions of the intervention, encompassing their overall impressions, thoughts on the intervention's content, duration, implementation method, and suggestions for improvement. All interview questions were open-ended in nature followed by additional probing based on participant's response (Supplementary Table S2). In case the participants encountered any difficulties in responding or providing further details, the interviewer made efforts to rephrase the question and allowed sufficient time for a response. Participants were encouraged to continue sharing their thoughts if they had not fully completed their explanation, until natural break. Comprehensive notes were taken during the interviews, which were audio-recorded and securely stored in the university's cloud-based platform to ensure utmost safety and confidentiality. The recordings were transcribed verbatim while ensuring complete deidentification of participants' information. Thematic saturation served as the criterion for terminating the interviews.

Outcomes

Mental health was assessed using the Chinese version of the Depression Anxiety Stress Scale-21 (DASS-21), a 4-point Likert scale consisting of 21 items that measure levels of depression, anxiety, and stress in participants. Higher scores indicate greater severity of mental health problems. The overall scale demonstrated high internal consistency with a Cronbach's alpha coefficient of 0.944, while subscales for depression, anxiety, and stress showed good reliability with alphas of 0.906, 0.830, and 0.859 respectively [22].

The health-related quality of life was assessed using the 12-item Short Form Survey (SF-12), which is commonly employed as a measure of both quality of life and proxies for health status. SF-12 comprises two domains, namely the physical component summary and mental component summary. Notably, SF-12 has been validated as a reliable and sensitive instrument for assessing the Hong Kong Chinese population [23].

Caregiving appraisal was assessed using the Chinese version of the Caregiving Appraisal Scale [24], a 26-item Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores on this scale indicate more positive caregiving appraisal. The scale comprises four subscales: caregiving burden, caregiving satisfaction, caregiving mastery, and caregiving impact. The internal consistency of the total scale was satisfactory with a Cronbach's α coefficient of 0.837. The α coefficients for each subscale were as follows: subjective burden (0.899), caregiving impact (0.760), caregiving mastery (0.420), and caregiving satisfaction (0.862).

The psychological well-being was assessed using the shorter Chinese version of Ryff's psychological well-being scale [25]. This scale comprises 18 items and encompasses six subscales: positive relations with others, autonomy, environmental mastery, personal growth, purpose in life, and self-acceptance. Participants rated their agreement on a Likert 6-point scale ranging from strongly disagree (1) to totally agree (6). Higher scores indicate greater levels of psychological well-being. The internal consistency reliability of the scale was good (α for the overall scale = 0.937; αs for subscales were as follows: personal growth = 0.780; autonomy = 0.719; environmental mastery = 0.874; purpose in life = 0.853; self-acceptance = 0.828).

Demographics caregiver's age, gender, employment status, kinship relationship, educational attainment, duration of caregiving, care intensity; care-recipient's age and gender.

Data analysis

For the quantitative data analysis, R software was utilized. Descriptive statistics were employed to analyze the baseline data. Between-group differences were assessed at baseline. The assumption of normality for ordinal or ratio variables was examined using the Shapiro-Wilk test. If the assumption of normality was not violated, an independent t-test was conducted. In cases where non-normal ratio variables and ordinal variables were involved, the Mann-Whitney U test was performed instead. Nominal variables were analyzed using χ^2 tests. Descriptive statistics were used to examine feasibility outcomes. Generalized estimating equation (GEE) models were applied to assess intervention efficacy. A significance level of 5% was adopted in all analyses.

For the qualitative analysis, the verbatim transcription of the recorded interviews was completed within one week of each interview and the principal investigator verified the accuracy of the transcriptions. An inductive content analysis approach was applied, involving logical reasoning and consistent comparison to identify shared themes and categories [26]. Two researchers meticulously reviewed the test separately, applying codes to comprehensively describe its contents [27]. Codes representing similar ideas were organized into categories, which were further classified into boarder themes. By combining categories and themes, general statements were formulated to describe the phenomenon [26]. To ensure the rigor and reliability of the analysis process, any discrepancies in coding and interpretation were resolved through discussions with the principal investigator to achieve consensus on the categories and themes. Saturation of the categories and themes was achieved during the data collection process.

