Needs of the patient’s family carers regarding Palliative Care in dementia

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Background

- Dementia is associated with old age (WHO, 2006)

- Major cause of death in developed countries (Mitchell S. et al., 2009)

- 35.6 million people worldwide are living with dementia (WHO, 2012)

- Tripled by 2050 (WHO, 2012)

- Its natural course is unpredictable and prolonged (Lunney J. et al., 2002; Small N. et al., 2007)
Many people with dementia die in nursing homes or residential care settings (Mitchell et al., 2005; Kay et al., 2000)

Evidence suggests that people with dementia and their families receive poor quality of care in their end of life (Lawrence et al., 2011)

Failure to recognize dementia as a terminal illness both from Health Care professionals and family carers, resulting in excluding dementia patients to palliative care (Sampson et al., 2006; Field et al., 1999)

Luddington, Cox, Higginson & Livesley, 2001 stated that patients with advanced dementia have the same palliative care needs with dying cancer patients

Most Alzheimer’s care is provided at home by family carers mostly aggravating their own health and well being (Pinquart et al., 2007)
Background (3)

- Experiences of stress, burden, depression, anxiety regardless the ethnicity or race (Cox et al., 1995; Kim et al., 2007; Kosberg et al., 2007; McCallum et al., 2007; Skarupski et al., 2009)

- Patients’ family are often the people who are asked to decide about the patients course of treatment or End of life decisions causing them increased guilt and anxiety (Forbes et al., 2000)

- Family caregivers consist the most valuable asset of the governments as they offer their care to their loved ones without payment, facing at the same time tremendous difficulties (socioeconomically, psychosomatically). (Ory, Hoffman, Yee, Tennstedt & Schultz, 1999)

- Their actual needs are often missed out and unmet most of the times
Unmet need

A condition or series of conditions that exists when the burden of care provision is either exceeded the individuals resources or creates deficits in that persons life (Branch, 2000)
Palliative care (Definition)

- Improves patients and their families quality of life when facing a problem associated with life threatening illness
- Prevents and relieves suffering with early identification, impeccable assessment and treatment of pain and other distressing symptoms
- Other problems such as physical, psychosocial and spiritual
- Affirms life as a normal process
- Neither hasten nor postpone death
- Supports patients to live as actively as possible until death
- Supports family in coping during the illness and bereavement
- Uses a team approach in addressing the needs
- Enhances Quality of Life
- Applicable early in the course of illness combined with therapies to prolong life

(WHO, 2004)
Aim

- Investigate through a scoping review what are the family carers needs?
- If those needs are met?
Research design

- A scoping review of both qualitative and quantitative studies was used.

- Primary studies were sought from four electronic databases including Science Direct, CINAHL, PubMed and MEDLINE.

- Four quantitative studies involving 1480 family carers and seven qualitative studies involving 494 family carers met the inclusion criteria and were included.

- Methodological design: 4 comparative, 6 descriptive and one interventional.

- Selected studies were categorized and assessed according to international research criteria of COREQ and STROBE.
Search strategy

- Published articles the needs of the family caregivers and their satisfaction surrounding Palliative Care in general

- From May 2016 until October 2016

- “Palliative Care”, “family caregiver needs”, “dementia Patients”, “Palliative Care needs”

- English and Greek articles
Total: 675 titles
- 554 irrelevant with research topic
- 6 duplicates

115 abstracts
- 5 foreign languages
- 40 irrelevant to research topic
- 13 no article available

57 articles
- 46 irrelevant to research topic/literature reviews
- 11 articles reviewed
Quantitative

- STROBE tool as design by von Elm et al., (2004)
- Checklist of 22 items (the STROBE Statement) that relate to the title, abstract, introduction, methods, results and discussion sections of articles.
- The recommendations of the tool are not prescription for designing or conducting studies as its stated by the authors.
- The appraisal statement tool’s results of the chosen articles that would be included in this particular review varied from 16/22 checked items to 20/22.
- Three of the quantitative studies rated as high quality and remaining one rated as moderate quality.
- ¾ studies limitation on generalizing their findings, 2/4 majority of participants were Caucasian less likely non Caucasian, ¼ multiple surveys, ¾ surveyed other parties among with family caregivers
- Strengths in 2/4 created own surveys validated them, most of them were cross sectional and they retained anonymity of the participants
Qualitative

- COREQ appraisal tool which contains 32 criteria (Tong et al., 2007).

- Included studies results after the assessment by the tool, from overall 32 criteria there were met 19 - 26.

- 4/7 appraised as high quality and 3/7 moderate.

- Limitations 3/7 small sample size, 1/7 undetermined diagnosis of relatives dementia, 1/7 sampling was race based, 2/7 small geographical radius and cultural diversity.

- Strengths 4/7 narrative methods revealed complexities on the topic, 1/7 large sample of participants, provide depth and detail in analyzing findings concerning unmet needs and also feelings and behaviors of family carers in situations such as dementia.
Countries surveys conducted

- 4 USA
- Australia
- 4 UK
- Spain
- Germany
- Published between 2004 - 2016
Sample characteristics

- Most of the caregivers were identified female with mean age > 60 years old

- All of the studies examined their participants’ level of received information concerning Dementia

- Most of the surveys examined family caregivers who took care of patients with dementia at that time or before the time of the survey (bereavement stage)

- Most of the surveys examine patients as well as paid caregivers

- One survey was focused on racial difference of the family carers
Results

- Main findings were consistent with:
  
  More communication with the Health Care Providers and quality time, conversations with actual meaning between health care professionals and family carers
  
  All participants expressed the feeling of travelling blindfolded in the whole situation, lack of knowledge about the progression of the disease, lack of plan of action in bad situations
  
  Health care providers as well as family carers do not perceive Dementia as an illness with Palliative Care needs (mention Palliative Care late in the course of illness)
  
  Family caregivers need practical support from Health Care professionals
  
  Compassionate interaction between Health Professionals, their loved ones and their selves
Results (2)

- Health Care professionals to give them time to comprehend a loved one’s death before being sent out of the room
- More privacy with their loved ones at the time of death
- Most caregivers have to take care of fundamental issues before their grief continues
- Need for the caregivers to analyze subjects such as death and dying, deterioration status
- Family carers undergo emotions such as guilt, emotional burden, emotional and literal role entrapment, social isolation
- Keep the problem to themselves, fear of friends disappearing
Results (3)

- Exhausting all options before institutionalizing their loved one, feelings of abandonment
- Two faces of death (one living dead, death)
- Loved ones death as a relief and a blessing
- Some also need spiritual support
- Community support in dealing with the patient at home
- Suggest more education for Health Care professionals in dealing with dementia patients
Discussion

- Most of the family caregivers concerns are related with the patient not themselves
- Most questions concerned on how to deal with the deterioration caused by the disease
- Failure of a Health Care professional to explain the course of the disease makes decisions made difficult
- Struggle to live in two worlds (nursing home, wider society)
- Treatment of symptoms, aid with caregiver burden
- Preserve their loved ones dignity
- Poor communication adds on burden and helplessness experienced
- Higher levels of anxiety among women
Conclusions

- Raise awareness about Palliative Care in Dementia
- Provide adequate information about the disease to the family
- State the facts in order to decide for their loved ones course of treatment without making them undergo unnecessary and painful medical exams (less hospitalizations)
- Creation of community based services to help family carers at home
- Educate Health care professionals in actually dealing with dementia patients preserving their dignity
- Meet the caregivers needs in order to alleviate their suffering and anxiety
- Treat with compassion
Thank You!