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The Quality of Home Care of an Older Adult: A Multidimensional Framework

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Abstract:

This paper **describes** the case of an older Bahraini man, and the impact of his caregivers on his physical and psychosocial health, grieve and death. The **aim** of the study is to understand the predictors of quality of life amongst older adults and suggest targets for interventions, it also provides health professionals a case reference for understanding the complexity and the impact of caregiving and dying of older adults in the comfort zone of their home.To guide the description of the quality of care, a balanced and synchronized multidimensional perspective **model was adopted** and modified from Roper Logan Tierney Model Activities of Daily Living Scale (ADLs). The relevant **care dimensions** included mobilization, eating and drinking, elimination, sleeping, personal cleaning and hygiene, safe environment, managing loss and grief, and ultimately dying at home**.** The **outcome** ascertains that healthy aging and dignified death can be achieved provided that the caregivers understand the physical and psychosocial challenges inherent in the aging process, cooperate and adopt a family centered care model, and provide quality and timely intervention.

Keywords: Homecare, death and dying, cultural values, healthy ageing.

Introduction

According to the United Nations' "World Population Ageing 2020 Highlights", the world population is aging rapidly. In 2020, an estimated 727 million people were aged 65 years or over worldwide. By 2050, this figure is expected to double to over 1.5 billion people representing 16 percent of the global population. By mid-century, one in six people globally will be aged 65 years or older (United Nations Department of Economic and Social Affairs Population Division, World Population Ageing 2020 Highlights, 2020, https://www.un.org/development/desa/pd/).

The Eastern Mediterranean Region's population is also aging at a rapid pace. In 2000, those aged 60 and older in the region were around 26.8 million (5.8% of the total population). By 2025 projections predict that the figure will be 8.7%, and by 2050 nearly 15% of the population (World Health Organization, A strategy for active, healthy ageing and old age in the Eastern Mediterranean Region 2006-2015, 2006, http://applications.emro.who.int/dsaf/dsa542.pdf?ua=1).

Aging is the sequential or progressive change that leads to increased risk of disease, debility, and death, it is a normal developmental stage. It is very important to interpret aging in a life course and historical context (Hareven, 1995). Aging is not an anomaly; it is rather a stage that brings normal and general decline in body functioning. Regardless, people can age healthily, and healthy ageing has been defined as an ability to lead a healthy, socially inclusive lifestyle

relatively free from illness or disability (McPhee et al., 2016). Old age quality of life indicators includes health, functional capacity, and coping mechanisms, as intra-individual conditions for quality of life, while factors in the biophysical and sociocultural environment are described as external conditions (Sarvimäki & Stenbock-Hult, 2000).

Extending dignified care and respect to older adults, are among the basic values of Arab people, and indeed all ethnicities, and because of this, many older adults continue to enjoy home care, close to their families. However, with the fast pace of life, the modernization of households, the transition from extended to nuclear families, and social and economic burdens, many older people find themselves trapped between yesterday and today's world, and as a result their requirements for dignified comprehensive care in all domains of health and wellbeing is compromised (World Health Organization, Technical paper: Health care of the elderly in the Eastern Mediterranean Region: Challenges and perspectives, https://apps.who.int/iris/handle/10665/122147).

This paper is a case presentation of an older male adult referred to by a pseudonym "Ebrahim" to protect his identity and maintain confidentiality. The case will be presented unaltered and as observed and lived by his close caregivers. It aims at providing health professionals and the community with the challenges faced by Ebrahim and his caregivers at home and within his social context. It will also conceptualize a multidimentional framework to guide aspects of older adult care at home. Additionally, this case may provide a base for an indepth quantitative or qualitative phenomenological research.

Methodology

A chronological detailed history was documented by Ebrahim's direct family caregiver. Another source was the information recorded by the community nurse who visited Ebrahim once a month, and the notes recorded by the nurses who were hired on hourly basis to care for Ebrahim. The information included Ebrahim's vital signs, sleep and mood pattern, diet and fluid intake, elimination, administration of medication, mobility, daily hygiene and skin condition, and any alteration in his health condition.

