

Life Story Book to Enhance Communication in People with Dementia: A Systematic Review of Reviews

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Abstract

Background: Life Story Book (LSB) has been commonly used in promoting person-centred care in elderly care especially for people with dementia. This involves collecting the life stories and memories and then being compiled to produce a tangible output, usually a book often termed the Life Story Book. However, the use, benefits and the influences of Life Story Book in dementia care is still scarce and requires an overall review. The aim of this systematic review is to collect past reviews and provide a thorough overview on the use, benefits, and impact of the Life Story Book for the person with dementia, the relatives, family and caregivers.

Methods: The electronic databases PubMed, Scopus, Science Direct and Web of Science as well as grey literature through Google Scholar were searched to select the relevant studies.

Results: Seven studies that meet the inclusion criteria were selected and data was synthesised. Findings revealed that the use of the Life Story Book has no specific guidelines and has been described with numerous characteristics and varied methods of implementation. The Life Story Book intervention is found to provide significant positive outcomes for the person with dementia and the carers involved. Six out of the seven studies reported that Life Story Book enhanced communication between persons with dementia, relatives, care staff and residents.

Conclusion: The review extends the current evidence on the usage of the Life Story Book in dementia care and confirms that the use of life stories leads to better care in various setting. However, more research is needed to reveal the potential of Life Story Book in enhancing communication and the guideline or training for staff and carers to deliver the intervention.

Introduction

Dementia is an umbrella term used for a group of diseases characterised by progressive decline in global function including cognition, social functioning as well as behavioural changes occurring in a state of clear consciousness [1, 2]. The prevalence of dementia has increased with the fast-growing ageing population, where it is estimated to currently affect over 50 million people globally and is estimated to increase to 152 million by 2050 [3].

A person with dementia generally experiences a gradual decline of a wide range of abilities over the years and a gradual loss of independence in daily function [4]. This loss of function requires reliance on a caregiver to fulfil their needs. The increasing numbers of persons with dementia has raised the demand for the provision of care. Treatment of persons with dementia is through multifactorial management, which can be categorised into pharmacological and non-pharmacological treatments [5]. The current pharmacological treatments for person with dementia are only symptomatic and are administered by medication that have been approved by the American Food and Drugs Administration (FDA) [6]. However, medications only ameliorate the conditions and frequently provide only moderate desired outcomes in terms of managing the symptoms. Non-pharmacological treatments are recommended by experts as the first line of treatment to help person with dementia [7] to both improve the condition of the dementia and the quality of life [8] and their caregivers. Non-pharmacological treatments includes cognitive training and rehabilitation, music-based therapy, light therapy, psychological therapy, cognitive stimulation therapy and reminiscence therapy [9].

Reminiscence therapy is an established non-pharmacological treatment option in dementia care that involves activities recalling past events and experiences of the person with dementia, aided by familiar items, artefacts, photographs, music and songs that help to trigger the memory [10, 11]. The usage of Life Story Book is one of the approaches of reminiscence work. Based on McKeown et al. [12], the Life Story Book is described as an approach that involves the person with dementia and/or their family to look at their life, history, collecting and compiling the information relating to the person with dementia and then using the information in the care of the person. The creation of a Life Story Book involves discussing the individual's past and present life using related images, sentences or memorabilia that benefits the individual to recall and focus on a specific segment of life which are later verbalised in the context of guided communication [10]. The Life Story Book which is commonly used in clinical practice in many countries [13], outlines a collection of photographs and written captions regarding the past and present story of the person with dementia and is often collated in a chronological format [14, 15].

The major focus in the creation of the Life Story Book is to facilitate person-centred care by following the main principles and philosophy of its development, which is to maintain and promote person-hood in dementia care [16]. In recent years, person-centred care approach has been vastly implemented by those practitioners and nurses that are working with people with dementia [10]. The key elements of person-centred care approach include valuing the person as they are, understanding the biography of the person and developing relationship between family, relatives, and caregivers [17, 18]. There is some evidence that states the experience of creating a Life Story Book is immensely beneficial such as improving communication, promoting better relationship between family, friends, and caregivers, as well as better delivery of care for persons with dementia that it becomes more person-centred care as a result [19].

