

# Does therapeutic writing help people with long-term conditions? Systematic review, realist synthesis and economic considerations

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## Scientific summary

### Therapeutic writing for long-term conditions

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# Scientific summary

## Background

Long-term conditions (LTCs) may cause reduced health-related quality of life (HRQoL) and considerable health service expenditure. Alternative and complementary therapies, other than the usual medical treatments, are increasingly being introduced within clinical practice. Therapeutic writing (TW) has been widely reported in psychology textbooks and scientific journals as having the potential to improve physical and mental health but its effectiveness in people with LTCs is not clear.

## Objectives

To establish the clinical effectiveness and cost-effectiveness of TW in LTCs, through systematic reviews and economic evaluation, and to evaluate context and mechanisms by which it might work, through realist synthesis.

## Methods

A protocol was lodged with PROSPERO – CRD42012003343. A group of practitioner experts informed and validated all review phases in regular meetings and compared research findings with their UK clinical experience.

## Data sources

### Systematic reviews

Electronic searches were conducted for primary studies in the following databases: MEDLINE, EMBASE, PsycINFO, CAB Abstracts, Physiotherapy Evidence Database, Published International Literature on Traumatic Stress, The British Library's Electronic Table of Contents, Science Citation Index (SCI), Social Sciences Citation Index, Linguistics and Language Behavior Abstracts, Periodicals Index Online, Applied Social Sciences Index and Abstracts, Education Resources Information Center, Allied and Complementary Medicine Database, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Central Register of Controlled Trials and Database of Abstracts of Reviews of Effects from inception to March 2013. Additional searches to January 2015 were made in those databases yielding all of the previous primary studies (MEDLINE, EMBASE, PsycINFO, CINAHL, The Cochrane Library and SCI). Additional hand-searches and cross-referencing were implemented for both sets of searches. For the realist synthesis, searches were conducted from the database created from the 2013 searches. After initial screening, further purposive and iterative searches linked to the included studies in the effectiveness review were performed: related papers and relevant papers cited in the reference lists were used.

### Study selection (inclusion criteria)

One reviewer carried out first and second screenings, and 10% of studies were screened by a second reviewer working independently.

### Systematic reviews

We included any type of comparative study of TW compared with no writing, waiting list controls, attention controls or placebo writing, in patients with any diagnosed LTCs. Studies had to report at least one of the following: relevant clinical outcomes; quality of life (QoL); health service use; psychological,

behavioural or social functioning; adherence; or adverse events related to the TW intervention. For the resource-use systematic review, those studies included in the effectiveness systematic review reporting any resource-use outcomes were included.

### Realist synthesis

Any type of study design assessing TW in people with LTCs was of interest.

### Data extraction

#### Systematic review

One reviewer performed data extraction in full. All numerical results and each study quality assessment were checked by a second reviewer working independently. Authors of primary studies were contacted for unreported, or inadequately reported, numerical data. Study quality was assessed with the Cochrane risk-of-bias tool [for randomised controlled trials (RCTs) and non-RCTs] or the Newcastle–Ottawa Scale (for cohort and case–control studies). Studies were categorised by facilitated TW/unfacilitated emotional writing (EW) and then by ICD-10 (*International Classification of Diseases*, Tenth Edition) code.

### Realist synthesis

One reviewer selected relevant sections on context, mechanisms and outcomes from the included studies, process evaluations and discussion papers to refine the programme theory. Included studies were rescrutinised to search for data that were relevant to the revised theory. Publications were selected if they were relevant, and quality assessment used the concept of rigour.

### Data synthesis

#### Systematic review

Narrative and tabular synthesis was used. Meta-analysis was conducted when three or more studies reported the same outcome, using RevMan version 5.2.6 (RevMan 2012, The Cochrane Collaboration, The Nordic Cochrane Centre, Copenhagen, Denmark).

#### Economic considerations

Resource use was systematically reviewed using the same methods as outlined above. Costs and resource use were estimated given de novo economic modelling was not possible owing to lack of information.

### Realist synthesis

Realist and Meta-review Evidence Synthesis: Evolving Standards methodological standards were followed. Programme theory was developed with extensive input from TW practitioners. Data extracted were used to develop and refine programme theory. This was presented diagrammatically, detailing how and why inferred mechanisms and key contextual influences potentially influence intermediate and final outcomes.

## Results

### Systematic reviews

From 14,658 unique citations, 284 full-text papers were reviewed and 64 studies (59 RCTs, one non-randomised controlled study, three controlled cohort studies and one matched case–control study) were included in the effectiveness reviews. Thirty-nine studies were conducted in the USA. The largest study had 507 participants, but half of the studies included fewer than 50 participants in each arm. Five studies were in facilitated TW, and examined positive writing, enhanced meaning writing, song, poetry and internet chat forums. Fifty-nine studies were of unfacilitated TW and used either standard EW or an adapted version. Studies reported mainly psychological, physical and QoL outcomes, with 172 instruments used and more than 300 different outcome measures reported. Follow-up was mostly at between 1 and 3 months.

Five studies from different countries were included. Studies used very different TW intervention methods and different instruments or subscales to report relevant outcomes, which included physical and psychological assessments. Data to inform quality assessment were scarcely reported, and all five studies were at unclear risk of detection bias. The studies could not be meta-analysed because of a lack of consistency in measurement and heterogeneity in participants' LTCs and the interventions. However, all studies reported significant improvement in all but one outcomes in favour of the TW group.

### **Unfacilitated emotional writing**

A total of 59 studies assessed an unfacilitated EW intervention. Twenty-seven ICD-10 codes were used to categorise over 30 LTCs in the included studies. The most frequently investigated were breast cancer (eight studies) and human immunodeficiency virus (HIV) (six studies). Only one study was reported on each of the following ICD-10 categories: type 2 diabetes mellitus, sickle cell disease, cystic fibrosis, dementia, bulimia nervosa, amyotrophic lateral sclerosis, tension and migraine headaches, and chronic obstructive pulmonary disease.