To guide the case description and discussion, the authors adopted a modified Roper Logan Tierney Model Activities of Daily Living Scale (ADLs)(Holland & Jenkins, 2019), table 1. The scale is a widely used instrument and deemed suitable for this case presentation, it assesses 12 primary and psychosocial dimentions of human beings. Only the relevant aspect of ADLs will be discussed. Sexuality, working, and playing were not relevant and hence not included. According to the model, the five factors that influence the activities of living are: biological, psychological, sociocultural, environmental, and politico economic.

Table 1.
Comparison of Roper Logan Tierney ADL domain to Mr. Ebrahim's ADL domains.

Roper Logan Tierney ADL domain	Mr. Ebrahim's ADL domains.
Safe Environment	Safe Environment
Communication	-
Breathing	-
Eating / Drinking	Eating / Drinking

Elimination	Elimination
Personal cleaning & Hygiene	Personal cleaning & Hygiene
Body Temperature	-
Mobilization	Mobilization
Working/Playing	-
Sleeping	Sleeping
Sexuality	-
Death	Death

Note. ADL stands for activities of daily living

Reliability and validity are assured by referring to direct sources of information, observation, tracing, and interpreting nursing notes that were written during the last phase of Ebrahim's life.

Written consent from Ebrahim's direct family was obtained. The consent included the aim and benefits of writing this publication, assuring, and maintaining confidentiality, privacy, and dignity of Ebrahim.

Background of the Case

Mr. Ebrahim was born in 1929 in Manama, the capital of Bahrain, the eldest of 4 brothers born to healthy conservative middle class parents. He was taught religious and cultural values from an early age, and he grew up as an energetic healthy young boy. At five years of age, he entered school where he remained until the fifth grade. He then joined his father's business as a car mechanic. At the age of 18 he got married, and was blessed with seven daughters and three sons. He loved his wife, both parents shared in raising the family, teaching them discipline and good manners. Neither parent suffered from any chronic diseases; they did not smoke nor drink alcohol. Ebrahim established a car-repair business, and his income was fairly good. During the following three decades; Ebrahim's family grew to include thirty-five grandchildren, he was a proud grandfather who loved the company of his family.

At the age of 70, Ebrahim developed lower back problems, and was diagnosed with lumbosacral disc prolapse. He was advised to rest, start physiotherapy, and take analgesics. The pain worsened and referred to his lower left leg and foot. He was taken into emergency surgery to release the nerve impingement, but as a complication of late treatment he developed drop-foot. Thereafter Ebrahim's physical activity declined, he wore a prosthetic shoe to support his paralyzed foot and be able to walk steadily. His tilted stature overtime caused him further chronic back pain.

In 2006, aged 77, Ebrahim's 50 years of marriage abruptly ended, when his wife died of a sudden cardiac arrest. He was devastated and felt like his world had ended. For a while he tried to maintain a normal life, he drove to the mosque and other community gatherings, and he travelled to holy places with assistance of a minder and by a wheelchair. To help him with his daily care, a housekeeper was hired.

Ebrahim's back pain grew worse over time and became intolerable. In 2012, aged 83 he underwent another emergency surgery for a lumbar nerve decompression, and a laminectomy was performed. The pain subsided and he gradually went back to most of his normal daily activities except driving.

General medical care was provided by two means: by the district health center through monthly nursing home visits, and by private hospitals. Ebrahim suffered the occasional flu, constipation, diarrhea, fever, and on several occasions, he was treated for urinary tract infections. Later on he also suffered from depression, psychosis, and Alzhiemer's. Table 2 indicates the medications Ebrahim was prescribed.

