

The Journal of DementiaCare Research Focus

This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

Recognising the needs of children of younger people with dementia

While research has explored the impact of caring on younger people, little is known about the impact on children of having a parent with dementia. Emma Svanberg summarises the process children go through in order to adapt to dementia in a parent, and suggests ways in which services can take their experiences into account.

The children of younger people with dementia have been largely excluded from research and service development. Recent research (Svanberg *et al* under review) has suggested that the carers of younger people with dementia have higher levels of burden (eg Freyne *et al* 1999), but most studies have focused on spouses. Those which have included children have suggested that they experience psychological and emotional consequences (Luscombe *et al* 1998), they may have additional caring challenges (Gilliard 1999) and their developmental tasks may be affected (Garbutt 2006). Studies with young carers of parents with other conditions have found that caring at a young age can have an extensive impact (Becker *et al* 1998). However, little is known about the impact on children of having a parent with dementia and how services may adapt to meet their needs.

A recently completed qualitative study (Svanberg *et al* awaiting publication) aimed to bring to light the experiences of these children. We carried out interviews with twelve participants aged 11-18, from around the UK. Results focused on areas including: learning about dementia, noticing changes and gaining support from family and friends. During the study we found that children emphasised the process they had to go through in order to adapt to the many changes dementia

brought into their family. We created a three-stage process model in order to summarise this (see Box 1 opposite). By exploring the stages identified in Box 1, we can see how these children could be better supported, in order to enhance a continued relationship with their family.

Grief for the 'parent before dementia'

As the young person noticed changes in their parent with dementia, they had to accept the loss of the parent they used to have before the illness. This may have meant accepting no longer being looked after, and learning that they could not expect the parent to do tasks such as help with homework. For many, this led to a realisation that they had also lost the parent they expected to have in the future, who would share significant events with them. Grief seemed to be a fitting way of viewing this stage in their experience.

Previous research into carer experiences with older people with dementia has explored the grief felt by adult child carers, with similar reports of the loss of the relationship with the person they used to know before the onset of dementia (Lindgren *et al* 1999). The majority of participants in our study spoke about their experiences with little display of emotion, despite describing a fundamental loss of the parent they knew before. This is also reflected in previous literature, such as

the finding that adult child carers with parents in early stages of dementia minimised the changes they were experiencing (Meuser & Marwit 2001). These researchers viewed grief as additive, with the different losses over time exacerbating the sense of loss. Others have described the concept of 'dual dying' (Ott *et al* 2007), which might apply to these children, who experience the loss of the parent they used to know before dementia developed, and the eventual loss when they die.

With the realisation of this loss, the children went through a process of separating the parent with dementia from the parent they remembered before their diagnosis. This could suggest that they may complete some of the tasks involved with grief, reaching a stage where they have emotionally withdrawn from their parent, even though this may be years before their death (William Worden 2003). The anticipation of loss may have given these children the opportunity to say goodbye and accept this loss (Saldinger *et al* 1999),

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This *Research Focus* section of the *Journal of Dementia Care* aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda.

We would like to hear from you, specifically with the following:

- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

Each *Research Focus* will include a comprehensive review by a leading expert of significant research in a subject area.

enabling them to focus on the task of caring for the parent as they now exist.

Emotional detachment from the parent

As children accepted the loss of their parent before dementia, they then seemed to detach themselves from the physical parent who was left. (This contrasts with the findings of Hellström *et al* (2005, 2007) in their qualitative research with couples affected by dementia. They proposed that couples strive to maintain a 'nurturative relational context' to sustain the relationship despite dementia.)

This detachment may come from the children's experience of 'ambiguous loss', with the parent seen as 'physically present but psychologically absent' (Boss 1999, p9). With little support to face the diagnosis, the children began to see the parent as a new person, frequently like a child, who they were then able to separate from. This echoes the 'depersonalisation' of the person with dementia described by Kitwood (1997): it enabled a detachment when retaining closeness may have been too distressing. Detachment could also be due to anger at feeling abandoned.