Results

Participant flow

In total, 111 interested caregivers registered for eligibility screening, out of which 79 accepted the screening. Among these, 60 caregivers consented to participate in the study and were randomized into the intervention or control groups. The reasons for exclusion included not meeting the inclusion criteria ($n = 12$), declining to participate due to perceived lengthy intervention period ($n = 4$), and could not be reached after screening ($n = 3$). Two consented participants from the control group dropped out before baseline data collection; one due to hospitalization of the care recipient and another without providing a reason. Hence, 58 participants received their allocated interventions, with 30 in the intervention group, and 28 in the control group. Additionally, one participant from the control group withdrew from the study following the decease of the care recipient (Fig. 1).

Baseline data

The average age of caregivers was 57.41 (SD, 13.63), with the majority being female (79.3%). Half of the caregivers were working caregivers, with 27.6% working full-time, and 22.4% working part-time, while 41.4% were retired and 8.6% were jobless. A significant proportion of caregivers had attained at least a middle school education level or higher qualifications (91.4%). The caregivers consisted predominantly of daughters (44.8%) and spouses (20.7%) of the care recipients. On average, they have provided care for the recipients for a duration of 5.94 (SD, 4.99) years, dedicating approximately 10.71 (SD, 2.89) months per year and an average of 9.41 (SD, 7.98)

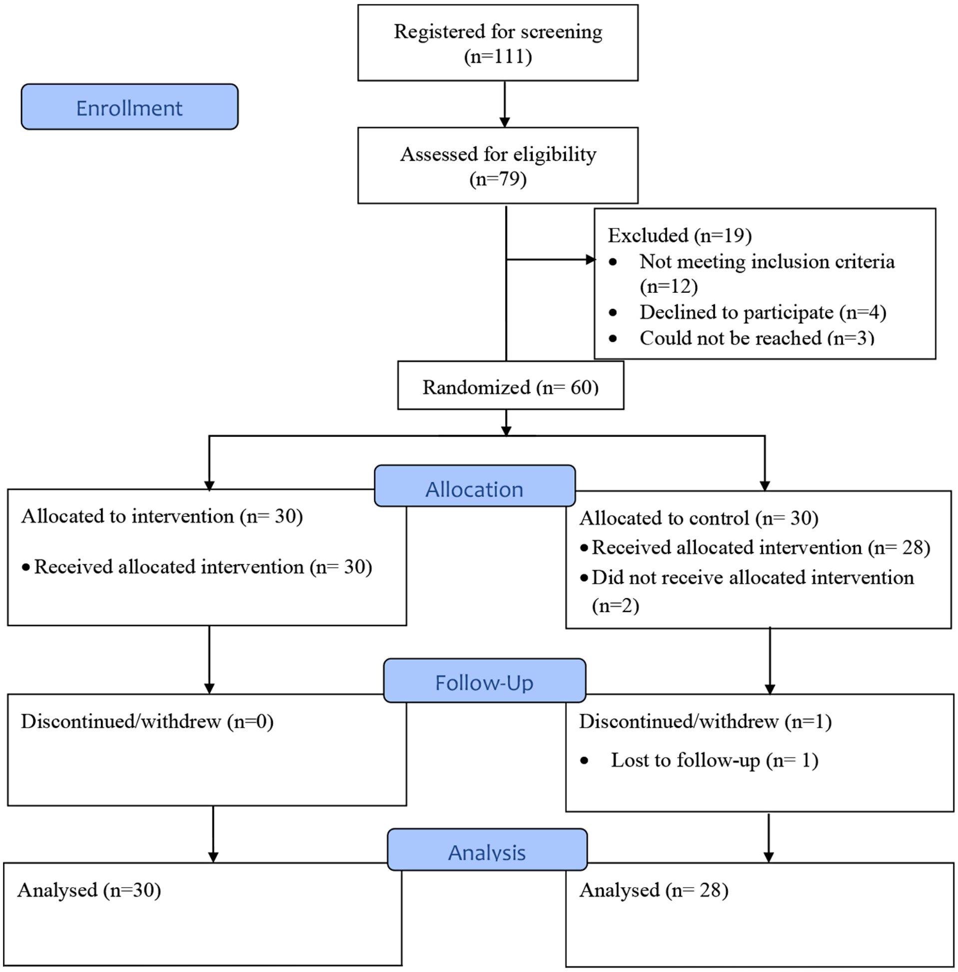

Fig. 1 Flow diagram of this study

hours per day to caregiving duties. The mean age of care recipients was 82.79 (SD, 9.41). There were no statistically significant differences in demographics between the intervention and control groups (Table 1), and baseline outcomes of interest also showed no significant differences (Table 2).