Language and communication problems from the deterioration of cognitive functioning are commonly experienced by a significant number of persons with dementia that necessitates professional assistance [20, 21]. This, in fact, had impact persons with dementia's ability to express their daily needs and thoughts to their family, friends and caregivers, which in turn reduces their self-esteem and quality of life [22]. The role of a Speech-Language Pathologist (SLP) is crucial in managing and care for persons with dementia. They are required to assess, diagnose, and provide the best intervention for persons with dementia that presents with language, communication, and cognitive deficits [23]. Life Story Book is known to benefit persons with dementia by improving their communication, memory and cognitive functions [10]. SLPs could therefore use the Life Story Book as a memory cue and as an intervention strategy to improve communication, language, and cognitive skills among persons with dementia [24].

A few systematic reviews have been published which have discussed the usage of Life Story Book among person with dementia and evidenced the effectiveness of the Life Story Book in treating person with dementia. Although there were no standard protocols reported in the systematic reviews in terms of the protocols of conducting this intervention, the general findings reported that Life Story Book effectively improves the quality of care in terms of cognition, depression, positive mood, communication, quality of life, autobiographical memory, and social interactions. As such, the objective of this paper was to perform a systematic review of the usage of Life Story Book among person with dementia. This paper aims to present a thorough synthesis of available systematic review literature concerning the advantages of using Life Story Book for person with dementia, the standard procedure in preparation and usage of the Life Story Book and the impact of the use of

Life Story Book on families, relatives and caregivers. It systematically reviews past reviews on how Life Story Book is used in dementia care with three guiding questions, following PICO model framework (Population, Intervention, Comparison and Outcomes) [25] as below:

1. What are the characteristics and standard protocols in using the Life Story Book for people with dementia?
2. What are the benefits of Life Story Book for person with dementia?
3. What is the impact of using Life Story Book on family, relatives and caregivers of person with dementia?

Method

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [26]. A systematic review of reviews is commonly used to provide a summary of primary literature that includes many primary studies in the area and include interventions from various levels, age populations and settings [27]. In this paper, separate reviews were compared, contrasted, and synthesised into a thorough overview of a large body of work. All methods were performed according to relevant guidelines.

Inclusion and exclusion criteria

The eligibility criteria for study inclusion were developed using PICOS as a guideline (Table 1).

Table 1
Eligibility Criteria for Study Inclusion

Criteria	
Population	Reviews of studies were limited to adult persons with dementia, across all stages of dementia (e.g. mild - severe), and at any setting.
Intervention	The review of studies of the Life Story Book: All forms of the Life Story Book (e.g. tangible book, multimedia, memory album) were included. For the purpose of this study, the Life Story Book was defined by any process that involves working with a person and/or their family to collect and record the information and/or stories about the person's past and present life to be used to benefit in their care [28], that is often supported with photographs, text or memorabilia, relevant to the person's life [13].
Comparator	This review did not intend to compare the Life Story Book to/with any other forms or types of intervention.
Outcome	In order to include the study in this review, the study outcomes should have reported the advantage of using the Life Story Book among person with dementia, and/or present the guidelines in using the Life Story Book, and/or discuss the impact of using the Life Story Book for the caregiver/relatives.
Study Type	Any review paper was included (systematic review, scoping review or narrative review).

Search Methods for Identification of Reviews

The literature search was performed in four electronic databases: PubMed, Scopus, Science Direct and Web of Science on 30th July 2021. An updated search was performed on 18th August 2021 through the same databases. The grey literature for relevant studies was also conducted through Google Scholar. The key search terms included were 'life story book' OR 'life story' OR 'life story work' OR 'memory album' and in combination with the Boolean operator 'AND' along with the search terms 'dementia' AND 'Alzheimer' AND 'review'. The

searches were limited up to and including the year 2020 and English language only. The results of the searches were extracted into Microsoft Excel Worksheet and de-duplicated manually by the researcher. Eligibility assessment was performed by PT and PS independently and any disagreement between reviewers were resolved by SS's consensus.

Study Selection

The title and abstracts of all articles obtained from the electronic search were screened. The reference list of selected articles was also searched. All relevant articles were accepted for the next round of evaluation. Acquisition of full texts of articles with inadequate information in the title and abstracts allowed for precise screening. Full texts of all articles selected following the screening rounds was then obtained. These full-text articles underwent an assessment process using the inclusion criteria (Table 1) independently. Articles that met the inclusion criteria were then evaluated for methodological quality assessment.

