The psychological impacts of nostalgia for people with dementia

Submission date 17/07/2014	Recruitment status No longer recruiting	[X] Prospectively registered [] Protocol
Registration date 31/07/2014	Overall study status Completed	 [_] Statistical analysis plan [X] Results
Last Edited 30/12/2022	Condition category Mental and Behavioural Disorders	Individual participant data

Plain English summary of protocol

Background and study aims

Reminiscence and life review therapy is a way of remembering, talking about and sharing the important events and memories of one's life. The treatment is thought to help provide comfort and meaning to a person's experiences. Music, photographs, videos, and items that have special meanings can all be used to trigger memories and the sharing of stories. The therapy is often used with people with dementia. However, it is not really known what it is about remembering the past that is of benefit. It's possible that it is a particular type of memory that is helpful. This study looks at whether remembering different types of memories (nostalgic versus non-nostalgic memories) generates different psychological feelings. Research with people who don't have dementia has shown that different types of memory can produce different psychological effects. The aim of this study is to see whether the same effects hold true for people who have recently been diagnosed with dementia.

Who can participate?

People who have been diagnosed with dementia (Alzheimer's disease, vascular dementia, dementia with Lewy bodies or mixed dementia) and mild to moderate memory problems

What does the study involve?

This research involves two separate experimental studies. In Study 1, each person who takes part is randomly allocated into one of two groups (nostalgia or control). Each participant from the nostalgia group is asked to remember a nostalgic event from their past. They are then asked to describe how they feel at that moment. Afterwards, they complete a series of questionnaires on how they feel at that moment. Participants in the control group are also asked to remember an ordinary event from their past. Like the nostalgia group, they are then asked to describe how they feel at that moment and complete the same series of questionnaires. In Study 2, each participant who takes part is randomly allocated into one of two groups (nostalgia or control). Each participant in the nostalgia group is asked to listen to a song which they have previously identified to hold a special meaning for them. They are then asked to describe how they feel at that moment and complete the same series of questionnaires as in Study 1. In the control group, each participant listens to a song which they have not identified as having special meaning to them. They are then asked to describe how they feel at the series of questionnaires. Before the participants begin each experimental study, the researchers go through a brief

questionnaire with them to get a better idea of how well their memory is working. At the end of each the study, they are asked about their experiences of taking part in the study. At that point they are also given more detailed information about the project and their role in the study. Each study lasts about 20 minutes.

What are the possible benefits and risks of participating?

The researchers do not believe that there has been any research with people with dementia which involves asking participants to recall memories in this way. However, there has been a great deal of research into reminiscence and life story work, which are both often used as therapy in dementia care. Although there are reports of adverse reactions, such as people being distressed during the therapy, these are rare. In general, both reminiscence and life review are reported to have either beneficial or neutral effects.

Where is the study run from? The University of the West of England, Bristol (UK)

When is the study starting and how long is it expected to run for? October 2014 to April 2016

Who is funding the study? The University of the West of England, Bristol (UK)

Who is the main contact? Mr Sanda Ismail sanda.ismail@uwe.ac.uk

Contact information

Type(s) Scientific

Contact name Mr Sanda Ismail

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers N/A

Study information

Scientific Title

The psychological impacts of nostalgia for people with dementia: a parallel randomised controlled experimental study

Acronym

PsychNosDem

Study objectives

Aim of research: To explore the psychological impact of nostalgic memories compared to nonnostalgic memories on people affected by dementia.

Ethics approval required

Old ethics approval format

Ethics approval(s)

NRES Committee East of England – Norfolk, 27/01/2015, ref: 14/EE/1237, IRAS Project ID: 161394

Study design Parallel randomised controlled multi-centre experimental study

Primary study design Interventional

Secondary study design Randomised controlled trial

Study setting(s) Other

Study type(s) Quality of life

Participant information sheet Not available in web format, please use the contact details to request a patient information sheet

Health condition(s) or problem(s) studied Dementia

Interventions

Study 1: Narrative nostalgia versus Control Study 2: Music-evoked nostalgia versus Control

Current interventions as of 29/01/2015:

Nostalgia groups:

1. Narrative nostalgia - Participants will be instructed to bring to mind a nostalgic memory. Specifically, they will be instructed to do the following: "According to the New Oxford Dictionary, 'nostalgia' is defined as a 'sentimental longing for the past.' Please think of a nostalgic event in your life. Specifically, try to think of a past event that makes you feel most nostalgic. Bring this nostalgic experience to mind. Immerse yourself in the nostalgic experience. How does it make you feel? Please spend a couple of minutes thinking about how it makes you feel. Please describe this nostalgic event (i.e., describe the experience)."

