Perceptions of Staff members on the use of a Biographical approach in the care of Persons with Dementia

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Abstract

Biographical approaches offer a promising outlook in the care of persons with dementia. This research study sought to determine the perceptions of members of the interdisciplinary team regarding the use of life story books in the care of persons with dementia. For the purpose of this study, life story books were created for two persons with dementia residing in two psycho-geriatric wards within an institution for the elderly. Consequently these booklets were left available to members of staff involved in their care. Staff members were then interviewed so as to obtain their perceptions on the use of such booklets. Findings indicate that use of life story books led to enhanced person centred care, enhanced understanding of the resident's present behaviour and enhanced communication. Such findings shed light on the importance of using life story work in the care of persons with dementia.

Introduction

According to the World Health Organisation (WHO), Dementia is a syndrome characterized by a deterioration in higher cognitive functions (including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement) which are accompanied or preceded by a deterioration in emotional control, social behaviour and motivation (Gibson, 2004). However, "the presentation of dementia varies significantly with the individual and the stage of the condition" (Cara & McRae, 2005, p.339). In spite of these individual variations, persons with dementia are often considered as a uniform group of individuals, frequently labelled by care staff as 'confused'. Thus the individuality and uniqueness of each person is often lost (Chandhury, 2002). Use of a person-centred approach to the care of persons with dementia is therefore imperative. One such approach is the use of a Biographical approach. A Biographical approach is one which provides "older people with opportunities, if they so desire, to talk about their life experiences, family, friends, work history, hobbies-often using photographs and personal belongings as triggers to discussion" (Clarke, Hanson & Ross, 2003, p.698).

Life story is a form of biographical work (Clarke et al., 2003). Life story work was defined by Murphy (2004), as "finding out, recording and making use of relevant facts from the individual's life story-past and present" (p. 89). This information can be then recorded in a life story book. A Life Story Book (LSB) is defined by Baker (2001) as "a personalized collection of photographs and other mementos linked with simple

text detailing the important events, people and memories in a person's life" (p.185).

The aim of this research project was to determine the perceptions of staff members regarding the use of life story books in the care of persons with dementia. The sections below will give a synopsis of the literature review and outline the three research questions. This will be followed by a description of the methodology, the results and a discussion of the research findings.

Literature Review

The Incidence of dementia

As the World's population ages the number of persons diagnosed with dementia is increasing and this is placing increasing pressures on family caregivers as well as on health and social welfare resources (Gibson, 2004). Through the EURODEM study (European community concerted action on the epidemiology and prevention of dementia group), the Malta Dementia Society has estimated a prevalence of about 3500 persons with dementia in Malta (S. Abela, personal communication, March 8, 2006). Due to the absence of published data here in Malta, it is difficult to determine how many of these persons are living in their own homes, in nursing homes or in residential homes. Abroad it is estimated that half of all the residents in nursing facilities have dementia or a related disorder (Gibson, 2004).

In view of the increasing incidence of dementia interventions to improve the care of persons with dementia are necessary. Specifically there is the need for interdisciplinary approaches to the care of persons with dementia (Warchol, 2004). Upon reviewing the literature it was discovered that life story work has actually been put to use by different professionals including nurses, nursing assistants, psychologists, speech language pathologists, social workers and occupational therapists (Baker, 2001; Chaudhury, 2002; Clarke et al., 2003; Gregory, 1997, Haight, 2001, Haight et al., 2003; Haight, Gibson & Michel, 2005, Hansebo & Kihlgren, 2000; Murphy, 2000; Murphy, 2004; Webster & Whitlock, 2003). One common reason for using life story work across all disciplines appears to be its ability to allow professionals to get to know the person behind the dementia.