Table 2.
Mr. Ebrahim's Medicines and Adverse Effect – Prescribed between 2010 to 2020

The Psychiatric Medications:	**Indication**	**Combined Adverse Effect**
Risperidone 25 mg. OD	Antipsychotic reduces irritability.	Diarrhea, constipation, increased appetite.
Cipralex 10mg OD	Antidepressant improves serotonin uptake.	Insomnia, difficulty sleeping, fatigue, agitation, dry mouth.
Quetiapine 25mg. BD	Antipsychotic / anti depressive drug	Weight gain, dizziness, headache, tremors.
Memantine 5mg. OD	Dementia, Alzheimer	Confusion, aggression, depression, sleepiness, diarrhea, constipation
The non -psychiatric Medications:	**Indication**	**Combined Adverse Effect**
Amlodipine 5mg. OD	Maintains BP and heart function.	Drowsiness, fluid retention, headache, abdominal pain, nausea
Bisoprolol 5mg. OD	Improves heart function	Headache, nausea, feeling dizzy, weak, diarrhea, constipation.
Omeprazole 20mg BD	Reduces gastroesophageal reflux and indigestion.	Ulcers in the mouth, Difficult / burning urination, feeling of discomfort.
Lactulose 15ml OD	Laxative	Gas, bloating, nausea, cramps
EU carbon 1tab BD	Reduces bloating, gas, carminative, mild laxative.	Abdominal cramps, nausea, diarrhea
Agio lax 1tsp BD	Relieves constipation.	Diarrhea, nausea, cramps, vomiting.

Home Care & Ebrahim's Activities of Daily Living

Older adults prefer to continue living in their own communities (Fricke & Unsworth, 2001). A positive correlation between ageing in familiar surroundings with a deeper sense of satisfaction and contentedness has been proven (Wilmoth, 2000) and fewer adverse health outcomes and lower risk of hospital admissions (Young et al., 2017).

Older people perhaps feel strong attachment not only to the physical setting, but also to the experiences, memories, and expectations embodied there (Hidalgo & Hernandez, 2001 cited in Stones & Gullifer, 2014). Home offers them historical continuity, a sense of being settled, and preserves the elements of life and personal objects that maintain one's self-concept or identity during the later years. Having these objectives in mind, Ebrahim's direct caregivers cared for him at home, and his care included all the activities of daily living as presented in the following section:

- Mobilization:

Frailty is recognized clinically as a geriatric syndrome that arises due to multiple deficits in body systems (McPhee et al., 2016). Frail people experience severe impairments to physical and mental function that restrict their ability to complete necessary activities of daily living. Although Ebrahim did not suffer from major chronic diseases (heart diseases, renal diseases, blood pressure, cancer, or diabetes) he suffered, an accumulation of 'deficits', including low physical activity level, weakness, psychological deterioration and Alzheimer's disease, weight gain, which necessitated many prescribed medications. Furthermore, his health was not always stable as he had lumbosacral operated prolapse, dropped right foot, occasional UTI due to an enlarged prostate, incontinence, constipation, and pressure sores. All these factors suggest Ebrahim was frail at the age of 80 and very frail at the age of 85.

Ebrahim's family were aware of his physical deterioration and the limitation of his movement and its effect on his general health. Therefore, a rehabilitation program was arranged for him. Daily walking and regular physiotherapy to maintain his motor and muscle strength became part of his daily routine, aimed at increasing the size and strength of limb muscles in order to combat sarcopenia, the loss of muscle mass (Maden-Wilkinson et al. 2013; Rosenberg, 1997 cited in McPhee et al., 2016). This is important since low muscle mass and power are associated with mobility impairments in older age. Furthermore, physical activities reduce fall risk and the risk of developing cardiovascular disease and contributes to improved mental functions, physical independency and quality of life (Buchner et al., 1997; Davidson et al., 2009 cited in McPhee et al., 2016).