Outcomes and estimation

Of the 79 potential participants who assessed for eligibility, 60 agreed to join the project, and were randomized to the intervention ($n = 30$) or control groups ($n = 30$). All participants in the intervention group successfully completed the study. However, three dropouts were observed in the control group, resulting in a dropout rate of 5%. Regarding the mode of intervention delivery, participants favored a combination of manual instructions and daily use messenger applications WhatsApp. Conversely, social media platforms such as Facebook were not preferred due to either lack of an account or reluctance to share personal account information. The overall completion rate for weekly tasks was generally satisfactory; most participants were able to complete all or most of the video watching (97.05%) and manual reading (87.91%), while over half managed to finish all or most of the exercise sessions (56.28%) (Fig. 2). The reason for non-completion of video watching and manual reading was attributed to participants' busy schedules. Similarly, the main factor contributing to incomplete exercise completion was also participants' busy schedules, with secondary reasons including fatigue, difficulties in writing, or perceived lack of necessity for completing exercises. Regarding weekly task completion rates for individual sessions, they ranged from 75.57 to 84.47%, with an average rate of 79.32%. Additionally, the correct rates for post-session exercises were consistently high, ranging from 75.32 to 98.66%.

Efficacy of social media-based bibliotherapy

The social media-based bibliotherapy demonstrated efficacy in enhancing the mental health of caregivers. Significant group-by-time interaction effects were observed for both the total score of DASS (Wald $\chi^2 = 8.918$, $p = .003$) and its subscales, including caregiver stress (Wald

Table 1 The demographics of participants at baseline ($n = 58$)

	Total	**Intervention group ($n = 30$)**	**Control group ($n = 28$)**	**t/χ^2(df)/z**	***p***
	***n* (%)/M(SD)**	***n* (%)/M(SD)**	***n* (%)/M(SD)**		
Caregiver age	57.41 (13.63)	55.4 (14.80)	59.57 (12.16)	1.168	0.248
Caregiver gender				3.083 (1)	0.053
Female	46 (79.3%)	27 (90.0%)	19 (67.9%)		
Male	12 (20.7%)	3 (10.0%)	9 (32.1%)		
Caregiver employment status				7.759 (3)	0.051
Working full time	16 (27.6%)	11 (36.7%)	5 (17.9%)		
Working part time	13 (22.4%)	3 (10.0%)	10 (35.7%)		
Retired	24 (41.4%)	4 (13.3%)	1 (3.6%)		
Jobless	5 (8.6%)	12 (40.0%)	12 (42.9%)		
Caregiver education level (n, %)				0.366	0.714
Primary school or lower	5 (8.6%)	3 (10.0%)	2 (7.1%)		
Middle school	24 (41.4%)	11 (36.7%)	13 (46.4%)		
Diploma degree	8 (13.8%)	4 (13.3%)	4 (14.3%)		
Undergraduate	10 (17.2%)	6 (20.0%)	4 (14.3%)		
Post-graduate	11 (19.0%)	6 (20.0%)	5 (17.9%)		
Relationship with the care-recipient (n, %)				5.866 (4)	0.209
Spouse	12 (20.7%)	6 (20.0%)	6 (21.4%)		
Son	5 (8.6%)	1 (3.3%)	4 (14.3%)		
Daughter	26 (44.8%)	17 (56.7%)	9 (32.1)		
Daughter in law	3 (5.2%)	2 (6.7%)	1 (3.6%)		
Other relative	12 (20.7%)	4 (13.3%)	8 (28.6%)		
Duration of caregiving (years) (M, SD)	5.94 (4.99)	5.85 (5.37)	6.036 (4.64)	0.140	0.889
Average months of caregiving each year (M, SD)	10.71 (2.89)	10.93 (2.50)	10.46 (3.28)	−0.614	0.542
Average hours of caregiving each day (M, SD)	9.41 (7.98)	10.2 (8.10)	8.55 (7.91)	−0.782	0.437
PWD age (M, SD)	82.79 (9.41)	83.17 (9.12)	82.39 (9.85)	−0.311	0.757
PWD gender				0.000 (1)	1.00
Female	41 (70.7%)	21 (70%)	20 (71.4%)		
Male	17 (29.3%)	9 (30%)	8 (28.6%)		

