

Person-Centred Care/Dementia Care

Person-centred care for institutionalized elders is increasingly more recognized as synonymous with best quality care (Edvardsson, Fetherstonhaugh and Nay, 2010). This paper discusses person-centred care as an ethical approach to care for people with dementia living in long-term care residential settings. It examines the effects of this approach on the individual, the family, staff and the health care system, and concludes with strategies for instituting person-centred care practices in long-term care settings.

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Person-centred dementia care:

An essential component of ethical nursing care

Person-centred care for institutionalized elders is increasingly being recognized as synonymous with best quality care (Edvardsson, Fetherstonhaugh and Nay, 2010). Considering the fact that the majority of nursing home residents in Canada have some form of dementia (Barnes, 2009), the implications for providing individualized care that enhances the personhood of the individual can be significant.

Sound care approach

This paper will discuss the concept of person-centred care as an ethically sound philosophic approach to dementia care. It will further describe the impact of patient-centred care on the individual with dementia, the family, caregivers and the health care system, and will suggest clinical strategies to enhance this approach in dementia care.

Persons with dementia are at risk of being stigmatized as less than fully human. One common misconception about dementia is illustrated in the description of the person with dementia as being robbed of all humanity (Wyllie and Gains, 2009). Ethical care for dementia sufferers evolves from a belief in and the valuing of the personhood of

each individual regardless of cognitive status.

Ethical nursing practice is embodied in the provision of safe, competent, compassionate and ethical care, in the promotion of clients' health and well-being, the promotion and respect of informed decision-making, the preservation of dignity, and the promotion of justice, fairness and equity (CNA, 2008), and is supported by the values of autonomy, beneficence, non-maleficence, and distributive justice (CARNA, 2005). Person-centred care provides for each of these ethical aspects of professional caring at the same time as it protects and capitalizes on the individuality and personhood of the client with dementia.

New culture of dementia care

Person-centred care has been defined as a "new culture" of dementia care that "acknowledges the full personhood of the individual to ensure that people living with dementia are included, heard, and understood" (Burton, 2008). It focuses on the person with dementia as the centre of the care process and is achieved when the physical, psychological, social and spiritual needs of the individual are

met (Ibid., 2008). This approach to care is not just something to be done, but represents an internalization of values that support the humanity and autonomy of the individual (Wyllie and Gains, 2009).

Practical application of the approach relies on detailed knowledge of the physical, psychological, social, family, spiritual and historical aspects of the individual; empathetic understanding of the individual; clear-cut, individualized communication strategies; supportive, individualized environment; and relationships based on respect, caring and trust (Burton, 2008; Wyllie and Gains, 2009; McKeown, et al., 2010; Edvardsson, Fetherstonhaugh and Nay, 2010; Barnes, 2009; Ryan and Carey, 2009; Williams, 2006; Bone et al., 2010).

Levels of personhood

Burton (2008) recognizes three levels of personhood that have significance in the provision of care to people with dementia:

1. biologic personhood;
2. individual personhood; and,
3. sociologic personhood.

Biologic dementia care includes the provision of essential needs of food,

water, shelter, clothing, hygiene and medical care. Dementia challenges the recognition and treatment of these needs because of decreased cognition and communication skills. On-going and thorough nursing assessments are necessary for understanding the complex biologic needs and non-verbal communication of the person with dementia (Burton, 2008).

Individual personhood care encompasses efforts to preserve autonomy of the individual, and contribute to a more personalized care environment in which the individual can thrive (Burton, 2008). It embraces the unique life experience of the individual and considers the social, psychological and sensory needs along with the physical needs (Bone, Cheung and Wade, 2010). Specifically, this care is concerned with the individual's needs for sensory and cognitive stimulation, human connection, and meaningful, purposeful occupation (Ibid., 2010).

Sociologic personhood care focuses on supporting the individual as part of a community, providing an environment where social relationships can flourish. Building on the maintenance of personhood at the individual level, a reduction of socially inappropriate behaviours can allow full participation in group activities, and encourage the person with dementia to be a contributing member of a community (Burton, 2008).

Person-centred care has the potential to improve the quality of life for nursing home residents living with dementia. It has been suggested that "attention to preserving personhood is essential for the physical and mental well-being of persons with dementia" (Burton, 2008). Increased communication, decreases in maladaptive behaviours and increased positive interactions with others have all been shown to result from person-centered care interventions, according to Burton (2008).

One study which used individualized strategies to enhance engagement of people with dementia in occupations

and activities suggested that person-centred interventions could reduce the number and severity of neuropsychiatric symptoms, improve self-care, decrease daytime somnolence, and increase positive social interaction (Bone et al., 2010).