2. Music-evoked nostalgia - Participants in the music-evoked nostalgia group will listen to one of the three nostalgic songs that they had previously identified. They will be asked to spend a couple of minutes immersing themselves in the nostalgic experience. They will then be asked to describe how they feel and their experience after listening to the song.

Control groups:

Narrative control - In the narrative control group, they will be instructed to bring to mind an ordinary event in the past: "Please bring to mind an ordinary event in your life. Specifically, try to think of a past event that is ordinary. Bring this ordinary experience to mind. Immerse yourself in the ordinary experience. How does it make you feel? Please spend a couple of minutes thinking about how it makes you feel. Please describe this ordinary event (i.e., describe the experience)".
 Music control - In the music-control group, participants will receive the song of a yoked partner in the music-evoked nostalgia condition. They will be asked to spend a couple of minutes immersing themselves in the nostalgic experience. They will then be asked to describe how they feel and their experience after listening to the song.

Previous interventions:

Intervention groups:

1. Narrative nostalgia - Participants will be provided with a definition of nostalgia and instructed to bring to mind an event that makes them feel nostalgic. Specifically, "According to the Oxford Dictionary, nostalgia is defined as a 'sentimental longing for the past.' Please think of a nostalgic event in your life. Specifically, try to think of a past event that makes you feel most nostalgic. Bring this nostalgic experience to mind. Immerse yourself in the nostalgic experience. How does it make you feel? Please spend a couple of minutes thinking about how it makes you feel. Please write down four keywords relevant to this nostalgic event (i.e., words that describe the experience)".

2. Music-evoked nostalgia - Participants will listen to one of three nostalgic songs that they have previously identified. They will be asked to immerse themselves in the nostalgic experience. They will then be asked to write down four keywords relevant to this nostalgic event (i.e., words that describe the experience).

Control groups:

 Narrative control - Participants will be instructed as follows: "Please bring to mind an ordinary event in your life. Specifically, try to think of a past event that is ordinary. Bring this ordinary experience to mind. Immerse yourself in the ordinary experience. How does it make you feel? Please spend a couple of minutes thinking about how it makes you feel. Please write down four keywords relevant to this ordinary event (i.e., words that describe the experience)".
 Music control - Participants in this group will be given the favourite nostalgic song of a yoked partner in the music-evoked nostalgia group to listen to via an audio device. They will then be asked to write down four keywords relevant to this event (i.e., words that describe the experience).

Intervention Type

Other

Phase Not Applicable

Primary outcome measure

Current primary outcome measures as of 21/06/2017:

 Feelings of nostalgia, measured using the nostalgia manipulation check scale
 Social connectedness, self-esteem, meaning in life, self-continuity, optimism and positive and negative affect, measured using the State Functions of Nostalgia Scale (SFNS)
 All outcomes measured immediately following the nostalgia manipulation and there were no baseline measures of these variables or follow up.

Previous primary outcome measures:

1. Self-esteem, measured with the State Functions of Nostalgia Scale and The Rosenberg Self-Esteem Scale. The State Functions of Nostalgia Scale is a 12-item scale with 4 sub-items measuring state self-esteem (1 = Strongly disagree; 6 = Strongly agree). The Rosenberg selfesteem scale is a 10-item scale that measures global self-esteem and rated from strongly agree to strongly disagree. For items 1, 2, 4, 6, and 7: Strongly agree = 3; Agree = 2; Disagree = 1; Strongly disagree = 0. For items 3, 5, 8, 9, and 10 (which are reversed in valence): Strongly agree = 0; Agree = 1; Disagree = 2; Strongly disagree = 3

