

Candlelight Group: a pilot project for people with dementia

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Introduction

Religion is important to older people ^{1,2} and most individuals over 70 years of age who were born in the United Kingdom are from a generation for whom attending church and going to Sunday school was an integral part of everyday life. Those who have been active members of their parish and regular churchgoers may no longer be able to participate for a variety of reasons, from poor mobility to social disengagement, the latter often caused by isolation and compounded by cognitive failure. In individuals with dementia, those who live with a family member may no longer be taken to church or included in activities because of behaviour that may appear inappropriate or cause embarrassment to their relatives.

Factors that contribute towards spiritual health include a sense of identity, an awareness of one's relationship with God, oneself, others and the environment. The feeling that life has a sense of meaning and purpose is also important ³. Spiritual needs have been linked to religious beliefs, the need for religious ritual and also for the desire to understand oneself. The latter includes seeking a deeper understanding of normal experiences, holding onto our sense of personal identity and contemplating the meaning of life ⁴. For people with dementia, this is more difficult because of the problems they are experiencing with memory and communication.

It has been suggested that people who participate in a spiritual life may have an easier time coping with the losses that occur as a result of ageing ⁵ and people with dementia are coping with loss on a huge scale on a daily basis. Their sense of security is taken away as personal identities become blurred and memories of people and places fade ⁶. Loss of dignity and self-respect may also occur. By attempting to meet the spiritual needs of these people we may help in some way reduce their sense of loss and isolation.

For people with dementia who may be struggling to interpret what is going on around them, the security of their faith may bring great comfort - for example, hearing familiar hymns may bring back memories.⁷ Religious rituals are therefore important as these memories may have been laid down in childhood and so may be comforting and still familiar ⁴. The use of religious symbols can also connect the present moment to the whole of one's life, where these may have been present throughout ⁸.

We describe a small pilot project designed to address spiritual needs of individuals with dementia attending a Day Hospital for assessment and treatment.

Method

The Candlelight Group is a weekly prayer group designed for people with dementia attending Downs Day Hospital in Sutton, UK. The Day Hospital is part of the older people's services provided by South West London and St. George's Mental Health NHS Trust. There are places for up to 35 people a day living in the London borough of Sutton. The day hospital clients are referred by the community psychiatric nurses from the local Community Mental Health Team for Older People. Those referred have complex mental health and social care needs, and the cognitive impairment is often accompanied by significant psychological distress and / or behavioural difficulties.

Format of the service

The Candlelight Group was designed by the Ward Manager in collaboration with the appointed Trust Pastoral Advisor (Chaplain). The format was adapted to people with dementia. The duration of the service did not exceed 20 minutes and its structure was kept simple, with an uncomplicated order of service. Large font was used in the sheets provided as some people may have poor eyesight. The format of the group was the same every week and the same hymn was sung to start each service.

A multi-sensory approach was chosen, including items that would involve:

- sight: lighted candles and different coloured tablecloths, liturgical images and icons
- sound: familiar hymns and prayers
- touch: holding hands, beads and other sacred items
- smell; fresh flowers, incense

The group was run by the Chaplain and his assistant. On average five or six people with dementia attended.

Aims and Objectives of the pilot study.

The group was set up to try and develop a means of meeting the patients need for religious activity and the purpose of the pilot study was:

1. to record the response of clients attending the group
2. to standardise the method prior to a later formal qualitative study

Twenty-four patients (18 female, 6 male) at various stages of dementia were invited to join the prayer group. Twelve (10 female 2 male) patients expressed a desire to participate in the group, which was held weekly. A different group of four patients attended the group each week for three weeks. The age range of the participants was 64-93, which reflected the age range of people who attend the day hospital. (Fig 1) Immediately after the group the Investigator interviewed each patient using open-ended questions (See Appendix).

Results.