McKeown, et al. (2010), using case study as a research method, identified a sense of enjoyment, pride, positive feelings about themselves and a sense of achievement as benefits of the person-centred strategy of life story work to people with dementia. Telling and recording of the life story can provide an alternative narrative to that of deficit and loss for the person with dementia (McKeown, et al., 2010). It appears that person-centred care strategies may assist the person with dementia to thrive - not just exist. These strategies positively affect families as well.

Family-centred involvement

Families benefit significantly when person-centred approaches are offered to their family member with dementia.

Families of individuals with dementia who have engaged in life story work value the opportunity to have the voice of their loved one heard, and their personhood honoured through the telling of their life story (McKeown, et al., 2010). Others found that life story work helped them to preserve their loved one's personhood for themselves as well (Ibid., 2010).

In a study by Edvardsson, et al. (2010), families identified that person-centred care included families and significant others in the life of the individual with dementia as part of the unit of care. Families appreciated that their in-depth knowledge of their loved one was used by staff in planning care.

Person-centred care approaches encouraged families to maintain their continuing relationship with the individual with dementia, offering a sense of continuance of self and normality (Edvardsson, et al., 2010). The families found that person-centred care environments brought an "atmosphere of life" to the long-term care setting,

contributing to socialization of both family and the individual with dementia, and offering meaningful conversation starters and areas of reminiscence (Ibid., 2010). Teamwork in providing person-centred care is beneficial for the individual with dementia and their family, as well as for care staff.

Staff education and support

Burton (2008) asserts that when nursing staff are educated and trained in person-centred care strategies they report greater job satisfaction and there is decreased staff turnover. Paternalistic staff attitudes that depersonalize and disempower the individual with dementia are decreased; this in turn supports positive, functional relationships between staff and clients (Ibid., 2008).

Strategies such as life story work and memory boxes help care staff to see the person beyond the patient. The personal knowledge available through these strategies highlights the person rather than the behaviours that staff find challenging (McKeown, et al., 2010). It could also provide clues about behaviours and suggest interventions such as effective distraction or engagement methods.

Care staff needs to be educated and supported in providing person-centred care. Medically oriented institutions may not value the time required for staff to attend to the personhood needs of the resident with dementia and may not recognize that person-centred approaches can save time and money in the long run by decreasing disruptive behaviours of dementia sufferers and decreasing staff turn-over.

Instituting person-centred practices can be a challenge for nursing homes - which are traditionally medically focused and designed to accommodate caregivers rather than care receivers. Staffing patterns and policy and procedure are often developed to focus primarily on attending to the physical needs of the residents (Burton, 2008).

In the experience of this writer, the inspection functions of licensing author-

ities for nursing homes also concentrate on protecting the biological needs of residents and neglect protection of the personhood of the most vulnerable of the nursing home population.

Person-centred care practices can be costly in terms of staff time and training, individualized care regimens, and expertise in specialized programs such as occupational and activity programs, and life story work.

Providing care in a way that respects and nurtures the personhood of residents requires changed perspectives on the part of the health care system and a move away from the medical model when designing, managing and evaluating long-term care facilities. It is a financially costly and philosophically demanding change, but care that is based on the ethical principles of beneficence, non-maleficence, autonomy and justice demand that the change occur; and nursing is well positioned to provide momentum to this change.

Instituting culture change

Nurses have a responsibility to provide the best possible professional nursing service to the public, basing their practice on evidence from nursing science, other science and humanities and maintaining competence within their field of practice (NANB, 2005).

In the area of long-term residential care to the elderly, nurses are obligated to be knowledgeable of best practice methods that address all aspects of their clients' lives, and maintain the highest possible quality of life for their client's and their families. Person-centred care practices have moved into the forefront of best practice for elderly long term care (Edvardsson, et al., 2010) and must be considered as part of high quality nursing care in these settings. Nursing can lead the way in instituting small changes that could reap big dividends in quality of life for residents and their families.

It is also essential that nurses in long-term care settings document patient-centred changes to care and the resulting effects to clients in order to provide

evidence to support further change. Separating out individual components of patient-centred care would be helpful in planning for organized and coordinated change in care practices.

Components of person-centred care

The components of person-centred care could be seen as the following:

- in-depth knowledge of the person;
- inclusion of the family and/or significant others as the unit of care;
- individualized communication;
- meaningful occupation and activity;
- supportive, individualized environment; and
- active involvement in a community.

Nurses can initiate change within traditional long-term care settings that support each of these components and contribute to better lives for their clients.

Knowledge of the person

Person-centred care begins with knowledge of the person, and giving staff the ability to recognize the life and individuality of the person under their care. Most nursing homes begin their care planning based on a health history and assessment at admission; but this is not enough to meet the needs of person-centred care.

Understanding the biography of the person is essential for understanding the meaning behind what people say, for understanding behaviours, for reinforcing identity and facilitating relationships (McKeown, et al., 2010). Life story work is a creative method for discovering the person behind the patient, and identifying the biography of the person.