Fading identity in dementia

Our story contributes to our identity (Murphy, 2004). Unfortunately persons with dementia may have difficulty relating or remembering their story (Hansebo & Kihlgren, 2004). Thus they can easily become isolated (Haight et al., 2005). Daniel Kuhn (2004) claims that Auguste Dieter, the woman whom Dr Alzheimer first identified as having symptoms of brain disease, was not understood by those persons surrounding her. He claims that:

> *Her potential for living with her symptoms [italics added] was never realized. People in her life failed to understand what she was experiencing and what she needed to cope successfully with her confusing world. They did not appreciate her*

need for intimacy, community and meaningful activity [italics added]. They did not believe that their own attitudes and behaviours needed to change to suit her needs (p.266).

Daniel Kuhn (2004) also adds that unfortunately, although this episode dates back to the 1902, in today's day and age some people are still living in the same conditions in which Auguste Dieter lived. It is therefore obvious that in the face of such a disorder where the person's identity is gradually lost (Kitwood, 1997) interventions need to address this loss and should attempt to help the person with dementia retain and regain a sense of self. Use of a person-centred approach to the care of persons with dementia is therefore imperative.

Person centred care

It was Dr Tom Kitwood who originally coined the term "person-centred care" and emphasised the necessity to consider persons with dementia as a person first (Kitwood, 1997). According to Kitwood (1997) personhood "is the standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust" (p.8). In fact Kitwood claimed that biographical knowledge is essential in order to prevent the fading of a person's identity. Kitwood stated that when the person with dementia is unable to hold on to his/her own identity due to memory loss, this identity can still be conserved by others who are knowledgeable about the person.

Kitwood (1997) outlined five main psychological needs which need to be met if person-centred care is to be provided in the case of persons with dementia. Two of these needs are the need for occupation and the need for identity. The need for comfort, attachment and inclusion are three additional needs which together overlap in the central need for love and contribute to the maintenance of the person's personhood and thus to the provision of person-centred care.

Linking biographical work with OT: Conceptual framework

According to Wicks & Whiteford (2003), life stories conform to the humanistic values and assumptions of the OT profession since by using life stories one would be preserving the integrity of the individual and accepting the person's experiences as credible. Yerxa (1983) also holds that adopting humanistic values is central to the OT profession. Burke & Kern (1996) state that life history and narrative data can be useful at each stage of the OT process including evaluation, goal setting, treatment planning and discharge. This view is further strengthened within the OT Practice Framework: Domain and Process (OTPF) which includes the importance of including life history as part of the evaluation process, specifically within the occupational profile. The latter is partly defined as "the initial step in the evaluation process that provides an understanding of the client's occupational history and experiences, patterns of daily living, interests, values and needs." (AOTA, 2002, p. 614).

Various documents were found relating to the specific use of life stories by occupational therapists both in research and in practice (Burke & Kern, 1996; Duchek & Thessing, 1996; Geyla, 1996; Larson & Fanchiang, 1996; Wicks & Whiteford, 2003). All of these articles claim that use of life story work is beneficial in occupational therapy practice. Use of biographical knowledge is especially important when developing therapeutic activity programmes for the person with dementia. Warchol (2004), an occupational therapist by profession, holds that one of the key elements in developing a therapeutic activity programme in nursing homes lies in ensuring that activities are customized to the interests and roles of each resident. In offering generic activities to the person with dementia, it is not surprising that the resident appears detached, bored or exhibits behavioural problems (Warchol, 2004).

Who benefits from life story work?

According to several literature sources, life story work has benefits for the person with dementia, staff members and family carers (Baker, 2000; Chaudhury, 2002; Clarke et al., 2003; Hansebo & Kihilgren, 2000, Hansebo & Kihilgren, 2004; Murphy, 2000; Murphy, 2004).

A major benefit of life story work for family carers is that it "reinforces the whole person for family carers/ extended family" (Murphy, 2004, p.95). Additionally life story work can help family carers to see the person with dementia in his/her legitimate role (such as the role of a spouse) rather than as an ill person who needs to be cared for. Life story also offers an activity to do at home and gives the carer a feeling of continued involvement (Murphy, 2004).