Alongside this detachment, used as a coping strategy to deal with the distress of the loss, the children also seemed to discover that both parents were less able to meet their needs (Saldinger *et al* 1999). To be able to help to look after their parent with dementia, they began to act as an equal to the other parent (where one was present), sharing tasks and working as a team. Where care was usually provided only by the family, this led to a fragile situation. It seems the children realised that they were not able to put additional burden on to their other parent. Instead, they tried to become autonomous, taking responsibility and learning to cope without relying on their parents. They coped by detaching both emotionally and physically, and by leaving when things became too much. While this may have promoted resilience, in their ability to adapt to dementia, this self-sufficiency may be premature. The children became discreet helpers, sharing the burden on the family without drawing attention to any difficulties they were having.

Becoming a grown up

As a result these children became like adults. During the interviews, they often appeared surprisingly mature. Research on 'parentification' sheds some light on the impact of this maturity. Parentification has been defined as 'children or adolescents assuming adult roles before they are emotionally or developmentally ready to manage those roles successfully' (Stein *et al* 1999, p193). The children in this study experienced this both in role reversal with the parent with dementia and in their role

Box 1: The process of adapting to dementia

Grief for the 'parent before dementia'

The children went through tasks of grief for the loss of the parent they used to know before dementia developed, and the loss of the relationship they had and expected to have. They began developing a new relationship with the parent, but described them as being a different person who they saw as being child-like.

Emotional detachment

The children tried to 'get on with' the tasks of caring. By detaching themselves from the parent with dementia they were able to do this without acknowledging any distress this could cause. They also began to treat their other parent as an equal in caring.

Becoming a grown up

The increased independence resulting from the above led to children feeling more grown up, proud and mature. However, little recognition was given to their own needs or contribution.

as friend to the other parent (Earley & Cushway 2002).

While this may teach responsibility, encourage self-esteem and a healthy identity (Jurkovic 1997), it could be dangerous when the child is burdened excessively in an unsupportive environment (Warren 2007). Byng-Hall (2008) draws attention to the sense of inadequacy that may be felt by a child who appears to be capable but may feel that they are not able to fulfil the role expected of them. This was reflected in the participants' statements that they could not be called 'young carers' as they were not doing enough.

Particularly during adolescence, when young people are discovering their identity (Erikson 1959), they may also start to identify themselves as carers, for example by becoming 'caretakers' in other relationships (Hooper 2007). While there are positive aspects to taking on an identity of caring for others, these children may find it difficult to care for themselves and may 'abdicate' their status as children (Chase 1999).

This is reflected in a conversation I had with the mother of one participant. When discussing with her how little she had spoken to her son about dementia, she described a conversation when she had encouraged him to talk and he responded 'I can't, because I'd be talking about your husband'. This left me with the overriding impression of children trying to 'get on with it', and ignore their own struggle, in order to help the family and in the absence of external support.

Offering support

During the interviews, participants rarely mentioned support from services. Where

services were discussed, they were often spoken about in the context of failures. However, children who had been offered counselling or personal support described this as helpful. Recent changes in service provision both in children's and dementia services suggest they might adapt to recognise the needs of these children. Small changes to tackle each stage of the process of adapting to dementia, such as including children in decision-making and encouraging them to talk about dementia, may allow these children to recognise their distress, maintain a fulfilling relationship with the family and enjoy a continued childhood. Even just the acknowledgement of the child taking on caring tasks could encourage the child to think of themselves as fulfilling an important role for the family, while retaining their status as a child (Byng-Hall 2008).

Recently there has been a drive by the UK government and young carers' initiatives towards working with the whole family. Promotion of whole family, interagency practices (Frank 2002, Leadbitter 2008) could target each step of the process outlined above, simply by recognising the place of the child in the family network. Additional support for families could also release the pressure on parents, enable them to meet the needs of their child and promote the relationship with the parent with dementia, regardless of their diagnosis.

The implementation of the National Dementia Strategy (Department of Health 2009) is also taking place. While there is little mention of younger people with dementia in this document, there is recognition that care may be carried out by the under-18s, and the emphasis placed on early intervention, increased awareness and improved support could also improve the situation for younger people and their families.