50% of the patients expressed a desire to participate in the prayer group. The responses of the people with dementia suggest that the prayer group was overall a positive experience, which may have helped to meet their religious needs. Most individuals reported feeling satisfied with the experience and one lady also stated that it was helpful in expressing her emotions (See Appendix).

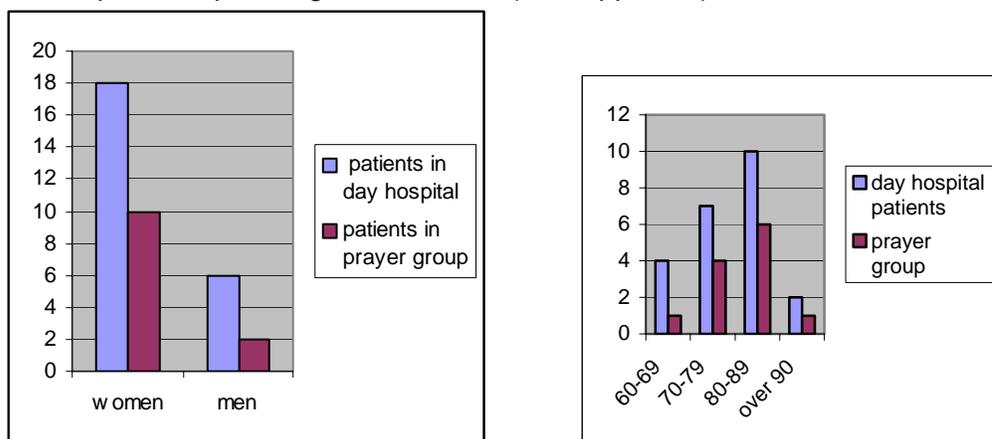


Fig. 1

Discussion

The day hospital aims to provide a stimulating environment for people with dementia through a variety of therapeutic activities. The focus is on providing person-centred care, which promotes independence and the utilisation of existing skills, plus the social aspect of sharing and meeting with others. Prior to the development of the Candlelight Group, religious services had for some time been held for patients at Christmas, Easter and Harvest festival, and the patients generally seemed to respond well.

The Candlelight Group was set up to allow individuals with dementia attending a Day Hospital the opportunity to participate in congregational religious worship. This might have been unavailable to them because of their condition and lack of opportunities in their current circumstances. The service was adapted to their cognitive abilities and its duration proved compatible with their anticipated degree of appreciation and participation. It was expected that some people may become restless during the service, however everyone remained seated. Most people joined in with the familiar hymns and nearly everyone could remember the Lord's Prayer.

Furthermore, the feedback from those who attended was generally positive, yet it was observed that when interviewing the patients after the service, those interviewed later had lesser recognition and were less able to provide reliable answers. For the purpose of future projects, it was therefore decided that only one or two participants would be interviewed following each service. Interviews with the same patient would also be repeated on different occasions. This would in future allow a more extensive qualitative analysis on a larger number of individuals.

It was felt that people with dementia might welcome the opportunity to take part in regular religious activity especially if it has been an important part of their lives. The observed participation in the Candlelight Group confirmed an element of 'normalisation' within a dementia Day Hospital, in which individuals would in this way share with others familiar experiences derived from their original upbringing, therefore satisfying an unmet need in their lives. Words from old hymns and sacred readings were recalled, and behaviours associated with mutual worship were evoked by the carefully created atmosphere and order of service. In general, the group appeared at ease, comfortable and relaxed, and each individual seemed to be more in tune with their own individuality than at other times in the Day Hospital.

Furthermore, although the people who attended the group were all experiencing difficulties especially with their short-term memory, by following the same format each week some appeared to recognise and remember aspects of the service.