Murphy (2004) claims that there are numerous benefits of life-story work for the person with dementia. He holds that it reinforces a sense of identity and self, improves self-esteem, it is a failure free activity, offers enjoyment, reinforces long term memory, helps to maintain/ build relationships with staff members and it reinforces social skills.

Through the use of a biographical approach, many members of staff involved in such a challenging task have reported major benefits. Three major advantages include the provision of person centred care, the role of life story work in understanding the person's behaviour as well as its role in improving communication between staff members and the elderly person (Murphy, 2004).

Following this literature review, the following three research questions were devised in order to answer the above mentioned aim.

1. Does the use of a life story booklet aid in the delivery of person-centred care?
2. Does life story work lead to a greater understanding of the older person's present behaviour?
3. Does life story work affect the communication patterns between staff members and the older person?

Methodology

Research design

A qualitative approach was adopted for the purpose of this research study as the aim was to obtain the participants perceptions. After consulting the literature it was found that other studies involved collection of personal life story information over a period of time (Haight et al,. 2003 & Haight et al., 2005). According to Yin (2003), when a case must be studied at more than one point in time, a single case study design can be adopted. Yin additionally holds that use of at least 'two-case' case studies has considerable advantages over the use of a single-case design. Use of two cases would provide the possibility of direct replication and enhance the generalization of findings (Yin, 2003). In view of these findings multiple (two-cases) qualitative case studies using patients with dementia was adopted for the purpose of this research study.

Context

This research study was carried out within a state-run residence for the elderly. This residential setting was chosen since most of the literature consulted was conducted in such a context (Chaudhury, 2002; Haight et al, 2005; Haight et al., 2003 & Murphy, 2004). Specifically the psycho-geriatric wards (both male and female wards) within this residence were chosen to implement this research study.

Population and sampling strategies

There were two groups of participants involved in this research study namely the person with dementia and their relatives and the members of staff. Purposive sampling was used when choosing both groups of participants. Persons with dementia who might benefit from this research study were nominated after consultation with professional staff members (the nursing officer and consultant geriatrician) and they were chosen on the basis of the following four criteria:

- the person must have a diagnosis of dementia
- the person must be classified as having mild to moderate dementia. This was determined through the use of the MMSE.
- the person must have relatives who know their life history
- the person must have been in the ward long enough to become familiar with the environment of the ward (approximately eight weeks).

Purposive sampling was employed when choosing members of staff as the researcher chose all those professionals who were directly involved in the care of the person with dementia. A type of purposive sampling called maximum variation sampling was used when choosing staff members. Nurses and nursing aides where selected using random sampling since all the nurses/nursing aides appeared to be involved with the person to the same degree.

Research Instruments

Three instruments were used during this study. These were the Maltese version of the Mini Mental State

Examination (MMSE), the *'Life Story Interview'*, and a semi-structured interview guide used with members of staff. The *'Life Story Interview'* was devised by the researcher and was based on the *'Personal Life History Booklet'* prepared by Kate Gregory (1997) for Alzheimer's Australia, SA. Australia. Both English and Maltese versions of the interview were developed. This interview was divided into six sections, namely: "My family, Childhood, Adolescence, Young Adulthood, Middle Age and Later Years". A semi-structured interview guide was constructed to be used with all staff members. The interview guide consisted of twelve open ended questions. Both English and Maltese versions of the interview guide were developed.

Research Procedure

This research study consisted of three distinct stages. **The first stage** involved administering the MMSE to ensure that the residents (chosen through purposive sampling) had mild to moderate dementia. When all participants had given their consent, collection of life story information was initiated by conducting the *'Life story interview'*. The life story interview was conducted first with the relatives and subsequently with the residents. The information obtained was then recorded in a *'Personal life story booklet'*. During **the second stage** the life story book was left in the medical file of the resident for six weeks and members of staff were encouraged to make use of this booklet and the information within it. **The third stage** involved interviewing staff members regarding their perceptions on the use of the life story booklet in the care of the residents in involved.