- Diet & Fluid:

The major reason for the increase in body fat in older persons appears to be weight gain rather than a true age-related increase in percentage body fat (Silver et al., 1993).Despite his depression, Ebrahim had a good appetite for food. His breakfast began by a plate of mixed sliced fruits, followed by cereal and a slice of brown bread or a croissant, boiled eggs were included two to three times a week, and a glass of milk with a spoon of honey. His lunch included a bowl of rice, chicken, or beef curry, fresh vegetables, or salmon. His dinner was milder with chickpeas, a slice of bread, or a bowl of vegetable soup. Ebrahim enjoyed his meal- times and usually emptied his plate. He drank plenty of water.

However, due to reduced physical activities, Ebrahim began to gain weight, and was difficult to move, it was therefore necessary for Ebrahim to reduce and maintain his weight. Furthermore, he often developed abdominal gas and pain that is mostly associated with reduction in the gastrointestinal motility that comes with normal aging process (O'Mahony et al., 2002). In addition, many frequently used drugs in older people cause disordered gastrointestinal motility. These drugs include anticholinergics, especially antidepressants with an anticholinergic effect and opioid analgesics (O'Mahony et al., 2002) all of which were prescribed for Ebrahim. Therefore, a dietitian consultation was sought by Ebrahim's family. The recommendations were to reduce his food intake to two meals per day, breakfast, and early dinner, with a small snack in between to normalize his weight. The family eliminated all types of gas producing foods and his food was pureed, made soft, and easy to swallow. Thereafter, his abdominal pain was substantially reduced.

- Elimination:

Among common aging changes, incontinence has multiple etiologies with great therapeutic challenges (Honorio & Dos Santos, 2009). Incontinence has a significant impact for both older adults and caregivers. Losing control over bodily functions such as emptying the bowels, is most closely related to losing the control over one's situation and therefore losing dignity. Fecal incontinence is associated with discomfort, pain, and embarrassment (Saga et al., 2013; Dugan et al., 2000).

Constipation and fecal impaction may lead to leakage of stool and vice versa, because of the failure of the anorectal angle to open, widening of the ano-rectal angle and the reduction of rectal sensation (Camilleri et al., 2000). Bowel-symptoms are found to be related to decline in cognitive function, chronic diseases, and depression (Saga et al., 2013; Tamanini et al.,2009). Cognitive impairment in specific is related to the ability to cognitively know that you need to go to the toilet, to know where the toilet is, to be able to move, undress and then dress or use the toilet independently, all of which are essential factors in being able to manage one's bowels independently.

Ebrahim developed dual incontinence at the age of 85. It started with confusion that made him soil himself before reaching the toilet. His condition worsened as he got heavier, physically dependent, and occasionally constipated. Impact on Ebrahim's functional status and quality of life caused psychological effects including social withdrawal and agitation. His physical and hygienic needs were nevertheless improved by adopting preventive measures such as using of urinal and adult napkin diapers, regular ambulation and physiotherapy, adequate fluid intake and fiber containing diet and the regular use of laxatives.

- Sleep:

Lower levels of physical health, depressed mood and lower physical activity consistently emerge as significant risk factors for prevalent, persistent, and incidence of late-life insomnia (Morgan, 2003), this applied to Ebrahim as he experienced regular disturbed sleep patterns. It is also found that habitual activities which are emotionally and intellectually satisfying may, irrespective of energy cost, contribute to sleep quality through their contribution to improved mood and wellbeing (Morgan, 2003). In his later life, Ebrahim's family managed to keep him as active as possible. His daily routine included getting up early, given his morning care, taking his breakfast and medication, and sitting daily in his living room for two to three hours. When the weather was fine, his son took him around the block on his wheelchair. During weekends Ebrahim enjoyed the company of his children and grandchildren. All these activities kept him restful and eased his nighttime sleep pattern. However, disturbed sleep in his later days was increased, he would wake up few times at night and try to come out of bed, so his family decided to hire another nurse to look into his needs and safety.