Quality Assessment

Studies included were evaluated using the Measurement Tool to Assess Systematic Review (AMSTAR) checklist for assessing the methodological quality [29]. The AMSTAR is a validated tools to assess the methodological quality of systematic reviews, which contains 11 items. Final grading of each systematic review was based on the overall score (total score: 11) and being reported as 'high' (score ≥ 8), 'medium' (score 4–7) or 'low' (score ≤ 3). For narrative reviews' articles included, the methodological quality was assessed based on Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) statement guidelines. ENTREQ summarised statement consists of 11 items grouped into five main domains: introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings (Tong et al., 2012). The quality of assessment of each paper was completed by AG and PT independently, and crossed-checked by PS.

Data extraction

From each of the included studies, the following data were collected: the publication year, the years and number of the primary studies included, the databases searched, the study population and setting, the outcome measures and the AMSTAR score for quantitative and ENTREQ evaluation for qualitative review articles. An excel spreadsheet was created for the data extraction purposes.

Results

Study identification and selection

The PRISMA diagram (see Fig. 1) summarises the databases hits exclusion and final inclusion in a flow diagram. A total of 141 studies were found; PubMed (13), Scopus (15), Science Direct (9), Web of Science (18), Google Scholar (86). After removing the duplicates, 98 papers remained and underwent a second round of screening for title and abstract. Based on the title and abstract, 79 studies were removed as the studies did not relate to Life Story Book in dementia care. The full text of the remaining 19 studies were assessed for the inclusion criteria and 12 studies were discarded as they did not meet the inclusion criteria. Finally, a total of seven studies met the inclusion criteria and were included in this systematic review.

Figure 1. Flow diagram for Life Story Book review articles for People with Dementia

Study characteristics

The seven review studies included were published between 2006 to 2019. All papers were written in English. Table 2 depicts the basic characteristics of the included reviews. Out of these seven studies, five studies were systematic review [10, 13, 30–32] and two studies were qualitative review studies [14, 33]. The population included in the primary studies were persons with dementia, except for studies by Doran et al. [32] where two of the primary studies included did not specify the diagnosis of the participants involved. After verifying the total number of persons with dementia in each study, at least 737 participants were included as two of the studies did not report the population involved. In these reviews, literature searches were performed from 1984 to 2017. There was a range of different settings involved: 30 studies were conducted at nursing homes, 43 studies at residential cares, 11 studies at participant's home, one study at a memory clinic and 14 studies that did not specify the setting.

The AMSTAR evaluation is summarised in supplementary Table 1. Three studies were rated moderate quality (score 4–7) and two studies were rated high quality (score 8–11) (Supplementary Table 1). ENTREQ summarised statement was used as a guideline in assessing the methodological quality of a qualitative review. When judged against the ENTREQ statement for studies by Moos et al. [33], the studies were methodologically poor due to the inadequate information for research questions, inclusion criteria, study screening, appraisal and data not being synthesised appropriately. Kindell et al. [14] showed good methodological quality with adequate and appropriate information provided. The appraisal and synthesis of the findings, however, were unclear. The summarised ENTREQ statement is reflected in supplementary Table 2.

Table 2. Overview and characteristics of the included studies.

Table 3. Summary of characteristics and implementation of life-story work.

Table 4. Summary of the benefits and effects of life-story work in dementia care.

Characteristics and standard protocol in using the Life Story Book

Out of 93 primary studies included in this systematic review of reviews, 42 studies reported to have a tangible product of Life Story Book, with one study that did not specify the type of Life Story Book used. Table 3 summarises the characteristics and protocols for implementation of the Life Story Book in each of the included studies. The Life Story Book product used varied and ranged from the traditional Life Story Book [10, 13, 14, 30, 32, 33] memory book [33], life history collage [13, 32], biographical history [13, 33], pen picture [13, 30] digital application of life story [30] and a rummage box [30]. A wide variety of materials were used in creating Life Story Book such as photographs, memorabilia, stories, narration, owns words/quotation, favourite songs and music. The Life Story Books' in Elfrink et al. [30] depicted the life stories of the individuals that were arranged in chronological order illustrated with photographs and captions from childhood until the present. However, other studies reported the Life Story Book arranged according to topics of interest [14] with the person with dementia compiling it in the way they wish to narrate the story, with assistance from family members and carers [10]. The number of pages in the Life Story Book varied from between two pages (pen picture) to 70 pages and the

duration of the digital life story (which then was converted to life story movie) ranged from 12 minutes to 27 minutes with an average of 18 minutes [30]. The Life Story Work reported by Kindell et al. [14] was as an informal activity that the person with dementia could use to engage with relatives or carers while also having the potential to be a formal intervention. The Life Story Book session was reported as being delivered by the researchers, caregivers, nurse, family members, relatives, and dyads of volunteers and therapists. Only some studies reported on the provision of training and supervision. In terms of the process of creating the Life Story Book, three of the reviews reported studies used the structured Life Review and Experiencing Form (LREF) by Haight et al. [34] while other reported to use the Couples of Life Story approach [30], Family Biography Workshop [41] and General Reminiscence approach [35]. The actual use of the Life Story Book in terms of the number of sessions, frequency and duration of the session varied across the studies included in this review and is reflected in Table 3.

