

‘Spirituality and faith in dementia’

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Background:

DementiaPlus, the dementia services development centre for the West Midlands, is based in Wolverhampton and supported by

- Wolverhampton City Primary Care Trust
- Wolverhampton City Council
- Wolverhampton University
- National Institute for Mental Health England

It has a remit across the whole of mental health in later life (including dementia at all ages, mood disorders, suicide, alcohol related illnesses, paranoid states, the graduate population, and delirium) and provides gathering and sharing ideas, training and education, networking, consultation, and research and audit. Interest and activity in the field of spirituality and health has been expanding and includes a conference with chaplains in 2004, involvement in evaluating Back to Church Sunday in September 2004, and a seminar series. There are links with the Centre for Ageing and Mental Health at Staffordshire University and the Special Interest Group at the Royal College of Psychiatrists. Previous projects at Dementia Plus, the Twice a Child project in Wolverhampton (Dementia Plus, 2001) and the Tale of Two Cities project with Bradford (Dementia Plus and Bradford Social Services, 2003), had highlighted the importance of spirituality in relation to mental health.

These initiatives encouraged us to endeavour to discover more about the relationship between dementia, spirituality and faith and how these are addressed in routine clinical situations in the UK:

- how are spirituality and faith affected by dementia?
- how are spirituality and faith affected by caring for someone with dementia?

- how do religious communities view dementia and respond to its presence within their membership?
- how is the experience of dementia modified for patient and carer by their spirituality and faith?
- Are there opportunities for strengthening spirituality and faith and/or improving life for patients and carers in this situation?

We have taken the first steps towards answering these questions by an exploration of spirituality and faith amongst people with dementia and their carers who attend the memory Clinic at Penn Hospital, Wolverhampton.

Penn Hospital Memory Clinic

Penn Hospital is a Community Mental Hospital, which provides the main in-patient base for the Wolverhampton Mental Health Service for people of working age and older people.

Wolverhampton is a small city, population 280,000 of whom 40,000 are aged 65 years or older. Mental Health services were improved to a community model during the late 1990s (Jolley et al. 1997). The service for older people is innovative and well integrated with other services for older people (Jolley, Jenkins and Dixey 1996). It has developed a Memory Clinic from 1997. This has become a useful component of the service and undertakes research and audit as well as teaching (Lyle 2003, Grizzell and Jolley 1999, Millson, Jolley and Ward 2002).

All clients of the Memory Clinic receive a thorough multi-dimensional assessment and their status and progress is monitored by regular, routine measurements of cognition (Mini-Mental State Examination: Folstein et al 1975), non-cognitive symptoms (Mini-Mouse: Allen et al 1996), behaviour (Crichton Royal Behaviour Rating Scale: Wilkin and Thompson 1989), general health and weight. Stress upon main informal carers is monitored using the General Health Questionnaire (GHQ) (Goldberg and Hillier 1979). The Memory Clinic receives roughly 200 referrals per annum. At any one time it carries 180-210 patients within treatment.

We report here on an initial analysis of quantitative findings from an exploratory study of spirituality and faith amongst patients and carers attending Penn Hospital Memory Clinic.

Research methodology

This research was designed in four stages:

Stage 1 – Demographic data to be collected from administrative records within the memory clinic. All patients attending the memory clinic have an established diagnosis and a completed Mini Mental State. Their capacity to take part in the study was confirmed with the team caring for them.

Stage 2 – Quantitative survey. Patients and carers were to be asked to complete three questionnaires:

- The Royal Free Interview for Religious and Spiritual Beliefs: self-report version (King & Speck 1995; King, Speck and Thomas 2001). This questionnaire has been constructed, standardised and validated for use in the

UK. It has sound mathematic characteristics. Most subjects find that the shorter, self-report version (2001) takes no more than 20 minutes to complete. The main measures of interest are contained in a series of questions requiring categorical answers and seven, ten-point Likert scales. This was to be its first known use in assessing the religious and spiritual beliefs of people with dementia.

- General Health Questionnaire-28 (Goldberg 1981)
- Satisfaction with Life Scale (Diener et al. 1985)

Stage 3 – Qualitative design. A semi-structured interview was to be carried out with 25 people with dementia and their (main) carers.

Stage 4 – Qualitative design; semi-structured interviews to be carried out with local faith leaders.

All three of the questionnaires and rating scales were made available in large print.

Semi-Structured interview schedules were produced for use with an opportunity sample of patients and carers and a selected group of Faith Leaders: These interview guides were devised specifically for this project. They pose a series of seven questions designed to trigger more detailed description and dialogue on areas of interest. The findings will be reported elsewhere.

Population and sample:

1. People with dementia who were attending Penn Hospital Memory clinic, autumn 2004, and having a score of 12 or above on the Mini-Mental-State Examination (MMSE) scale of cognitive function (Folstein et al 1975).