Recent policies from different government departments recommend that teams should support families as a whole: in the National Dementia Strategy this is to be done through dementia advisers; in the Children's Plan (Department for Children, Schools and Families 2007), through family pathfinders.

If services implementing the National Dementia Strategy consider the benefits of whole family working, it is likely that children's contributions could at least be recognised, and they could be signposted to young carers' projects if appropriate. At the very least, when a younger person with dementia is given a probable diagnosis, or approaches services with possible symptoms, there should be an obligation on staff in all services to ask whether there are children at home who may need additional support (HM Government 2006, Social Care Institute for Excellence 2007).

Our study revealed the process through

which children adjust to dementia and suggested ways in which they could be supported. The children who took part are managing unusual and sometimes tragic circumstances. Although they appear to be coping with competence and adaptability, taking on what is required of them usually without question, we need to recognise their struggle and do what we can to alleviate it.

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'New beginnings': towards distributed responsibility in memory services

Sean Page, Kevin Hope and Chris Maj describe the second phase of the New Beginnings project in the Ashton, Wigan and Leigh Memory Assessment Service. The project's first phase showed that experienced nurses, working in a supportive environment, can be highly accurate in formulating hypotheses about the diagnosis of dementia. The second phase aimed to develop these skills in other members of the multidisciplinary team.

Positive changes can occur when members of a memory assessment service team other than doctors are empowered to undertake comprehensive assessment and formulate hypotheses on the diagnosis of dementia. By this we do not mean that diagnosis-making authority should move away from the consultant psychiatrist, but that involving others increases the quality of initial assessment.

We know that trained nurses can detect the presence of a dementia syndrome with 94% accuracy (Page *et al* 2008). Specificity, the ability to correctly identify the proportion of people who do not have the specific condition, was 96%.

But what about other practitioners? An opportunity to move our 'New Beginnings' project along by testing this arose in early 2009 with the introduction of a new Memory Assessment Service in Lancashire.

The Ashton, Wigan and Leigh Memory Assessment Service

There are 2400 people with dementia in the borough of Wigan (projected to rise to approximately 4,000 over the

next 15 years). Provision for the early detection and treatment of dementia has been piecemeal and inadequately resourced. Memory clinics were patchy, focused exclusively on access to 'anti-Alzheimer' medications, and staff resources were diverted from community teams.

The evolution of the current local model originates in an assessment and treatment centre for early presentations of cognitive impairment. Prompted by the National Dementia Strategy, key principles and assumptions emerged:

- There would be devolved responsibility from a single professional group (psychiatrists) towards a multi-practitioner-led service supported by them.

- The core team would consist of nurses, occupational therapists and social workers, all undertaking assessments aimed at making a provisional hypothesis.

- Initial hypotheses would be confirmed by the multidisciplinary team, led by the consultant psychiatrist; confirmation

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would lead to formal diagnosis of a dementia syndrome and sub-type.

- The new way of working would be accurate, reliable, evidence-based and professionally acceptable to patients, carers and to staff, who would augment their profession-specific skills alongside complementary new skills.
- The service would work within a person-centred approach and ultimately people would be told their diagnosis by whichever person was best placed to do so.

The challenges around such a change should not be underestimated; the new service model necessitated a very different model of practice. Addressing this, through training, was a fundamental aspect of the New Beginnings project.

Programme development

The training programme devised was the second stage of the New Beginnings project. It aimed to meet the learning needs of practitioners who would play a key role in the assessment and diagnostic process. Dialogue, collaboration and negotiation with the service manager helped identify what was needed (see Box 1).

An appreciation of, and alertness to, the social and psychological impacts of dementia were viewed as fundamental. The team wanted assessment, as far as possible, to promote a sense of self and self-identity in clients, enhance coping and minimise excess disability. Staff needed to be confident that they were conveying reliable and accurate information.

Learning outcomes for the programme were identified (see Box 2) with emphasis on assessment being both a task and a process. 'Task' is the purpose of assessment (why it is done) while 'process' is the manner of assessment (how it is done). We explored what these might mean in practice.

