Online Supplement 1

1. Example of search strategy

Database / information source: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>
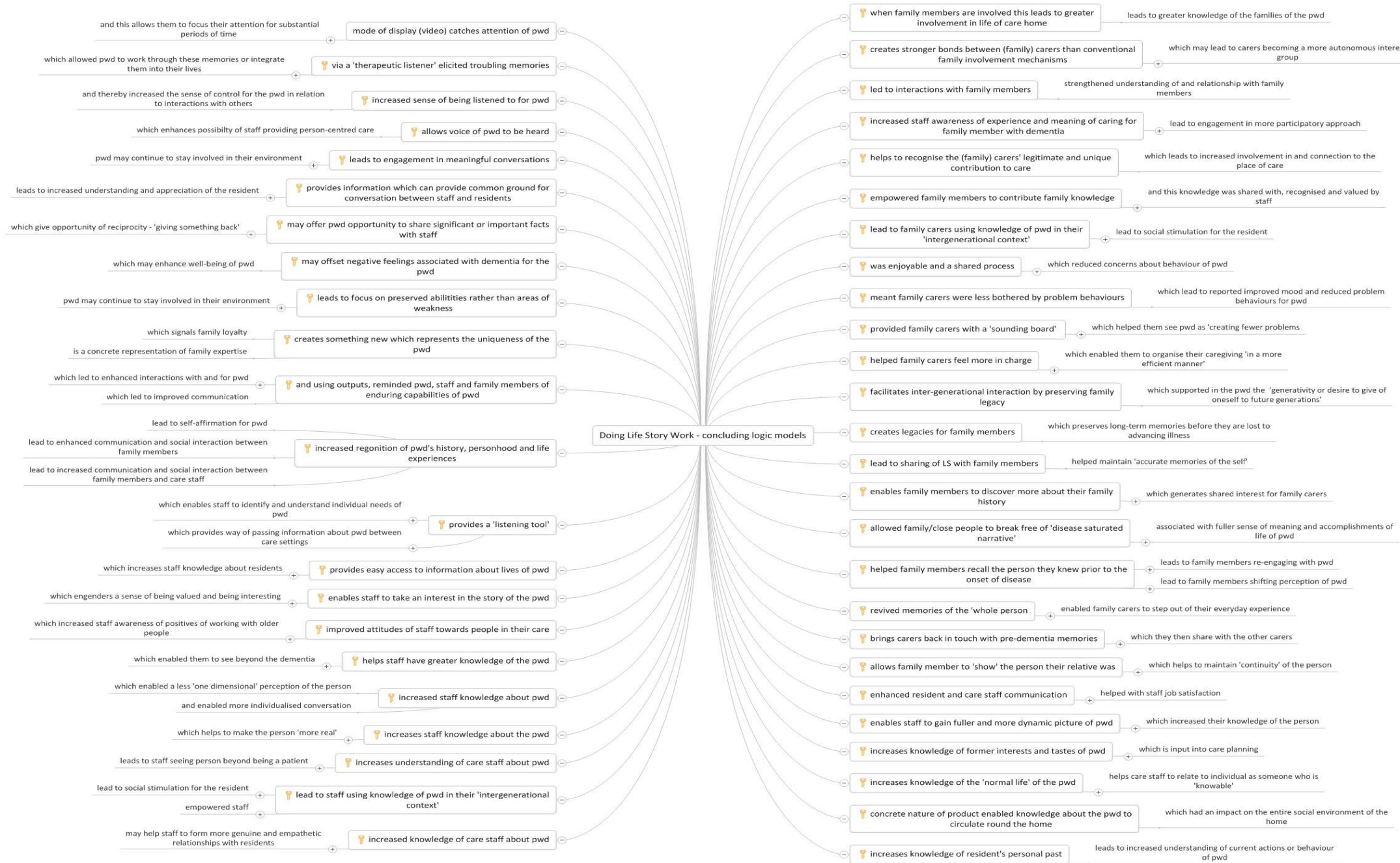
Interface / URL: OVIDSP

Search date: 28/08/12

Retrieved records: 123

Search strategy:

1   dementia/ or alzheimer disease/ or aphasia, primary progressive/ (87566)

2   (dementia or demented or confused).ti,ab. (69187)

3   alzheimer$1.ti,ab,jw. (80263)

4   or/1-3 (140560)

5   (life adj4 story$).ti,ab. (471)

6   (life adj4 stories).ti,ab. (279)

7   (life adj4 review).ti,ab. (1831)

8   (life adj4 history).ti,ab. (9320)

9   (life adj4 histories).ti,ab. (1457)

10   (life adj4 narrative$1).ti,ab. (280)

11   or/5-10 (12965)

12   4 and 11 (146)

13   animals/ not humans/ (3678892)

14   (rat or rats or mouse or mice or murine or rodent or rodents or hamster or hamsters or pig or pigs or porcine or rabbit or rabbits or dogs or dog or cat or cats or cow or cows or bovine or sheep or ovine or monkey or monkeys or horse or horses).ti. (1686732)

15   12 not (13 or 14) (145)

16   limit 15 to english language (123)