Patients with a score less than 12 were excluded on the basis that they were likely to have difficulty in understanding the invitation to participate in the study and/or cope with the questionnaire or interview. The capacity of individuals with scores of 12 or more on the MMSE to cope with the tasks was assessed by their consultant at the Memory Clinic. Patients from all faiths were eligible for inclusion in the research. Interpreters at the memory clinic were available should the need arise.

2. The main carer of the person with dementia.

3. In addition faith leaders from five local faith communities: Roman Catholic, Church of England, Methodist, Islam and Buddhist were interviewed. Their observations on dementia in their faith will be reported elsewhere.

Findings:

There were 184 patients registered with the clinic during the autumn 2004. Women outnumbered men. The majority (more than two thirds) were aged 75 years or older, and a small minority (5 percent) were under 65 years old. Most lived in private households: a quarter lived alone and over half with a marital partner. The religious affiliation of all but two was known to the clinic.

All but three were Christian or agnostic: almost two thirds belonged to the Church of England.

All these patients carried a diagnosis of dementia, of which Alzheimer's disease accounted for three quarters. They had been known to the clinic for between one month and nine years, with an average of two years. Their cognitive function had not, on average, declined since first registering with the clinic, mean score on the MMSE being 21. Carer stress as measured by the GHQ had fallen, as had evidence of non-cognitive symptomatology, but overall dependency or behavioural problems as reflected by the Crichton Royal Behavioural Rating had increased.

Only 117 patients had scored 12 or more on the MMSE at their most recent assessment. Of these, only 85 were judged by their consultants likely to cope with the invitation to contribute to the study without difficulty or distress. These patients and their main carers were approached by the research assistant, supported by clinic personnel.

Twenty-nine patients agreed to contribute to the study (34% of those invited). Carers sometimes indicated that they would be pleased to be involved themselves, but that they felt the patient should not be approached. This view was always respected. In four families two carers contributed responses, thus carer data relates to a possible 33.

The 29 patients contributing to the study were different in profile from the whole pool of 184: the gender balance was even more skewed to women, whereas carers were predominantly male (husbands). This may have reflected lack of interest amongst male patients, but was also a function of the views of their wives on their likelihood of complying/ coping. There were fewer patients included (50%) in the over 75-age group.

None of the patients was living in residential care; over two thirds were living with their marital partner (carer) in their own home. The religious affiliation of these patients was similar to that of the whole pool; carers were a little less likely to confirm a faith. Only one patient-carer couple was Black. All but six patients had scored 20 or more on their most recent MMSE, the mean being 24.

The pattern of scores on the Royal Free scale of spirituality by patients and carers, showed many similarities. Both groups rated personal experiences of spiritual influence more highly than the possibility that natural disasters or world events such as wars might be controlled by a supernatural power. Both patients and carers rated their personal beliefs as strong and important in their daily lives, with modal scores being within the highest band. Both found helpful influence in their daily lives, carers more so than patients.

Discussion:

This paper reports preliminary findings from the quantitative component of this multi-layered exploratory study. It has taught us that an approach to measuring spiritual aspects of dementia amongst patients with dementia and their carers through a Memory Clinic is feasible. Conducting the exercise as a special investigation beyond the routine work of the clinic, and addressing the full membership of that clinic, has resulted in information being gleaned from a subset of patients and their carers. Patients included (compared with the whole Memory Clinic population) are likely to score more highly on MMSE, to be female, and to live at home with a spouse.

Within this sub-group, both patients and carers have found the Royal Free Scale of spirituality acceptable and within their capacity. Patients' spirituality profiles are similar to those of their carers. This encourages us to know that both patients and carers have spiritual lives and may have needs arising from these related to their experience of illness or caring. In the early stages of dementia there is no obvious reduction of spiritual awareness amongst patients when they are compared with those caring for them.

There is limited normative data available from published studies using the Royal Free Scale. The scores registered within this study are a little higher than those reported elsewhere from patients and controls, but lower than scores from dedicated religious groups. (King and Speck 1995; King et al 2001). This may be a function of the process whereby patient and carer couples chose whether to contribute to the study. It was clear that the very mention of spirituality or faith produced responses which often included anxiety or guilt that individuals had neglected to attend a place of worship, or in other ways had failed to address responsibilities in these areas of life. Thus only the more confident or more committed may have felt comfortable to join the study. In the absence of independent normative data, it seemed reasonable to use carers as comparators for patients, and the similarity in their profiles would seem to substantiate this.

These findings provide additional ammunition to those championing the involvement of patients in planning and conducting their own care programmes and developing services for people with similar problems and need (Cantley et al 2005): there is no denying that these patients with dementia stand equal with their carers in spirituality and faith.

They confirm that those of us providing services must learn more about the spiritual characteristics and needs of patients and carers. More will be learned by introducing questions of spirituality and faith in routine assessments and the revision of care plans to accommodate identified needs. This will bring dementia services into line with palliative care services. It will be important to monitor findings and responses to such initiatives and should lead to wider utilisation of the approach in healthcare generally, including healthcare of people with other mental disorders.

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