- Personal Cleaning and Hygiene:

With aging, the skin undergoes progressive structural and functional degeneration that leaves it prone to a wide variety of serious conditions and diseases such as xerosis and pruritus (Surber et al., 2015; White-Chu & Reddy, 2011) and friability of the skin exacerbates pressure ulcers for immobile older adults.

In the final phase of Ebrahim's life, he needed assistance with almost all the activities of daily living, including his personal hygiene. Immobility along with other intrinsic factors caused the

formation of small pressure sores on the ankle of his dropped foot. These were treated with daily sterile dressings and Actisorb (silver with activated charcoal dressing) and eventually healed. Measures taken by Ebrahim's care providers aided in preserving his skin and the recovery of the bed sores. Ebrahim's daily care continued to include getting out of bed, walking with the aid of a walker, and special attention to skin massage and daily physiotherapy. His position was frequently changed when in bed to alternatively relieve pressure from bony prominences. These measures improved circulation around the affected skin and enhanced healing. His diet was a blend of carbohydrates and protein required for skin buildup. His skin hygiene was meticulously maintained, and bed linen was changed daily and kept free of wrinkled surfaces to prevent friction and sheer to the skin. As previously described Ebrahim did not suffer from chronic disease, therefore his healing was achieved relatively fast.

Adult diapers were used sufficiently to protect Ebrahim from wetting himself and soiling bed linen, but despite that he developed redness on the buttock and scrotum following episodes of diarrhea. Wearing of absorbent hygiene products has been found to affect the skin and cause irritant contact dermatitis (diaper dermatitis) or incontinence-associated dermatitis (Bender et al., 2017). Ebrahim's skin condition was managed by sourcing better quality diapers and dressing with Actisorb. A holistic approach of using high-quality absorbent hygiene products in combination with appropriate skin care helps maintain good skin health (Bender et al., 2017). In addition, using cleansers and wipes that contain mild surfactants instead of soaps offered even more advantages by mildly cleansing the skin and caring for it like a lotion (Bender et al., 2017).

- Safe Environment:

A supportive environment, both physical and social, is essential for healthy ageing. Deprived living conditions are factors contributing to the poor health status of older people (World Health Organization, 1998 cited in Chaudhury et al., 2009).

Older adults are at greater risk of developing functional limitations and disabilities. Therefore, the chance of home injury increases in poor living conditions. Falls are one of the most common causes of injury-related morbidity and mortality in later life (Melillo et al., 2015). Research suggests that one-third to one-half of home accidents including falls can be prevented by means of home modification and repair to provide a supportive home environment (Edvardsson et al., 2005).

Ebrahim's family were aware of his condition and the safety measures required. They were also guided by the community nurse who visited Ebrahim regularly. Modifications were made which included keeping his room on the ground floor, installing handrails, widening the bathroom, and maintaining good ventilation in his room. Additionally, assistance with activities of daily living play an important part in accident prevention, especially when an older adult has sensory, perceptual, and motor difficulties. Ebrahim's family coordinated care provision among his care providers. These measures maintained safety and controlled risk factors to prevent falls and other accidents.

- Loss and Grief:

While aging, one may experience a sequence of losses leading to a natural process of disengagement, such as loss of career, possessions, health and most dramatically the death of a close relative (Van Baarsen et al., 2002).Although it has been suggested that people who are

prepared for the death of a loved one have less distress, the relationship between preparedness and post bereavement mental health is inconclusive. Despite the circumstances of death, many people perceived themselves as unprepared for the death of loves ones. These had more depression, anxiety, and complicated grief symptoms (Hebert et al., 2006).

After the devastating loss of his wife, Ebrahim grieved and felt isolated, for a few years he tried to resume his daily life activities as previously described. It is believed that activities act as buffering to prevent early symptoms of depression. Activity and lifestyle regularity level has been observed to be protective factors against bereavement-related depression in later-life (Prigerson et al., 1996).

