

Coping with less travel freedom choices for dementia patients and their caregivers, a qualitative approach

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Abstract

Dementia is considered as one of the biggest problems faced by persons and the society today. Its monetary cost of dementia has already exceeded the heart disease or cancer monetary cost in 2010 (Hurd, Martorell, Delavande, Mullen, & Langa, 2013) and is most likely the biggest social and economic challenge in the near future in the western world because of the rapid aging of population.

This paper addresses the freedom to travel as one very important choice out of several freedoms of choices that affected in the lives of persons suffering from dementia and also their caregivers. The freedom to travel contributes significantly in the well-being of people especially in the developed world. We are challenged to innovate in order to maximize the freedoms of choice in ways that will be beneficial to the economy.

We try to identify what constitutes freedom of choice for patients and their caregivers so that we can see how their welfare can be maximized under the economic constraints faced by the state and the households. The approach followed is a combination of brainstorming, in depth interviews and the application of the Critical Success Factors methodology with a focus group of 12 caregivers at the Entrepreneurship Living Lab (ELL)¹ of the T.E.I. (University of Applied Sciences) of Thessaly².

Keywords: freedom of choice, dementia, caregiver, monetary cost

JEL classifications: D8, I3, M1

Introduction

According to Kant's Doctrine of right in Byrd & Hruschka (2012) genuine freedom of choice is being independent of the choices of others and such independence is only possible if a legal and political order is in place that can determine and police the boundaries of such interactions. Ripstein (2009) review of Kant's theory adds that a person can acquire rights to objects, to other persons to perform an action (contract) and rights to persons akin to rights of things (status) in ways prescribed by the civic society.

Okada, Igarashi, Nomura & Tokuda (2013) refer to the need for travel and stay in hotels as a significant factor for wellbeing. Not much

¹ The Entrepreneurship Living Lab (ELL) of the TEI of Thessaly provides certified training to dementia caregivers under the auspices of The Hellenic Alzheimer's Society

² http://www.teithessaly.gr/index_en.php

knowledge exists about the restriction of freedom of choices for people with dementia. The relevant studies reveal that patients feel that their freedom to participate in decision making is limited (Tyrrell, Genin & Myslinski, 2006), little has been researched on how caregivers can elicitate decision making from their patients (Garvelink, Ngangue, Adekpedjou, DioufGoh, Blair, & Légaré, 2016), institutionalized care is depressing and lowers the feeling of dignity in patients (Heggstad, Nortvedt & Slettebø, 2013; Thein, D'Souza, & Sheehan, 2011).

The question is whether institutionalized care can be postponed and how can this be linked to patient freedom choices and especially choices to travel. In order to answer this question we need to take under consideration the wants and needs of the customer-patient and the economics of the alternative choices related to care facilities and hotels.

Research design and methodology

A focus group of twelve caregivers of patients suffering from dementia participated in the study. In a brainstorming session they presented the freedoms of choices that their patients felt they wanted most as understood and shared by themselves as their caregivers.

Each one was interviewed with an open question on what they consider as critical freedom of choices for both their patients and themselves in relation to issues of hospitality of any form. Their answers were discussed within the group and iterated using the Critical Success Factors methodology (Boynton & Zmud, 1984) until a common list of choices was constructed.

Results

Out of the brainstorming session many had similarities. The answers are categorized below after normalization:

- 1 Be able to be with the people I want when I need them.
- 2 Be able to do things myself (shopping, travelling, paying my bills,
- 3 Be able to move to where I want at the times I want
- 4 Be able to make new connections and pursue their development

Out of the interviews we tabulated the following patterns of travel freedom behavior for patients and caregivers:

- Friendly environments attract patients to visit and mostly to stay with friends and relatives where they feel "welcome".
- Patients in the early stages like and later do not have a problem when staying with their caregiver in an alien environment at night if other people with friendly social links stay as well.
- All caregivers experienced that environments (hotels, houses) where the patient had good time repeatedly in the past normally do not result in problematic behavior and/or disorientation during long visits.
- No patient wants to live in a nursing home or a health care clinic.
- Patients fear to even visit a health care clinic because they link it with other cases where friends and relatives spent their late lives there before they died.

- Patients in the early stages of dementia enjoy the services of hotels of their choice, social activities, eating out and dancing and sleeping in.

Out of the group iteration of discussions in relation to the freedom of choices related to the hospitality issues the following list was produced in hierarchical order:

- 1 Not being able to continue to travel for either for work or leisure is one of the most significant restrictions imposed to patients and caregivers and this restriction becomes a significant burden for their lives
- 2 Patients do not want and suffer loneliness and rejection if "hospitalised" in hospital like facilities
- 3 Patients on the contrary have no problem to go for a vacation, they are happy to visit a hotel and would enjoy their stay as tourists rather than as patients.
- 4 Caregivers would like such facilities to exist on demand in order to be able to "regain a lost degree of their freedom to travel."
- 5 Patients would prefer to be with their caregivers or members of their extended family or friends when staying in a hotel.
- 6 Caregivers would like to be able to go for vacations with their patients to suitable hotels that provide dementia capabilities if they were any. Preference would be given to hotels with special health care facilities.

In relation to the above, the most important problem that most of the caregivers stated in relation to fulfilling their travel freedoms of choice is their reduced income because of the care provision cost.

Another common understanding was that during the pre-detection phase most of the family caregivers could trace back an increased spending rate by their patient and the reason for this could be either because of exercising the freedoms of choice (have a good life while they can) or inability to control their transactions (being victimised).

Conclusions, Weaknesses and Points for Further Research

We have reached to an initial understanding of the travel freedoms of choice by dementia patients and their caregivers. The question to be answered next is whether and which of those freedoms can be economically feasible taking under consideration the costs of not-fulfilling these freedoms and whether they can be quantified.

The Dementia capable and friendly hotel business model could be a preferred strategic choice as alternative choice to the care facility business model for a significant part of the patients' lives. This option could make the initial stages longer and have a positive second effect.

The findings are based on a small number of caregivers. The research could be enhanced with larger focus groups, with patient groups and with quantitative research.

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