Note: PWD: people with dementia

$\chi^2 = 4.198$, $p = .040$), anxiety (Wald $\chi^2 = 7.667$, $p = .006$), and depression (Wald $\chi^2 = 9.127$, $p = .003$). However, only the caregiving burden subscale showed significant improvement in caregiving appraisal (Wald $\chi^2 = 4.954$, $p = .026$). Although the efficacy on health-related quality of life was not statistically significant, it is worth noting that the mental component subscale approached significance with a *p*-value of 0.057. Unfortunately, this study did not achieve a significant effect on improving psychological well-being (Table 3).

Participants' perceptions in joining the social media-based bibliotherapy project

A total of twenty caregivers were interviewed until data saturation was reached, comprising of eighteen female and two male caregivers. The average age of the participants was 54.25 (14.48) years. Consistent with the proportions observed in the baseline assessment, a majority of the participants were daughters (55%), followed by other relatives (20%), spouses (15%), sons (5%), or daughters-in-law (5%). In terms of education level, participants had completed middle school (35%), postgraduate studies (30%), undergraduate degrees (30%), diploma programs (10%), or primary school education (5%). On average, they had been providing care for individuals with dementia for 5.4 years (SD, 5.16), spending an average duration of 10.70 months (SD, 2.78). The caregiving intensity amounted to an average of 9.25 h per day (SD, 7.45).

The qualitative interviews further demonstrated the acceptability of social media-based bibliotherapy. Caregivers responded positively to the intervention, perceiving it as a source of relaxation and satisfaction. The manual was regarded as valuable and effective, enhancing caregivers' knowledge about dementia and facilitating their caregiving practices. The flexibility in training scheduling was highly appreciated. The intervention videos were universally praised for their comprehensiveness, conciseness, engagement, and liveliness. Caregivers reported significant changes in their approach to caregiving, emphasizing the importance of self-prioritization and self-relaxation. They also experienced a shift in perspective towards more positive caregiving attitudes

Table 2 The outcomes of interest at baseline ($n = 58$)

Outcome variable	Range	Total		Intervention group		Control group		t/z	*p*
		M	**SD**	**M**	**SD**	**M**	**SD**		
Mental health	0–63	16.16	11.08	15.43	10.71	16.93	11.61	0.510	0.612
– Stress	0–21	7.41	4.03	7.20	3.84	7.64	4.28	0.416	0.679
– Anxiety	0–21	3.90	3.57	3.93	3.89	3.86	3.27	− 0.080	0.936
– Depression	0–21	4.84	4.47	4.30	3.76	5.43	5.13	0.960	0.341
Caregiving appraisal	26–130	82.84	14.10	83.63	12.06	82	16.20	− 0.438	0.663
– Caregiving impact	5–25	14.26	3.50	14.20	3.31	14.32	3.75	0.131	0.896
– Caregiving mastery	4–20	13.91	2.46	14.23	2.24	13.57	2.67	-1.025	0.310
– Caregiving satisfaction	5–25	17.36	3.81	17.27	3.62	17.46	4.08	0.195	0.846
– Caregiving burden	12–60	36.17	8.53	35.67	7.42	36.71	9.69	0.464	0.644
Health-related quality of life									
– Physical component scale		43.83	10.04	42.41	8.67	45.35	11.28	1.118	0.268
– Mental component scale		36.90	9.49	37.16	8.69	36.63	10.43	− 0.211	0.834
Psychological well-being	18–108	77.86	13.01	78.40	12.09	77.29	14.14	− 0.323	0.748
– Positive relations with others	3–18	12.97	2.80	13.10	3.26	12.82	2.26	− 0.375	0.709
– Autonomy	3–18	12.09	2.39	11.83	2.10	12.36	2.67	0.833	0.408
– Environmental mastery	3–18	13.43	2.67	13.70	2.41	13.14	2.94	− 0.792	0.432
– Personal growth	3–18	13.86	2.83	14.23	2.64	13.46	3.02	-1.034	0.305
– Purpose in life	3–18	12.79	2.76	12.87	2.80	12.71	2.77	− 0.208	0.836
– Self-acceptance	3–18	12.72	2.66	12.67	2.54	12.79	2.83	0.169	0.867