Data Collection and Analysis

Analysis of the data was carried out by transcribing the interviews verbatim and consequently analysing the content of the available data. Data included the transcribed interviews and any field notes written on the day of the interview. The data was grouped according to the three research questions. Common themes and sub-themes were then developed from the data.

Findings and Discussion

In the case of persons with dementia, there were only three persons who fulfilled the criteria outlined in the methodology. One of the persons refused to participate, so that 2 persons (one from each ward) was the final resident sample. Thus, both wards had to be included in the research study as a minimum of 2 participants was necessary. Both participants were considered as having moderate cognitive impairment according to the Mini Mental State Exam (MMSE) score.

Out of the 15 staff members who were selected through purposive sampling, 2 staff members (a care worker and a nursing aide) refused to participate ending with a sample of 13 staff members. These were a consultant geriatrician, two occupational therapists, one physiotherapist, one speech therapist, 3 nursing aides, 3 nurses and one nursing officer.

Common themes and sub-themes between members of the interdisciplinary team

Research Questions	Findings
Does the use of a life story booklet aid in the delivery of person-centred care?	*Theme 1* The resident as a person- An Individual **Sub-themes** I. Increased understanding of the person *II. Changed attitudes towards the resident* *III. Becoming more knowledgeable about the person*
	Theme 2 Engagement in occupations *Sub-themes* *I. Planning individualised activities* *II. Enhancing participation during Occupations*
	Theme 3 Facilitation and continuity of care *Sub-themes* *I. Facilitation of care-giving* *II. Usefulness for non-permanent staff members* *III. Managing transitions smoothly*
Does life story work lead to a greater understanding of the older person's present behaviour	*Theme 1* Understanding aspects of the person's behaviour *Theme 2* Dealing with problematic behaviour
Does life story work affect the communication patterns between staff members and the elderly person?	*Theme 1* Facilitation of conversation with the residents *Theme 2* Usefulness for communication in later stages *Theme3* Reality orientation

The resident as a person- An Individual

Participants in this study claimed that life story work enabled them to look at the resident as a person because they were able to understand the resident more. Additionally they reported changed attitudes towards the resident and that they became more knowledgeable about the person. The outstanding view that life story work enables staff members to look at the resident as a person is consistent with literature from several sources (Baker, 2001; Clarke et al., 2003; Mc Keown, Clarke & Repper, 2006; Murphy, 2000; Murphy 2004).

Several participants stated that they had gained an *increased understanding of the resident* through the use of life story work because it helped them to see the residents in the context of their whole life. One participant stated:

> *When she [the resident] starts saying something about her past, her words might not make sense in that context and at that particular time. However, once you know about her life and what she went through, things start falling into place.*

Chaudhury (2002) and Murphy (2000) also outlined the importance of life story work to empathise with the residents. A number of participants reported *changed attitudes towards the resident.* Changes in attitudes included increased respect for the resident upon knowing their life story and feelings of compassion towards the person. One participant stated, "It helped us a lot because when you start reading you realise that you should respect these persons, like other persons, instead of ignoring what they say".

Additionally one therapist claimed that use of a life story book led her to reflect more on her practice and to a challenge the implied assumption that persons with dementia do not have the ability to improve. This enabled her to be more thorough in her treatment with the residents. Baker (2000), Clarke et al. (2003) and Murphy (2000) also outlined changed attitudes of staff members towards the person with dementia as a consequence of life story work. According to Kuhn (2004), if such changes in the attitudes of staff members occur, the needs of persons with dementia would be more suitably met.

Having access to the resident's life story book led to *improved knowledge about the resident,* according to the majority of participants. One staff member claimed that, "when you see their life history, what they've gone through and the many experiences they had in their life, you can see them more as individuals rather than as patients." Baker (2000) and Hansebo & Kihilgren (2000) also outlined the importance of having a resource of information about the person in order to view the person with dementia more as a unique individual despite his/her limitations.