Benefits of Life Story Book for people with dementia

The outcomes and benefits of using Life Story Books for people with dementia are presented in Table 4. The positive outcomes reported include significant improvement in autobiographical memory, mood, cognition, communication [10, 13, 30–32], quality of life [13, 30, 33], increased sense of self-integrity, identity, well-being, pride and self-esteem that will eventually lead to changes to better behaviour of person with dementia [31–33].

Effects of using Life Story Book on towards relatives, caregiver and care staff of people with dementia

The effect of using Life Story Books on the relatives, caregiver and care staff of people with dementia are presented in Table 4. Most of the reviews reported that Life Story Book plays a significant role in aiding communication. The improved quantity and quality of verbal interaction between people with dementia and the carer reported by Moos et al. [33] is in line with the other reviews that revealed that Life Story Book was proven to enhance interaction and promote point of reference to communicate to the staff and relatives [10, 13, 30–32]. The effect of the enhanced communication significantly helps in maintaining and building the relationship between the people with dementia and the family, relatives and caregivers. The relationship creates an effective engagement between person with dementia and the carer that eventually promotes better care of person-centred care towards the people with dementia. In addition, staff and carers reported that Life Story Book helps them to understand and have more knowledge about the person with dementia [13, 30] and enable them to alter the strategies to overcome aggressive behaviour more effectively [31, 32].

Discussion

The Life Story Book is one of the products of reminiscence therapy that can be used to enhance person-centred care among people with dementia [10]. However, across the studies reviewed, there is no single approach or standard definition of 'life story work' [42]. The definition appears to be varied between the approaches of life story work depending on the aim and objective of the life story work itself. This is consistent with the reviews by Kindell et al. [14] and Doran et al. [32] as to whether Life Story Book should be used as an informal activity for persons with dementia to be engaged in or as a formal intervention run by trained staff or therapists.

There is no consensus found in terms of the characteristics or standard procedure of creating a Life Story Book such as topics to be included, the order of memories, the number of pages or how it should be used in a session. With regards to the duration of each session, most studies reported that sessions lasted between 30

minutes to an hour, based on the condition of the people with dementia. Ingersoll-Dayton et al. [43] proposed that sessions were most productive when conducted on a weekly basis. This could provide Speech-Language Pathologists and other dementia care professionals with insights into the length and frequency of sessions that are adequate for an effective intervention.

Haight et al. [34] suggested that the tangible Life Story Book should be based on the outcome of the life review process. Kindell et al. [14] suggest that this intervention is reliant on the person who completes the Life Story Book. Similar recommendations were stated by Subramaniam and Woods [10] in which the Life Story Book should be created by the person with dementia using their own choices of pictures, props and words, with the order depending on how they would personally like to narrate their life stories. This has, however, raised an issue when a person with dementia with deteriorating memory, and poor cognitive abilities as the disease progress and they are unable to recall the memory and unable to maintain the sense of continuity between the stories [12]. More flexibility and naturalistic process are required according to the person's cognitive and emotional needs, as well as preference and progress [10, 42].

Despite that, promoting self-identity, self-value, improvement in social communication, and creating and building relationship between family, relatives and care staff, have been highlighted across all the reviews studied. The life story book focused on enabling the person with dementia to share and talk about their life stories and experiences [18, 28] and maintain their identity. This is similar to the findings of McKeown et al. [12] that Life Story Book helps to reinforce the sense of identity, self-esteem and pride for the person with dementia. As a consequence, the family, relatives and staff develop insight to see the person with dementia as a whole person, recognise their unique identity, history, interest and their whole life [12, 28]. This could further help carers and health practitioners to organise activities or exercises that of the best interest of the person with dementia.