Life story work "involves working with a person and their family to find out about their life, recording that information in some way, and then using the information with the person in their care" (McKeown, et al., 2010). The life history can be recorded in a book that includes text, photographs, and memorabilia.

A memory box that holds memorabilia

significant to the person has been suggested as an effective source of reminiscence, communication strategies and topics, and reminders to staff of the personhood of the patient (McKeown, et al., 2010). Knowledge of the person's life history provides data on which to base person-centred care strategies, develop communication strategies, understand and intervene effectively with disruptive behaviours, and support appropriate and fulfilling relationships and life continuity. Life story work also actively involves the family in the care of the individual.

Inclusion of family

For the person with dementia, the family is the main source of information about the individual and their life history. As well, in this writer's experience, the relationship between families and nursing home staff significantly influence the ability of staff to provide appropriate individualized care.

Families often have ambivalent feelings about giving care of their family member over to an institution and do not know how they can best maintain continuity of their lives with their family member. But, as families are welcomed as part of the care team and begin to reveal the life story of the person with dementia, they develop a trust in staff related to being acknowledged as an important component of care for their loved one (Edvardsson, et al., 2010).

Families also begin to trust that staff will communicate to them significant changes and events in their family member's care. Through relating the life history, they feel that they are providing a voice for their family member and helping to preserve the identity of their family member - for themselves as well as for staff (McKeown, et al., 2010).

Identifying the family as the unit of care can assist the family to find ways to continue with life in as normal a way as possible, and can encourage them "to maintain the relationship and life they had with the person - even after moving to a care facility" (Edvardsson, et al., 2010).

Individualized communication

From the life story work, staff begin to see beyond the patient to the individual person. They are reminded, through memorabilia and photographs, of the life that has been lived. This can provide them with topics for conversation that can facilitate communication and relationship building with the person with dementia.

Paternalistic attitudes and communication patterns on the part of staff are less likely to develop when characteristics of the individual's personhood are recognized (Buron, 2008). In turn, better communication and relationships can significantly decrease the patient's dissatisfaction with their situation, often expressed through disruptive behaviours (Ibid., 2008). A decrease in paternalism* also puts the patient's needs ahead of those of care staff, with the emphasis on the person with dementia rather than task completion (Edvardsson, et al, 2008).

Meaningful activity

Person-centred care acknowledges that individuals should be involved in the completion of tasks, transforming daily routines into "meaningful moments."

Engagement in meaningful and purposeful occupation is a significant element of human existence providing dignity and satisfaction to everyday life (Bone, et al., 2010). Person-centred care allows for an individualized activity program that arises from knowledge of the individual's life story and a thorough assessment of their social and emotional needs and abilities.

Individualized activity boxes that include tactile and personally significant items have been suggested as one method of engaging the person with dementia in meaningful activity (Bone, et al., 2010). Group activities that facilitate physical, mental, sensory, and social activity can also provide the benefits of stimulation, human connection and purposeful occupation (Ibid., 2010). Meaningful occupation can be facilitated when the environment is supportive and individualized for the resident (Ibid., 2010).

Supportive environments

Traditional nursing home environments are more supportive of the needs of staff than of person-centred care, but small, easily made changes can create physical environments that balance the physical and psychosocial needs of people

* *Paternalistic* refers to a policy that treats or cares for residents in a 'fatherly' manner, especially by providing for their needs, but without giving them rights or responsibilities.

Although considered by some to be a benevolent care strategy, often it is intrusive - something that residents, especially those with a dementia, may find demeaning and threatening.

It is a system of care under which the caregivers' authority is used to regulate conduct of those under their control in matters affecting them as individuals. The practice of providing paternalistic care, because it smacks of expediency, can be 'depersonalizing and disempowering' for the resident.

Product Licence

Product Number: 00009911

Brand Name: Fleet® Enema

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Name of licensee: Johnson & Johnson — Merck Consumer Pharmaceuticals of Canada
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Authorized for the following:

Dosage form: Solution

Recommended route of administration: Rectal

Recommended dose: Adults and children 12 years and older: 120 ml as required or as prescribed, but repeated usage at short intervals should be avoided. Children 2 to 12 years: 60 ml as required or as prescribed, but repeat usage at short intervals should be avoided. The preferred positions are: lying on left side with knees flexed, or in the knee-chest position. Self administration may be carried out with the individual lying on a towel, on the bathroom floor, or in the bathtub. ADMINISTERING ENEMA: Enema does not require warming: may be used at room temperature. Remove protective cap from pre-lubricated rectal tube before using. Insert tube, gently pointing it in the direction of the navel. Slowly squeeze bottle to empty contents into rectum. Withdraw the tube from the rectum. Note: It is not necessary to empty unit completely. (An extra amount of solution is provided to allow for the quantity normally remaining in the bottle after squeezing.) Body position should be maintained until a strong urge to have a bowel movement is felt; usually within 2 to 5 minutes. Contents of the bowel should then be expelled. Children under 2 years: consult a doctor.