Engagement in occupations

Staff members outlined two reasons why life story information allows engagement in occupations. Firstly such information allows for the planning of individually meaningful activities. Secondly it allows staff members to enhance the resident's participation during daily occupations.

The importance of life story work for planning individually meaningful activities according to the resident's previous interests and strengths, emerged from this research study. This is in line with the views of Warchol (2004), Chaudhury (2002) and Heliker (as cited in McKeown, 2006) all of whom outlined the value of incorporating biographical knowledge into care planning so as to develop individualised nursing care plans and activity programmes. It was concluded that participation in meaningful occupations can contribute towards meeting all the five major psychological needs for persons with dementia as outlined by Kitwood (1997). These are the need for identity, occupation, comfort, attachment and inclusion.

Participants within this research study additionally outlined the value of using life story information to facilitate the residents' participation in previous leisure activities, to enhance participation in personal activities of daily living and to facilitate participation during therapeutic groups. The latter two benefits are similar to the views of Hansebo and Kihilgren (2000) and Chaudhury (2002) respectively.

Facilitation and continuity of care

Three factors were seen as contributing towards facilitation and continuity of care-giving. These were the role of life story work for facilitating care-giving; it's usefulness for non-permanent staff members and its use in managing a person's transition smoothly.

The role of life story information in *facilitating care-giving* was clearly outlined by nurses and nursing aides from both wards. Use of life story work facilitates the challenging task of caring for residents with dementia especially in the case of nurses and nursing aids who spend the majority of time with the resident. One particular nurse stated:

> *If you don't know this person from Adam, how on earth can you deal with your client? I don't understand how they send staff members who do not usually work in this ward to deal with clients of this type.*

According to a number of participants life story information would be especially *useful for non-permanent staff members* who do not know the resident. According to the participants non-permanent staff would find the information more beneficial than permanent staff members who have got used to the resident. Such information should be short and to the point to maximise time management.

All the participants claimed that life story information would help in *managing transitions smoothly* for all

concerned. Murphy (2004) also outlines the benefits of life story work as the person progresses through different services. In this way person-centred care would not be limited specifically to the person's present situation. Rather one would be enhancing the possibility that good quality of care is provided according to the resident's needs regardless of the context in which this takes place or the persons who are providing the care.

Understanding aspects of the person's behaviour

The majority of staff members claimed that life story information helped them to understand certain aspects of the person's behaviour. This result tallied with those of Chaudhury (2002) and Murphy (2004). Murphy (2004) explained how the person's behaviours may reflect his/her previous lifestyle or employment. Similarly several participants in this research study claimed life story work enabled them to understand residents' behaviours in view of the person's previous context and personality rather that attributing them to their medical condition.

One participant stated that knowing about the person's past does not necessarily explain how the person behaves in the present. In fact she explained how one of the residents, an ex-teacher, exhibited inappropriate behaviour by blowing her nose in her dress. This participant attributed such behaviour to a change in the resident's personality because of her dementia. It can be argued that such behaviour might also reflect the resident's inability to communicate her needs. Such inappropriate behaviour might still reflect the resident's need for cleanliness. Staff members need to remember that all behaviour is meaningful (Chapman & Worthington, 2005). Consequently members of staff need to be more receptive to needs that cannot be expressed.

Dealing with problematic behaviour

Several participants explained how life story information helped them to deal with problematic behaviour. Staff members used life story information to distract the residents when exhibiting problematic behaviour or to attempt to understand the reason for certain behaviours and consequently deal with such behaviours. The latter approach is congruent with the views of Kitwood (1997) who claimed that, "all so-called problem behaviours should be viewed as attempts at communication, related to need. It is necessary to seek to understand the message and so engage with the need that is not being met" (p.136). Problematic behaviours usually reflect feelings of ill-being which can be minimized through better care (Warchol, 2006). More focus should be made on attempting to understand aggressive behaviours, rather than attempting to brush such behaviours away by distracting the residents.