Another notable benefit of the Life Story Book is enhanced communication among persons with dementia. The study found that Life Story Book acts as a valuable tool in aiding communication between person with dementia and their family, relatives and care staff. One of the theories of Life Story Book outlined by Parker et al. [31] is that Life Story Book helps others to get to know the person with dementia better, which eventually improves the interaction and communication between the person with dementia and the staff. This is consistent with the literature findings where the staff perceived Life Story Book as a point of common references to communicate with person with dementia and becomes a 'kit' as a prompt to aid the communication [13, 44]. As a result, fewer incidences of negative behaviour and mood changes can be observed among persons with dementia as they are able to express themselves better. However, quantitative findings on how Life Story Book was used to enhance verbal interactions and communication are still scarce and requires further research.

Utilising Life Story Book in dementia care supports the person with dementia to socialise and to feel being accepted as a part of the social network in their current surroundings and facilities [45]. Subramaniam et al. [15] reported that improvement in the relationship between the person with dementia and caregivers were observed right after the Life Story Book was introduced to them. The improvement in communication and enhanced interaction between them could possibly be the reason behind it [46]. This creates a better care practice, better quality of life and warmth relationship due to the enhanced relationship between the family, care staff, and the person with dementia itself [15]. However, the studies in this review mostly reported the

engagement and improvement of the relationship between person with dementia and their caregivers and staff in nursing or residential and care home settings [10, 13, 30, 33]. Similar findings were stated by Gridley et al. [47], where Life Story Book was widely used in hospitals and care home settings and less in home setting. Greater insights and benefits may have come from a focus on the engagement and bonding of the close family members and relatives in their home setting which they are more familiar with.

Moreover, the use of a Life Story Book is beneficial for Speech Language Pathologists when providing effective intervention for persons with dementia. From the present study, it is evident that Life Story Book promotes self-empowerment, improves communication skills and memory among persons with dementia. The service delivery of Speech-Language Pathologists and other healthcare professionals those who work closely with persons with dementia could focus on a wide range of communication and cognitive goals with the aid of Life Story Book. For instance, healthcare professionals could work on goals on promoting social participation, reducing frequencies of responsive behaviours and facilitate daily living activities [48] with the individuals and their family or caregivers. Thus, the Speech Language Pathologist could use Life Story Book as an effective intervention during their clinical sessions in managing persons with dementia. This is further supported by Bourgeois [24], where the researcher encouraged more professionals to use Life Story Book as a tangible product to provide a better care for them.

Apart from the benefits of Life Story Book, McKeown et al. [12] identified a few challenges in using Life Story Book. First, in terms of the content of the Life Story Work, it is challenging to the healthcare professional where sensitive information and personal disclosures emerge and the issues of upsetting memories are brought up in the life review process [14]. Having a person with dementia to tell their own stories could be a challenge with the nature their inability to recall the memories [12]. The Life Story Book might be overused or underused in dementia care due to lack of time and is identified to be one of the challenges among caregivers [49]. Thus, finding the right balance is important. Other barriers in using the Life Story Book as an intervention tool is the lack of a standard format for collecting information and the lack of available suitable resources to develop a personalised Life Story Book [12]. More guidance and training should be provided on how to use the Life Story Book to the Speech-Language Pathologists, families, relatives, care staff or individuals involved in delivering the services for persons with dementia [47]. This is crucial to support the implementation of this practice in dementia care and to ensure best outcomes of the intervention [21, 47].

Limitation

The search was limited to English language sources and relevant sources in other languages may contain useful information that were excluded in this systematic review. This systematic review incorporated review studies that aimed to explore different objectives in each study. The available review studies included in this study did not portray a consensus on the findings especially in terms of the characteristics and implementation of the Life Story Book. It was therefore a challenge to compare the studies and arrive at a consensus. Despite these limitations, this review provides a comprehensive overview of the usage of life stories in dementia care.

Implication

The Life Story Book assists in supporting dementia care and is a beneficial activity to the person with dementia, staff, nurses, families, relatives and caregivers. Life Story Book has become a form of evidence-based practice

and should be recognised by health care service providers including speech therapists, nurses, care staff and managers when planning services for dementia. It is recommended that Speech Therapists use the Life Story Book in planning the treatment as it is evident that the Life Story Book enhances communication and increases interactions when supplemented with communication strategies to elicit more meaningful conversations. Challenges that may arise highlight the importance and need for careful planning, education and support in the implementation of the Life Story Book in practice. Future research to explore the use of Life Story Book is recommended for enhancing communication, value of verbal and non-verbal interactions and the social interaction itself in direct communication intervention and in the long-term.