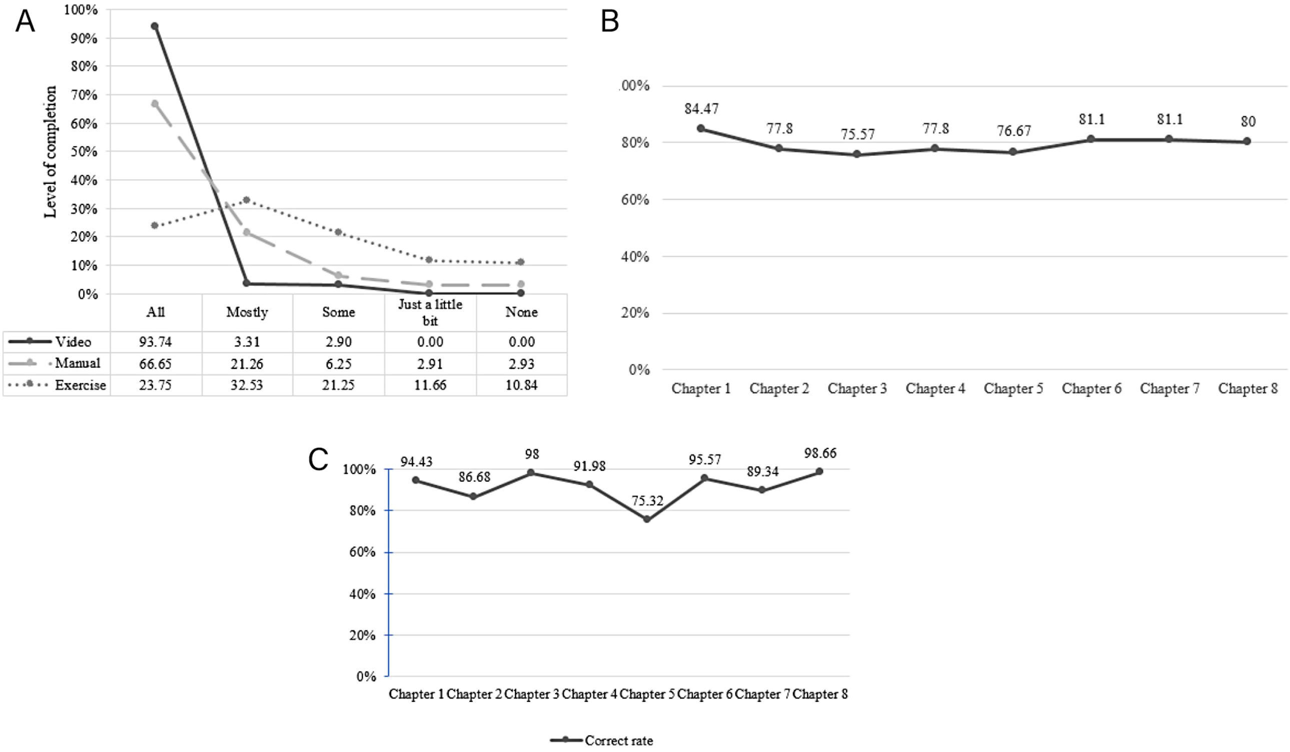

Fig. 2 Completions of weekly tasks. (**A**) General completion rates. (**B**) Completion rates of chapters. (**C**) Correct rates per chapter exercise

which resulted in a more relaxed caregiving experience overall. Furthermore, caregivers perceived that the social media-based bibliotherapy had a positive impact on their coping strategies by improving their ability to manage patient behavioral problems, communication skills, and seek appropriate assistance.

Suggestions were proposed for enriching the content, including the incorporation of comprehensive social support information, rare situation examples, and additional information on economics and legal issues. Moreover, participants expressed interest in integrating more interactive elements into the videos to enhance engagement.