Facilitation of conversation with the residents

Improved communication was reported by the majority of participants in this research study. Life story information was regarded as being beneficial to initiate conversation with the residents

as well as to provide topics for communication. Other literature sources (Baker, 2001; Chaudhury, 2002; Hazel, 1997; Moos & Bjorn, 2006; Murphy, 2000) reported enhanced communication with the residents following the introduction of life story work. Upon using the life story booklet physically with the resident, staff members reported improved communication, enjoyment and improved recall from the resident's side especially when photographs were shown to the resident. This is in line with the study by Clarke et al. (2003) where photographs provoked strong memories from the residents and acted as a talking point between staff members, the patients and their relatives.

Usefulness for communication in later stages

Conflicting opinions were obtained on the issue of whether the information would be useful in later stages of the disease. Several participants claimed that the information in the life story book would not be useful for communication in later stages when the residents cannot understand or can't communicate back. However, other participants stated that one can still use the information for communication in the advanced stages. The speech therapist and one of the OT's mentioned the usefulness of life story information for non verbal communication in the later stages. The speech therapist outlines this clearly in the following quote:

> *If you know that somebody, a person, disliked being touched, you won't touch her. Or if you know somebody liked to be touched you might say I'll use hand holding or a hand message or something as a way of getting through to her and communicating non-verbally. A person doesn't cease to be a person just because she can't communicate verbally.*

Hazel (1997) and Nygard (2006) both claim that the non-verbal dimension of language is useful when communicating with persons who have dementia. However from this research study, there appears to be a lack of awareness about the potential of using non-verbal communication with persons who have dementia. This is because several participants did not believe that communication is possible in later stages of the disease when verbal communication is significantly impaired. This lack of awareness may prevent members of staff from being receptive to aspects of non verbal communication in later stages of the disease. According to Warchol (2006), such non-verbal cues, like smiles and groans, can be used to evaluate the quality of life for the person with dementia. Thus, it is important that all staff members are sensitive to such non-verbal cues if the quality of life of residents with dementia is to be enhanced.

Reality Orientation

Several staff members highlighted the benefits of using life story information during conversation to keep the resident

oriented to reality. This is in line with the study carried out by Murphy (2000). However it was the occupational therapists who actually made use of the information formally in this way. Both occupational therapists cautioned about the need to use information sensitively so as not to overwhelm the residents with information. Moreover the consultant, in the same way as Murphy (2004), also outlined the need to avoid using the information to 'quiz' the person about his past. Such a sensitive approach is important as persons with dementia are still capable of experiencing different feelings (Kitwood, 1997). Providing training to members of staff regarding the use of life story work would enhance the probability that life story information is used appropriately.

Conclusion

The limitations of this study were mostly due to time constraints and, to a lesser extent, because of methodological factors. Several recommendations which can be implemented when using life story work emerged following this research study. Most importantly is the need to improve awareness amongst staff members about life story work, as well as the need to implement a strength-based assessment in the care of residents with dementia. A strength-based assessment is one which couples a life story assessment with a functional cognitive assessment (Warchol, 2006). The role of the occupational therapist in setting up activity programmes according to the resident's previous interests and strengths was also an important recommendation.

It is hoped that this research study has provided some insights into the beneficial effects of life story work in the care of persons with dementia, so that we may optimize the quality of life of this client group. Additionally it is hoped that occupational therapists realise the importance of obtaining knowledge about the person's previous occupations so as to be able to integrate such knowledge in daily occupations, thus enhancing the health of their clients with dementia.

It is obvious that the benefits of placing the person with dementia and his/her relatives at the centre of the team, through a greater awareness of the person's life story far outweigh the limitations of this tool. Life story work (a biographical approach) can be a useful therapeutic tool that can improve the quality of life of the person with dementia, his/her carers and the satisfaction of staff who dedicate their time to the care and well being of the older person.

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