2. Concluding theories (to level 2 only)

Central node: Doing Life Story Work - concluding logic models

Left side branches

- mode of display (video) catches attention of pwd
  - and this allows them to focus their attention for substantial periods of time
- via a 'therapeutic listener' elicited troubling memories
  - which allowed pwd to work through these memories or integrate them into their lives
- increased sense of being listened to for pwd
  - and thereby increased the sense of control for the pwd in relation to interactions with others
- allows voice of pwd to be heard
  - which enhances possibilty of staff providing person-centred care
- leads to engagement in meaningful conversations
  - pwd may continue to stay involved in their environment
- provides information which can provide common ground for conversation between staff and residents
  - leads to increased understanding and appreciation of the resident
- may offer pwd opportunity to share significant or important facts with staff
  - which give opportunity of reciprocity - 'giving something back'
- may offset negative feelings associated with dementia for the pwd
  - which may enhance well-being of pwd
- leads to focus on preserved abilities rather than areas of weakness
  - pwd may continue to stay involved in their environment
- creates something new which represents the uniqueness of the pwd
  - which signals family loyalty
  - is a concrete representation of family expertise
- and using outputs, reminded pwd, staff and family members of enduring capabilities of pwd
  - which led to enhanced interactions with and for pwd
  - which led to improved communication
- increased regonition of pwd's history, personhood and life experiences
  - lead to self-affirmation for pwd
  - lead to enhanced communication and social interaction between family members
  - lead to increased communication and social interaction between family members and care staff
- provides a 'listening tool'
  - which enables staff to identify and understand individual needs of pwd
  - which provides way of passing information about pwd between care settings
- provides easy access to information about lives of pwd
  - which increases staff knowledge about residents
- enables staff to take an interest in the story of the pwd
  - which engenders a sense of being valued and being interesting
- improved attitudes of staff towards people in their care
  - which increased staff awareness of positives of working with older people
- helps staff have greater knowledge of the pwd
  - which enabled them to see beyond the dementia
- increased staff knowledge about pwd
  - which enabled a less 'one dimensional' perception of the person
  - and enabled more individualised conversation
- increases staff knowledge about the pwd
  - which helps to make the person 'more real'
- increases understanding of care staff about pwd
  - leads to staff seeing person beyond being a patient
- lead to staff using knowledge of pwd in their 'intergenerational context'
  - lead to social stimulation for the resident
  - empowered staff
- increased knowledge of care staff about pwd
  - may help staff to form more genuine and empathetic relationships with residents

Right side branches

- when family members are involved this leads to greater involvement in life of care home
  - leads to greater knowledge of the families of the pwd
- creates stronger bonds between (family) carers than conventional family involvement mechanisms
  - which may lead to carers becoming a more autonomous interest group
- led to interactions with family members
  - strengthened understanding of and relationship with family members
- increased staff awareness of experience and meaning of caring for family member with dementia
  - lead to engagement in more participatory approach
- helps to recognise the (family) carers' legitimate and unique contribution to care
  - which leads to increased involvement in and connection to the place of care
- empowered family members to contribute family knowledge
  - and this knowledge was shared with, recognised and valued by staff
- lead to family carers using knowledge of pwd in their 'intergenerational context'
  - lead to social stimulation for the resident
- was enjoyable and a shared process
  - which reduced concerns about behaviour of pwd
- meant family carers were less bothered by problem behaviours
  - which lead to reported improved mood and reduced problem behaviours for pwd
- provided family carers with a 'sounding board'
  - which helped them see pwd as 'creating fewer problems
- helped family carers feel more in charge
  - which enabled them to organise their caregiving 'in a more efficient manner'
- facilitates inter-generational interaction by preserving family legacy
  - which supported in the pwd the 'generativity or desire to give of oneself to future generations'
- creates legacies for family members
  - which preserves long-term memories before they are lost to advancing illness
- lead to sharing of LS with family members
  - helped maintain 'accurate memories of the self'
- enables family members to discover more about their family history
  - which generates shared interest for family carers
- allowed family/close people to break free of 'disease saturated narrative'
  - associated with fuller sense of meaning and accomplishments of life of pwd
- helped family members recall the person they knew prior to the onset of disease
  - leads to family members re-engaging with pwd
  - lead to family members shifting perception of pwd
- revived memories of the 'whole person'
  - enabled family carers to step out of their everyday experience
- brings carers back in touch with pre-dementia memories
  - which they then share with the other carers
- allows family member to 'show' the person their relative was
  - which helps to maintain 'continuity' of the person
- enhanced resident and care staff communication
  - helped with staff job satisfaction
- enables staff to gain fuller and more dynamic picture of pwd
  - which increased their knowledge of the person
- increases knowledge of former interests and tastes of pwd
  - which is input into care planning
- increases knowledge of the 'normal life' of the pwd
  - helps care staff to relate to individual as someone who is 'knowable'
- concrete nature of product enabled knowledge about the pwd to circulate round the home
  - which had an impact on the entire social environment of the home
- increases knowledge of resident's personal past
  - leads to increased understanding of current actions or behaviour of pwd

Working from the centre of the mind map, the first columns on both sides show the first argued intermediate process from each included paper, and the second columns the next intermediate processes or final outcomes. As described in the text, some programme theories had several intermediate processes.