Table 3 Efficacy of social media-based bibliotherapy

Measures	Mean (SE)		Tests of GEE model effects					
			Group effect		Time effect		Group-by-time effect	
	Baseline	post	Wald χ^2	*p*	Wald χ^2	*p*	Wald χ^2	*p*
Mental health	16.18 (1.44)	16.52 (1.58)	6.834	0.009	9.031	0.003	8.918	**0.003**
– Stress	7.42 (0.53)	7.67 (0.59)	4.339	0.037	1.828	0.176	4.198	**0.040**
– Anxiety	3.90 (0.46)	4.15 (0.50)	4.934	0.026	4.221	0.040	7.667	**0.006**
– Depression	4.86 (0.58)	4.71 (0.61)	8.435	0.004	14.880	< 0.001	9.127	**0.003**
Caregiving appraisal	82.82 (1.85)	83.21 (1.95)	2.523	0.112	2.595	0.107	3.083	0.079
– Caregiving impact	14.26 (0.46)	14.23 (0.49)	0.042	0.838	0.023	0.880	0.012	0.914
– Caregiving mastery	13.90 (0.32)	13.69 (0.29)	5.111	0.024	0.055	0.814	1.023	0.312
– Caregiving satisfaction	17.37 (0.50)	17.51 (0.38)	0.055	0.814	0.346	0.556	0.211	0.646
– Caregiving burden	36.19 (1.12)	35.78 (1.16)	3.881	0.049	5.662	0.017	4.954	**0.026**
Health-related quality of life								
– Physical component scale	43.88 (1.30)	39.89 (0.85)	0.105	0.746	3.613	0.057	1.227	0.268
– Mental component scale	36.89 (1.24)	38.02 (1.10)	5.854	0.016	6.302	0.012	3.634	0.057
Psychological well-being	77.84 (1.70)	77.60 (1.50)	1.083	0.298	0.244	0.622	0.521	0.470
– Positive relations with others	12.96 (0.36)	13.29 (0.32)	2.810	0.094	1.892	0.169	1.353	0.245
– Autonomy	12.10 (0.31)	12.26 (0.28)	0.024	0.878	1.143	0.285	0.921	0.337
– Environmental mastery	13.42 (0.35)	13.14 (0.32)	0.080	0.777	2.348	0.125	0.301	0.583
– Personal growth	13.85 (0.37)	13.78 (0.32)	1.257	0.262	0.050	0.823	0.009	0.923
– Purpose in life	12.79 (0.36)	12.69 (0.30)	0.509	0.476	0.006	0.938	0.189	0.664
– Self-acceptance	12.73 (0.35)	12.41 (0.33)	1.183	0.277	0.081	0.776	2.332	0.127

Same as the quantitative studies, the main barriers encountered in completing the weekly exercises were attributed to busy caregiving schedules and difficulties associated with writing down exercises on smartphones. To address these concerns, suggestions for improvement included providing a user-friendly application that serves as a one-stop solution. Expectations for professional support has also been expressed (Supplementary Table S3).

Safety and harms

The intervention was generally deemed safe, with no reported occurrence of adverse events.

Discussion

Social media-based bibliotherapy was demonstrated to be an effective way for supporting informal caregivers of individuals with dementia, manifested by the favorable recruitment and retention rates. These rates surpassed those reported in our previous review [13] and pilot study utilizing traditional manual intervention delivery methods [14]. This may be attributed to the tailored intervention components designed to address caregivers' daily challenges, which likely motivated their participation. Additionally, the flexible nature of the intervention mode alleviated any perceived burden associated with joining interventions, effectively addressing critical recruitment challenges faced by dementia caregivers (Joshi et al., 2023). Weekly task completion was also promising, as most participants successfully completed their assigned tasks. Notably, videos and manuals emerged as highly preferred modes of delivery, comparable to findings from previous video-based bibliotherapy studies [28]. However, it is worth mentioning that approximately 22.5% of caregivers completed only a small portion or none at all of the post-reading exercises due to busy schedules or difficulties encountered when writing down tasks on mobile devices. To enhance usability and convenience for users, we suggest exploring more user-friendly technologies such as voice input for electronic bibliotherapy. Besides, Chap. 5 had a relatively lower completion rate, probably because the contents were relatively descriptive as compared to other chapters. However, in the qualitative interviews, caregivers mentioned that by participating in this study, they realized they have the "right" to care for themselves, and to be unhappy, as introduced in this chapter. Hence, more examples are suggested to the chapter's usability.