- Depression & old age Psychosis:

A sense of personal control appears crucial to the psychological wellbeing of individuals facing physiological changes and losses. Depression may result as dependence on others increases, and it is found to be associated with increased mortality, comorbidity, health services utilization, and decreased quality of life (Parmelee & Lawton, 2001 cited in Stones & Gullifer,2014; Dugan et al., 2000) . Ebrahim experienced psychological changes probably because of declined functional levels, loss of vitality and multi-losses. He became quieter, lost his joyful spirit, minimized talking with family and friends and was aggressive towards others.
In 2019, an MRI of his brain showed a deterioration in brain activity and signs of Alzheimer's disease. Patients with Alzheimer's disease may demonstrate physical aggression mostly towards family members and strangers (Liljegren et al., 2018). As in the condition of Ebrahim, many observations support the connection between degenerative brain processes and the onset of psychosis in old age (Van Os et al., 1995).

Ebrahim's family consulted a psychogeriatric to delay further deterioration and enhance adaptation to his situation. He was prescribed medication for Alzheimer's, anti-psychotics, and anti-depressants which helped to improve his sleeping, stabilize his mood, reduce aggressive behavior, and eliminate phobias.

- Grieving & Death:

According to middle eastern culture, the death of an older adult, who suffered from multiple ailments, is viewed as a source of comfort and salvation for the soul to its intended destination "Heaven" after being trapped in the physical body. However, even subtle losses in life can trigger a sense of grief (Nakajima et al., 2012) though its intensity depends on griever readiness and acceptance.

The decision of his direct caregivers was made in advance to care for Ebrahim at home during his final days. Religious rituals and practices were incorporated when signs of dying were observed. It began when Ebrahim lost consciousness for a few minutes,eyes rolled back, became pale, and blood pressure dropped to 100/57 mmhg. He was responsive to calls but deeply drowsy, as his blood pressure continued to drop. Ebrahim departed this world peacefully surrounded by his family members on the 30th of September 2020.

Ebrahim's family prepared themselves for grieving, and accepting his dying and death process. The family supported each other without blaming or guilting and were helped by eliminating

social stigma that might have resulted if Ebrahim was institutionalized and died in a residential facility.

Conclusion and Implication

This case history represents an example of multidimentional aspects of home care on the health and wellbeing of older adults. It also highlights on the positive impact of home care on the process of grieve, death and dying.

Caring for older parents at home is perceived by the Arab community as an obligation of the children, as it is culturally and religiously considered a blessing and rewarding to the care providers. From the same perspective older people expect to age at home respectfully and with dignity. Ebrahim's family made the decision to care for him at home surrounded by family, children, and grandchildren. This brought him comfort in his later life and allowed him to cope better with widowhood, physical and psychological stressors.

The findings of this case add to our understanding the largely unnarrated lives of the very old, it suggests a need for a framework for person-centered home-care management and support of significant family members to understand better what older adults require to live a dignified life until the end. This case has several implications for improving the quality of home care of the older people, these include:

1. Establish active and sustainable partnerships with formal health services to empower older people and their families to have informed decision and choices to live, age, and die in their own homes.
2. Informational support for older adults should be strengthened in community-based social care programs. Formal service providers, such as nursing professionals and social workers, are typical agents for disseminating information about best practices for older adult home care and community resources.
3. Develop and disseminate a comprehensive framework for care of older adults describing indicators of quality of life during aging that includes physical, emotional, financial, and psychological domains.
4. Secure through governmental and non-governmental agencies, adequate financial resources to provide safe physical environments, healthy diet, hygiene and skin care supplies, clothing, and medicine. This will directly and positively impact the health and quality of life of older people.
5. Encourage presence of family to support end-of-life care and confront death of the older adults in their home. Religious and spiritual needs throughout the dying process to be respected.

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