An assessment model for a memory assessment service was justified, described and its evidence base outlined. Aspects of the assessment model covered included:

Box 1: Commissioners' requirements for inclusion in training programme

- person-centred principles of dementia care, viewed essential as a basis for the service ethos
- developing confidence and competence in the use of psychometric measures
- improved understanding of the importance and function of engagement and assessment skills
- skill development in the task and process of assessment which supports the diagnostic endeavour
- development and subsequent application of pre- and post-diagnostic counselling work
- the need to develop, as the service progresses, skills and liaison with primary care, and support/training for care homes.

Box 2: Learning outcomes

At the end of this programme participants will have increased confidence and understanding of:

- core concepts that underpin different understandings of dementia
- how varying perspectives may impact upon subsequent care practices, and their impact on the lived experience of people affected directly and indirectly by cognitive impairment
- the need to value and incorporate into practice the unique experiences, needs and strengths of each person living with dementia
- best practice in the engagement and subsequent assessment of people living with dementia that emphasise person-centred principles within a multidisciplinary context
- best practice in sharing a diagnosis
- standardised application of the assessment portfolio adopted by the service
- options for post-diagnostic intervention.
- social history
- subjective history
- medical history
- assessment of cognition
- assessment of mood
- case formulation

The five-day programme was repeated twice to allow for the service to be maintained and provide flexibility for attendance. The three-day block was followed by two study days to consolidate and reinforce initial learning. Team members presented examples of the assessments they had undertaken and the group discussed their hypotheses.

Evaluation

Aspects of the training programme were evaluated:

1. Knowledge

Almost all respondents (20 out of 21) said their knowledge had improved over the duration of the programme. Comments included statements that "Knowledge definitely improved" and "Really enjoyed the three days especially the biomedical informa-

tion". Participants appreciated starting with a solid foundation of bio-psycho-social theory. Feedback confirmed that a balance between the theoretical and practical aspects of the programme was achieved.

2. Perceived impact on practice

The desire to influence practice positively was a central concern. Practical sessions were well received. Feedback included: "Definitely improved my knowledge and understanding particularly about how patients experience the tests," and "Improved my knowledge and helped me feel reassured and confident."

Did participants have greater confidence in undertaking an initial assessment following the course? Reassuringly, three quarters reported this was so. All said the course would benefit their practice and many had developed a clearer idea of what their role would encompass.

3. Satisfaction with teaching

Feedback was unequivocally supportive of the positive and

engaging learning environment, and included the following comment: "I enjoyed the three days. The course was delivered in a relaxed, well informed and understandable way."

Almost all respondents felt the programme was well organised, that their participation was encouraged and that the content of the course was clear and relevant.

4. Team building

Staff appreciated the opportunity to meet new colleagues, and had learned more about each other. They felt the programme instilled a sense of direction about the service, helped develop a common language, and understanding of its assessment function.

5. Impact on practice

There was a gap of three months between the initial training and the follow-up sessions. This allowed participants to begin to apply those things that they covered in the training. They presented case studies at the follow-up days to colleagues and the teaching team.

The model had been integrated into day-to-day practice with ease. Staff reported their increasing comfort and confidence in using the model and highlighted added benefits. They appreciated the structure it afforded to their clinical encounters, and felt clients on the receiving end of the assessment benefited from feeling that their concerns were being fully addressed. Staff reported how the revised framework had generated far more information about clients which was later used in care planning.

The team felt that attention could be directed towards consideration of post-diagnostic interventions to build on the baseline provided in the two days. We are taking this forward, possibly including support workers.

Conclusion

Phase two of the New Beginnings project appears to have met the needs of all involved, been well received with high levels of satisfaction with both content and process of teaching. Experienced

health and social care practitioners, who have not previously worked in the advanced way that is now required, can quickly assimilate new learning and apply it to practice. Furthermore those same practitioners can identify realistic benefits from this new way of working.

Phase three of the project will be a prospective study involving ten practitioners (four mental health nurses, three occupational therapists and three social workers) analysing data from the first 100 hypotheses that they generate and comparing them with the later psychiatrists' diagnoses. We look forward to seeing the results.

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