In terms of social media usage, WhatsApp was the preferred platform among all participants. Surprisingly, other platforms such as Facebook were not favored in this study. This could be attributed to the fact that the participants primarily consisted of middle-aged and older adults, with an average age of 57.41 years. Consequently, it may have been challenging for them to adopt and learn a new technique that they do not regularly use in their daily lives. Participants who already possessed a Facebook account also expressed concerns regarding privacy issues associated with divulging their personal account numbers to enroll in the research program due to their inclination towards sharing daily life updates on Facebook. These findings align with a previously published systematic review which identified barriers faced by older adults when using Facebook, including privacy concerns and preference for familiarity [29]. According to data from Statista, WhatsApp emerged as the leading social media platform in Hong Kong with an impressive monthly usage rate of 80% [30]. However, despite its convenience, WhatsApp also has limitations in delivering electronic bibliotherapy due to caregivers' difficulties in utilizing it for writing weekly assignments and the research team's inability to keeping track of weekly exercise tasks. Therefore, it is recommended to develop a tailored standalone application that offers enhanced readability [31]. Other technologies, such as virtual reality, has also been explored in supporting dementia caregivers [32]. Incorporating these technologies with bibliotherapy may be another area worth exploration in the future.

The significant efficacy in improving stress, anxiety, and depression among dementia caregivers may be attributed to the tailored intervention that addresses their specific needs and provides guidance for managing daily caregiving challenges. Caregivers reported finding the skill training and relaxation techniques useful during qualitative interviews. This finding aligns with a network meta-analysis [33], which demonstrated the effectiveness of interventions based on cognitive behavioral therapy mechanisms such as acceptance and commitment therapy and behavioral activation in reducing caregiver depressive symptoms. Bibliotherapy shares a similar cognitive reframing mechanism with these interventions but requires less therapist involvement [14]. However, while a systematic review identified psychoeducation as the only effective intervention for improving caregiver anxiety, this study also found significant effects through social media-based bibliotherapy [33]. This could be due to real-life examples in the bibliotherapy manual directly addressing users' difficulties and providing strategies to manage problems that contribute to caregiver stress and anxiety [13].

The efficacy in improving health-related quality of life appears promising, particularly on the mental component scale with p-values approaching 0.05. Although the sample size was adequate for the research design employed, the relatively small sample size may have limited the statistical power to detect more significant changes in mental health components. A larger sample size might be necessary to capture meaningful differences in this domain. Nevertheless, no significant effect was observed on the physical component scale. This could be attributed to bibliotherapy primarily addressing cognitive and psychological factors rather than directly targeting physical health, as evidenced by the lack of significant effect on the physical health component of SF-12. This finding is consistent with previous research on psychosocial interventions which consistently demonstrate more pronounced effects on the mental component summary compared to the physical component [34]. To improve the physical component summary, it is recommended to incorporate intervention components such as physical exercises and nutrition [35].

The qualitative data revealed shifts in caregiving appraisals, as evidenced by changes in their attitude towards caregiving challenges and increased attention to their own health. These findings were corroborated by the quantitative data, which demonstrated a significant reduction in perceived caregiving burden. However, unlike our previous pilot study [14], the efficacy on other subscales of caregiving appraisal did not reach statistical significance. This discrepancy may be attributed to the unique circumstances of conducting this trial during the COVID-19 pandemic, which imposed greater demands on caregivers due to social isolation and limited access to social support. Consequently, it became more challenging for caregivers to perceive positive caregiving appraisals such as satisfaction. Additionally, the inclusion of a higher proportion of working caregivers in this study might have contributed to this difference as well.

An intriguing finding of this study is that, despite the promising efficacy in enhancing caregiver mental health, the efficacy of social media-based bibliotherapy on improving psychological wellbeing was surprisingly insignificant. This could potentially be attributed to the fact that Ryff's psychological wellbeing scale was not specifically designed for caregivers, rendering it less sensitive within this particular population. It is also important to note that Ryff's scale primarily assesses positive aspects of caregiver status within the eudaemonic well-being model, such as environmental mastery, autonomy, and positive relations with others [25]. These dimensions may be constrained due to social isolation compared to pre-COVID conditions. Previous review has indicated that interventions directly aligned with Ryff's conceptual model tend to have the greatest impact on changes in eudaemonic wellbeing [36]. Therefore, incorporating components relevant to Ryff's model is recommended for enhancing psychological wellbeing. Additionally, the relatively small sample size may contribute to these results.