Recommended duration of use: Laxative products should not be used longer than one week unless directed by a doctor.

Recommended use or purpose: For relief of constipation, acts within minutes. As a routine enema for cleansing the bowel before rectal examination, pre- and postoperatively, to relieve fecal or barium impaction, collecting stool specimens, during pregnancy, before and after delivery.

Risk information: Do not use if you are experiencing abdominal pain, nausea, fever or vomiting, cardiac disease, severe dehydration or debility. Frequent or prolonged use of enemas may result in dependence for bowel function. Use only when needed or when prescribed by a doctor. Children and elderly persons are more sensitive to the effects of enemas and are more likely to show signs of weakness, increased sweating and convulsions. DO NOT ADMINISTER TO CHILDREN UNDER 2 YEARS OF AGE EXCEPT ON THE ADVICE OF A DOCTOR. In dehydrated or weakened individuals, volume of solution administered must be carefully determined, since the solution is hypertonic and may cause further dehydration. Care should be taken to ensure that contents of the bowel are expelled after administration. Repeated usage at short intervals should be avoided. Laxative products should not be used longer than 1 week unless directed by a doctor. Do not use this product if you have: Appendicitis (or symptoms of), intestinal blockage, ulcerative colitis, ileitis, heart disease, rectal bleeding, high blood pressure, kidney disease. Not recommended for infants under 6 months of age.

Medicinal Ingredient		Quantity per Dosage Unit	Extract	Potency	Source Material
Proper Name	Common Name				
Phosphorus	Monobasic sodium phosphate	16 g/100 ml	N/A	N/A	Synthetic
Phosphorus	Dibasic sodium phosphate	6 g/100 ml	N/A	N/A	Synthetic

This licence is issued by the Minister of Health under the authority of section 7 of the Natural Health Products Regulations. Sale of the described natural health product, including any changes thereto pursuant to section 11 of the Regulations, is subject to the Food and Drugs Act and to the Natural Health Products Regulations.

Issued: June 27, 2008

Revised/Amended: N/A

with dementia (Geboy, 2009).

Geboy advocates conceptualizing the physical setting as a potential therapeutic tool and outlines a number of design principles for residents and dementia care staff. (See Box, "Environmental design principles. . .").

Personalized environments are developed when the facility is aware of the life history of the person with dementia and is willing to be flexible in allowing personal items in the individual's private space. Providing areas to accommodate family photographs and other familiar objects is respectful of the individual's personhood, and contributes to individualized care.

Social interaction, a sense of community and connection to nature can also be supported by environments that are home like, aesthetically pleasing, include plants and flowers, provide beautiful outdoor views, and include quiet spaces for conversation and small group activities (Edvardsson, et al., 2010).

Community involvement

Involvement in the community is enhanced when person-centred care practices result in decreased disruptive behaviours and increased social interaction.

People with dementia can benefit from participation in community events such as parties, holiday celebrations, barbecues, and the like, with other nursing home residents and families.

Socialization and membership in community strengthens the status of personhood for the individual with dementia, bestowing value on him or her as a member of society (Buron, 2008).

Conclusion

Respect for the personhood of the resident with dementia is an essential component of ethical nursing care for these individuals. Person-centred care is an approach that can fulfill nursing's responsibility to "provide safe, compassionate, competent and ethical care" (Canadian Nurses Association, 2008).

Nurses are ethically bound to under-

Environmental design principles for residents and dementia care staff

1. Think of the space as a resource to be used. Move the furniture to suit your purpose.
2. Place seats at right angles to encourage social interaction and conversation.
3. Create conversation groupings for 2/3 people with seating and low tables.
4. Personalize the space with things reflecting the lives of those using the space.
5. Outfit the room with accessories that are meant to be picked up, looked at, and used.
6. Dining room tables should ideally seat 4, and not more than 6 participants.
7. Avoid "activity circle" furniture arrangements and "theatre style" seating. If furniture needs to be arranged this way for one event, move it back into conversation groupings after the event is over.
8. Avoid placing furniture around the periphery of the room.
9. Plan ahead for places for individuals who are in wheel chairs in order fully include them in activities. Avoid "parking" them where ever there is space.
10. Adapt the space to the user's needs - even if it means moving furniture every day.

(Geboy, 2009)

stand their clients' needs in order to provide individualized care. Person-centred care strategies strengthens the nurse's knowledge of the person with dementia, includes the family as the unit of care, enhances individualized communication strategies, and normalizes the client and family experience through meaningful occupations, supportive environments and participation in community events. ■

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