Family biography as a grounding for dementia care

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Biographical approaches

• Definition
• Uses
• Contributions
• Gaps
• Research Project
• Integration into practice
Definition

• Story telling and listening (Basting 2003, Cheston et al 2004)
• Sharing memories of past (Wood & Ashley 1995, Brooker & Duce 2000)
• Prioritises personal meanings, attitudes and values (Heliker 1999, Clarke et al. 2003)
• Reveals life experience, accomplishments (Hepburn 1997, Caron 1999) and life patterns (Keady 2007)
• Maintenance of self-identity (Surr 2006)
Uses

- Children (Ryan & Walker 1985, 1993)
- People with disabilities (Hewitt 1998, 2000)
- Older people in acute care (Clarke et al 2003)
Contributions in dementia care

• Coming to terms with trauma and change (Cheston et al 2004)
• Behaviour management (Gibson 1994, Moniz-Cook et al 2003, Egan 2007)
Contributions in dementia care

• Assisting in transitions between care environments (Murphy 2000)
• Improving relationships between care staff and family carers (Clarke et al 2003, Egan 2007, Keady 2007)
Gaps in biography research

• Family/PWD experience of biographical approaches
• Focus on seeing the person within his/her familial and intergenerational context
• Families perception of the impact of biography work on staff attitudes
• Family and PWD views on the effect of biography work on care
• Impact on relationships between staff, family and people in care
Background

• Industry collaborative project.

• The *Family Biography Workshop* (FBW) is a deliberate and structured effort to bring staff and family carers together and aimed at supporting them to co-create the family biography of the person with dementia in care.
Research Objectives

1. Ensure that the views of family and people with dementia were heard;
2. Understand the person with dementia in the context of his or her family and intergenerational history;
3. Influence conversation in order to reconceptualise the care-giving relationships between resident, family and staff;
4. Promote sensitive and relationship-centred care informed and shaped by knowledge of personal identity and meaning in life; and
5. Examine the influence of newfound biography knowledge upon attitudes, perceptions of care and subsequent participatory dementia care.
Method

Family Biography Workshop

• Six weekly two-hour sessions.

Purposeful Sample

• 7 family carers (2 adult children, 5 spouse)
• 7 relatives in care with dementia (1 mother, 1 father, 5 husbands)
• 7 staff members (2 nurses, 5 therapists)
<table>
<thead>
<tr>
<th>FBW Session</th>
<th>Content</th>
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<tbody>
<tr>
<td>Icebreaking</td>
<td>➕Introduction and icebreaking ➕Establish roles, rules &amp; expectations</td>
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<td></td>
<td>➕Genogram exercise</td>
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<tr>
<td>Story making &amp; timelines</td>
<td>➕What makes a story a story? ➕Review individual time-lines</td>
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<tr>
<td>Key life moments &amp; events</td>
<td>➕Identify key moments and events in the person’s life and development</td>
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<td>Memorabilia &amp; photo exercise</td>
<td>➕Review memorabilia and photos and select those most representative</td>
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<td>of person’s life and development ➕Individuals share selected photos</td>
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<td>and tell stories to the group</td>
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<tr>
<td>Themes exercise</td>
<td>➕Participants identify person’s life themes and links to stories</td>
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<td></td>
<td>➕Group sharing, editing &amp; authoring</td>
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<tr>
<td>Practice performance</td>
<td>➕Presentation of developed stories ➕Group sharing, editing &amp; authoring</td>
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Focus Groups

• The experience of being involved in the FBW and its benefits and challenges
• The impact and/or influence of participation in the FBW on knowledge, attitudes, perceptions, relationships and care involvement and practices.
Findings - Family

• Highlighting the meaning and accomplishments of the person’s life
• Supplementing a disease-saturated narrative
• Dealing with the impact of the dementing illness
• Grieving and healing

*I think it's made me, having to bring out the story of the life, it seems to have allowed me to let go of something that I was holding back, 'stand outside' and see the bigger picture.*
Findings - Staff

• Opportunities to connect
• Appreciating the family and intergenerational history
• Building relationship-centred care
• Developing care partnerships
I’ve found that it gives me a different way of looking at the person … I have I feel more respect for them instead of seeing them as a person with dementia I see them as a person first and the dementia is just (pause) an unfortunate sideline.

It was nice to put them together as a couple even though we know that they are married it’s still the wife goes back home and the husband is here. When you learn about their story and read the different things they have enjoyed, about the dancing, and put it together you can see them as close together as a couple (pause) it’s brought them together like a family, so that we could relate to Colin in a different way.

And just seeing how much you all care about your family member has been great (you know) that makes us feel like we are a part of that as well (you know) that we did really care and that we’re together.
Findings - PWD

- Being stimulated by personal communication and memories
- Feeling settled and calm

Knowing the history we know some things about her life and we know they are exciting for her or interesting for her.

He has always been so interested in building and making things. It might just be a point of giving him something in his hands that makes him feel safe so this knowledge I think is very important …I think its calming him.
Findings - Organisation

• Promoting community
• Timing – are families ready?
• Admission procedures
• Multi-disciplinary assessment
Organisational - challenges

- Start biography development in community
- Education strategy
- Partnership on residential admission
- Linking new and existing families
- Case review and case conference
Integration into practice

• Cultural and structural change
• Medical approach
• Changes in best practice
• Care practice organisation
• Values and the behaviour
• Change agent
• Priorisation
“Staff have commented that they no longer look at the behaviours of a resident as difficult mannerisms that need to be managed, but rather look to see if these behaviours were part of the person's quirkiness or personality prior to the onset of dementia. Staff have found a new level of understanding and patience for the individuality of each person and a new found respect for their worth and life experience.

This experience allowed staff the opportunity to gain insight into how their resident's touched the lives of their loved ones and colleagues. Those present at the final workshop believe that this was a real privilege.

The Family Biography Study has done wonders in realigning staff focus to the person that lies within the diagnosis, and has emphasised each persons individual worth and the value in their life experience, as well as highlighting the importance of humanity, compassion and spirit.”