2. Social connectedness, measured with the State Functions of Nostalgia Scale The State Functions of Nostalgia Scale is a 12-item scale with 4-sub-items measuring social connectedness (1 = Strongly disagree; 6 = Strongly agree)

3. Meaning/purpose in life, measured with the State Functions of Nostalgia Scale and The Perceived Purpose scale . The State Functions of Nostalgia Scale is a 12 item scale with 4-subitems measuring meaning in life (1 = Strongly disagree; 6 = Strongly agree). The Perceived Purpose scale is a self-report measure of purpose in life. It comprises of 8 items rated on 6 point Likert scale with scores ranging from 8 to 48

The outcomes measured immediately following the manipulation of nostalgia.

Secondary outcome measures

N/A

Overall study start date 01/10/2014

Completion date 30/04/2016

Eligibility

Key inclusion criteria

1. A diagnosis made by a consultant psychiatrist of either probable Alzheimer's disease according to the NINCDS-ADRDA criteria (National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association) or probable Vascular Dementia according to the NINDS-AIREN criteria (National Institute of Neurological Disorders and Stroke- Association Internationale pour la Recherche et l'Enseignement en Neurosciences) or dementia with Lewy bodies or mixed dementia

2. Participants must have a mild to moderate level of cognitive impairment before they commence the research e.g. an MMSE score of at least 18

3. All participants will have been told of their diagnosis as evidenced in their medical notes by a practitioner/ nurse/doctor

4. Participants should be identified as having capacity to give consent by a clinician with access to the patient's recent cognitive assessment in the memory clinic

Participant type(s)

Patient

Age group

Adult

Lower age limit

18 Years

Sex

Both

Target number of participants 84

Total final enrolment

111

Key exclusion criteria

Current exclusion criteria as of 29/01/2015:

1. Participants diagnosed with Fronto-Temporal Dementia

2. People who initially have capacity at the time of assessment but who have lost capacity to consent before the study session

3. People who have current health problems such as high levels of distress or other factors (e.g., a recent bereavement) that preclude involvement in the study

4. People with a known history of traumatic abuse or other incidence which can cause them pain while remembering such events

Previous exclusion criteria:

1. Participants diagnosed with Fronto-Temporal Dementia

2. Participants who have lost capacity to consent before the research session

3. Participants with significant pre-morbid mental health problems e.g. major psychotic breakdown or depression

Date of first enrolment 01/03/2015

Date of final enrolment 30/04/2016

Locations

Countries of recruitment England United Kingdom

Study participating centre Avon and Wiltshire Mental Health Partnership NHS Trust United Kingdom SN15 1GG

Study participating centre Research Institute for the Care of the Elderly United Kingdom BA1 3NG

Sponsor information

Organisation University of the West of England (UK)

Sponsor details Frenchay Campus Coldharbour Lane Bristol England United Kingdom BS16 1QY

+44 (0)117 965 6261 info@uwe.ac.uk **Sponsor type**

University/education

Website http://www1.uwe.ac.uk/aboutus

ROR https://ror.org/02nwg5t34

Funder(s)

Funder type University/education **Funder Name** University of the West of England

Alternative Name(s) UWE Bristol, UWE

Funding Body Type Private sector organisation

Funding Body Subtype Universities (academic only)

Location United Kingdom

Results and Publications

Publication and dissemination plan

Peer-reviewed journals, academic conferences and PhD thesis report.

Intention to publish date

01/11/2018

Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study will be stored in the University of the West of England research repository. All data collected are anonymised. Access to the data will need to be granted by the University of the West of England according to its data protection regulations. Participants have given their consent for the data to be stored and accessed in this manner.

IPD sharing plan summary

Stored in repository

Study outputs

Output type <u>Basic results</u>	Details	Date created 21/06/2017	Date added 26/06/2017	Peer reviewed? No	Patient-facing? No
Results article	results	01/03/2018	27/08/2019	Yes	No
Other publications		10/06/2021	30/12/2022	Yes	No
<u>HRA research summary</u>			28/06/2023	No	No