Limitations and implications

Although social media-based bibliotherapy is easily accessible for caregivers, there are several limitations that cannot be overlooked. Due to the social isolation during COVID, convenient sampling was employed for participant recruitment, potentially leading to selection bias. The caregivers recruited tended to have relatively high education levels, probably because higher education is associated with greater health literacy and awareness, enabling these individuals to proactively seek help via clinical trials. Furthermore, the relatively small sample size could potentially limit the generalizability of our findings. Additionally, the relatively small sample size might limit the generalizability of our findings. Since caregivers, regardless of co-resident status, experience caregiving distress when caring for a family member with dementia, we did not investigate the living arrangements between caregivers and care-recipients, nor whether they had domestic helpers. Consequently, we were unable to analyze the intervention effects on specific subgroups of caregivers. Future large-scale randomized controlled trials are recommended to further investigate these factors and perform subgroup analyses to evaluate the intervention effects. Given the nature of our interventions, double-blinding was not feasible and thus we could not avoid the Hawthorne effect. For future research endeavors, it is recommended to include more representative samples with larger sizes. The use of WhatsApp does not allow us to track participants' study progress, such as the frequency of reviewing intervention materials. Consequently, we had to rely on self-reported learning progress questions to monitor their completion of weekly tasks, which may introduce potential reporting bias. To address this issue, it is imperative to develop telephone monitoring or a dedicated application capable of effectively tracking user activities for future research [14, 31].

Despite these limitations, this study introduced an innovative and user-friendly intervention for informal caregivers of people with dementia. It would be especially helpful in regions where support services for caregivers are scarce. Caregivers experiencing challenges with caregiving duties and exhibiting mental health issues can utilize social-media-based bibliotherapy as a self-help tool. After appropriate training, healthcare professionals can serve as facilitators for bibliotherapy, thereby extending the reach and benefits of this intervention to a broader population.

Conclusion

This study represents one of the first endeavors in utilizing social media as a platform for delivering bibliotherapy, and it is the first study to employ this approach among informal caregivers of individuals with dementia. The utilization of WhatsApp as an electronic medium has demonstrated its acceptability and efficacy in this context. Notably, caregivers exhibited significant improvements in stress, anxiety, depression, and caregiving burden. Although the efficacy on other dimensions of caregiving appraisal remains somewhat limited, qualitative interviews revealed changes in caregiving appraisals. However, the current evidence on improvements in health-related quality of life and psychological well-being remains inconclusive, necessitating further investigation within a larger sample size, a modified intervention protocol, and a caregiver-sensitive instrument. Given its convenience, strong generalizability is expected in the future.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12912-025-02778-7.

Supplementary Material 1

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Author contributions

Conceptualization: SW; Design of the work: SW, ISHL, DSKC; Data analysis: SW, ISHL, AF, WJ; Draft of the work: SW, ISHL; Substantively revise the work: SW, ISHL, DSKC, AYML. All the authors have approved the submission of this manuscript.

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Data availability

Data are reported in this manuscript.

Declarations

Ethics approval and consent to participate

Ethical approval for this project was obtained from the Human Subjects Ethics Committees of The Hong Kong Polytechnic University. Prior to data collection, participants received a comprehensive briefing that included both verbal and written information outlining the objectives, methods, and procedures of the project. Participants were provided with clear explanations regarding the recording process, potential use of collected data, secure storage duration in password-protected locations, as well as the potential benefits and associated risks of their participation. Participants were explicitly informed of the voluntary nature of their participation in this project, emphasizing their right to withdraw at any time without providing justification. All data collected were treated with utmost confidentiality and anonymity was maintained throughout the study. The project prioritized participant safety. Furthermore, participants were guaranteed that their personal identifiers would not be utilized in all project-related reports and publications to safeguard their privacy. Informed consent to participate was obtained from all of the participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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