Conclusion

The Life Story Book is the product of a personalised collection of life events and memories that promotes person-centred care in dementia management. This systematic review collected and synthesised findings from a review of the usage of life stories among the dementia population. The challenges faced have been outlined to ensure better implementation of strategies while delivering the service. The positive outcome for the person with dementia was significant, although more quantitative research and analysis is needed to support the findings on how Life Story Book aids communication. There is, undoubtedly, a need to measure the impact and influences of Life Story Book towards the caregiver, family and relatives.

Declarations

Ethics approval and consent to participate

This systematic review study does not require ethical approval and consent from participants.

Consent for publication

Not applicable.

Availability of data and materials

All data analysed during this study are included in the published article and its supplementary tables.

Conflict of interest

The authors declare no conflict of interest.

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Authors' contribution

All Authors were involved in the conception or design of the work. P.T. and N.A.M.G. were involved in data collection, data analysis, and interpretation. P.T. and N.A.M.G were involved in drafting the article. P.S. and S.S.

carried out the critical revision of the article. All Authors were involved in the final approval of the version to be published.

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Tables

Table 1-4 are available in the Supplemental Files section.

Figures

Figure 1. Flow diagram for Life Story Book review articles for People with Dementia

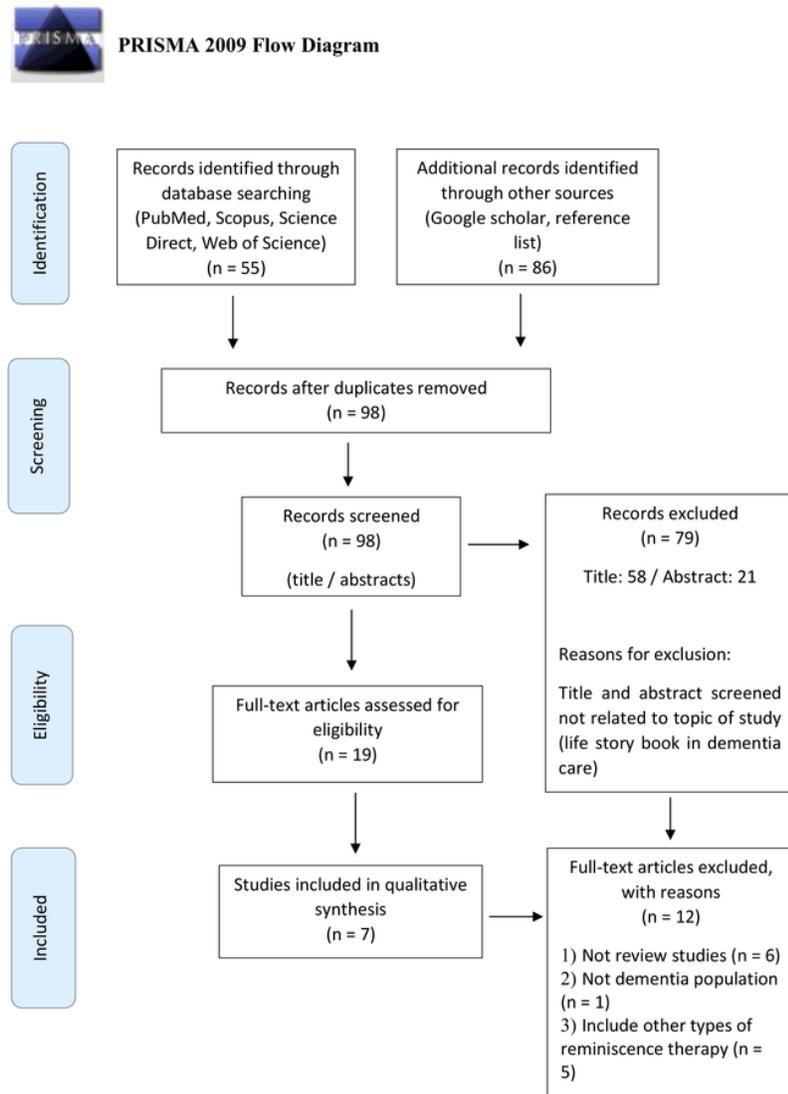


Figure 1

Flow diagram for Life Story Book review articles for People with Dementia

Supplementary Files

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- [Table1Eligibilitycriteriaforstudyinclusion.pdf](#)
- [Table2Overviewandcharacteristicsoftheincludedstudies.pdf](#)
- [Table3Summaryofcharacteristicsandimplementationoflifestorywork.pdf](#)
- [Table4Summaryofthebenefitsandeffectsoflifestoryworkindementiacare.pdf](#)
- [Supplementarytable1QualityassessmentratingsofreviewstudiesincludedAMSTAR.pdf](#)
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