Overall there was no, or very little, evidence of any benefit reported in the following conditions: HIV (six studies, overall unclear risk of bias); breast cancer (eight studies, overall low or unclear risk of bias); gynaecological and genitourinary cancers (five studies, variable risk of bias); asthma (four studies, low or unclear risk of bias); psoriasis (three studies, unclear or high risk of bias); inflammatory arthropathies (six studies, high or unclear risk of bias); and chronic pain (four studies, low or unclear risk of bias). There were five small studies of heterogeneous populations with mental health problems (low or unclear risk of bias) for which no clear patterns emerged. For all other LTCs there were either no data, or sparse data with no or inconsistent evidence of benefit.

### **Meta-analyses by International Classification of Diseases, Tenth Edition code**

Few meta-analyses could be performed because of heterogeneity. The analyses included different outcomes measured at different follow-ups in the following chronic conditions: HIV (depression at short term in 249 participants); breast cancer (depression in 562 participants, positive and negative mood at short term in 618 participants each); asthma (lung function at short term in 177 participants); mental and psychiatric disorders (anxiety at short term in 127 participants); inflammatory arthropathies (disease activity at both immediate and short term in 146 participants); and fibromyalgia and chronic pain (pain severity at two different short-term assessments in 216 participants).

Differences between EW and control groups were not significant in almost all of the outcome measures meta-analysed, except for disease severity in people with inflammatory arthropathy, for which significant differences in favour of the EW group – at short-term follow-up only – were found [ $n = 216$ , standardised mean difference (SMD)  $-0.61$ , 95% confidence interval (CI)  $-0.96$  to  $-0.26$ , with a random-effects model and with non-significant heterogeneity,  $I^2 = 1\%$ ].

### **Consideration of outcomes across long-term medical conditions**

Twenty-four studies among 12 different LTCs reported either physiological or biomarker outcomes. The EW intervention groups did not show better results than controls in any of the physiological and/or biomarker outcomes reported, except for diastolic blood pressure (but not systolic blood pressure) in Willmott *et al.* (Willmott L, Harris P, Gellaitry G, Cooper V, Horne R. The effects of expressive writing following first myocardial infarction: a randomized controlled trial. *Health Psychol* 2011;**30**:642–50), which was significantly better in the EW group at the final follow-up (21 weeks).

The most frequently measured outcomes across the LTCs were depression and anxiety. Meta-analyses of depression showed no statistical significance at any duration of follow-up. For example, at 4–17 weeks' follow-up (17 studies) the SMD was  $-0.09$  (95% CI  $-0.31$  to  $0.14$ ) with substantial heterogeneity ( $I^2 = 71\%$ ).

Eleven studies assessed anxiety in 527 participants at immediate (197 participants) and short-term (330 participants) follow-up. Differences in anxiety between EW and control groups were not significant in either case.

### **Economic considerations**

No full economic evaluations were found. One study reported cost of EW at US\$130 per patient. Twelve studies reported on resource use, covering a wide range of disease areas and populations. Meta-analysis of health centre visits (seven studies) showed no statistical differences between EW groups and control subjects. Meta-analysis of medication use from three studies showed fewer medications with unfacilitated EW (SMD  $-0.28$ , 95% CI  $-0.54$  to  $-0.02$ ) than controls. Cost–consequence analysis suggested that there might possibly be a favourable balance of participant benefits to UK NHS costs for selected interventions in selected LTC groups. There is insufficient evidence to judge cost-effectiveness.

### **Realist synthesis**

The realist synthesis included 59 studies from the systematic review, a further single related paper describing additional aspects of one study, 13 studies excluded from the systematic review, and one additional paper. They provided information on qualitative research, process evaluation, and theoretical or methodological discussions, for the realist synthesis.

Two distinct TW programme theories were developed:

1. *For unfacilitated (individual) EW*, the main mechanisms and contexts were difficult to clarify as relevant explanatory data were not explored and/or reported within the studies – unfacilitated EW appeared to have been treated like a black box. It was unclear why participants would have wanted to undertake EW or what they would hope to gain from it.
2. *For the facilitated (group) TW*, there were multiple potential mechanisms that interacted in a complex way with each other and context to generate (intermediate) outcomes. In brief, mechanisms related to the forming of relationships and the group acting as a safe environment and an audience for TW. Unfacilitated TW was pragmatic in that it did not assume that TW was necessarily appropriate for all people with LTCs but instead provided opportunities for participants to try to see if it helped.

## **Conclusions and implications for health care**

Most interventions evaluated were unfacilitated and did not mirror those currently used by professional TW practitioners in clinical practice in the UK. There is insufficient clinically relevant evidence on facilitated TW to know whether or not it is beneficial. Unfacilitated EW was not effective for most outcomes in most LTCs, although data were very sparse in many areas. The effectiveness of unfacilitated EW in LTCs is not as immediately obvious, as might have been expected from research about this intervention in general populations reported in textbooks.

## **Recommendations for research**

Further research that evaluates facilitated TW interventions currently used in clinical settings is needed, using feasibility or pilot studies and progressing to cluster RCTs or stepped-wedge designs, evaluating patients with chronic physical and mental health conditions. The comparators could be standard practice without TW and also other comparable therapeutic interventions, such as relaxation CDs or reading bibliotherapy. Useful outcomes would be the standard clinical outcome measures or instruments for the patients' medical conditions, patient satisfaction, HRQoL and costs. The study sample sizes would need to be large enough to find a potentially modest effect.

## Study registration

This study is registered as PROSPERO CRD42012003343.

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