The multi-sensory approach was useful insofar as it evoked different memories associated with past religious experiences. The lighted candles were strong visual images and different coloured tablecloths, sacred images and icons were used corresponding to the colour of vestments worn at that time in the church's liturgical calendar. Familiar hymns were sung and well-known passages from the Bible read out. Music is especially important in a service for people with dementia,⁹ and even people who have lost the ability to speak fluently can sometimes sing along to a well-known song. Touch is important, and during the service the participants held hands during prayers, increasing the feeling of sharing and participation. During the services items such as crosses, crucifixes and rosary beads were passed around, evoking strong memories of earlier religious experiences¹⁰. The sense of smell was aroused by the use of fresh flowers or incense. In our service, the multi-sensory approach of religious ritual did not include taste, as communion bread and wine were not included, but literature suggests that this has a positive impact on people with dementia and this aspect may be introduced in the course of a later project.

Finally, whilst this small 'pioneer' prayer group was organised exclusively from a Christian perspective, in certain areas where a similar service becomes available there will be a requirement to consider inter-cultural and multi-faith religious rituals, accommodating the variety of worship represented by patients from different religions. This may pose complex issues including the finding of common grounds for worship and equally consideration of disparate needs. This is a topic that will be explored in another paper.

References

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Appendix – Samples of replies from participants to the Candlelight Group

Week 1

Q. Did you enjoy the group?

A. Mrs.A: I enjoyed it all. I was listening to everything that is going on. I am religious I'm a Catholic I listened to it all.

Q. How do you feel?

A. Mrs.A: I feel good.

Q. Are you glad you came into the room?

A. Mrs.A: yes, definitely.

Q. Did you enjoy the group?

A. Mrs.B: it was lovely.

Q. *Did you enjoy the group?*
A. *Mrs.C: I'm not religious I didn't enjoy it.*

Q. *Did you enjoy the group?*
A. *Mr.D: yes*

Q. *How do you feel?*
A. *Mr.D: I feel all right.*

Week 2

Q. *Did you enjoy the service?*
A. *Mrs.E: I did enjoy the... I joined in the singing. It touched me so much it brought tears to my eyes.*

Q. *Did you enjoy the group?*
A. *Mrs.F: I did, all of it, every bit. 'There is a green hill far away'.*

Q. *How do you feel now?*
A. *Mrs.F: very holy.*

Q. *Did you enjoy the group?*
A. *Mrs.G: I was surprised, I've been to church when I was younger, my mother was a turncoat. I like that it's lovely, very quickly done.*

Q. *Did you enjoy the group?*
A. *Mr.H: I loved that*

Q. *What did you like best?*
A. *Mr.H: the music. I don't know half the words, the music sounds lovely.*

Week 3

Q. *What did you like about the group?*
A. *Mrs.I: something I can join in with because I didn't for quite a time.*

Q. *What did you like about the group?*
A. *Mrs.J: all of it. I said my own prayer while they said theirs.*

Q. *How do you feel?*
A. *Mrs.J: I feel holy. I felt like I wanted to hear it again.*

Q. *Did you go to church?*
A. *Mrs.J: yes I did, not just when I was younger.*

Q. *Do you go now?*
A. *Mrs. J: no I haven't gone for some time- very bad of me.*

Q. *Was the prayer group like going to church?*
A. *Mrs.J: yes. it's a small group so I can remember everything that was said.*

Q. *Would you like to go to the group again?*
A. *Mrs.J: I don't know, I'll decide on the day.*

Q. *Did you enjoy the group?*
A. *Mrs.K: I enjoyed it all. In May I lost my husband and then my father. You keep on thinking about it, its nice to come here.*

Q. *What did you like about it?*
A. *Mrs.K: I find it very interesting. It seems to open your eyes to Christianity. I liked it very much.*

Q. *Did you go to church?*
A. *Mrs.K: I have been to church but my husband wasn't that keen so I stopped going.*

Q. *How did you feel after the group?*
A. *Mrs.K: I wouldn't say happy but much better than I have for a long time.*

Q. *Did you enjoy the group?*
A. *Mrs.L: I enjoyed it all but I'm not good at remembering.*

Q. *What did you like about it?*
A. *Mrs.L: we were all open and didn't try and hide anything from each other.*

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