

Shopping with Acquired Brain Injuries, Coping Strategies and Maslowian Principles

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Abstract. A positive outcome of the modern welfare state is prolonged life expectancy. In Sweden, the expected life span has increased with approximately 25 years during the 20th century [Statistics Sweden]. However, ageing is associated with an increased risk for acquiring cognitive and physical disabilities. This study is based on anonymized interviews with groups of older persons who experience cognitive problems and relatives. The interviewees were asked about everyday activities like shopping groceries, clothes or other necessities. The interviewees identified problems and described a series of strategies for coping. This paper uses fictionalized characters to present problems and coping strategies that the interviewees use to overcome cognitive challenges when shopping groceries. The strategies range from complete withdrawal, an increased dependency on proxies to the development of elaborate techniques to mask their problem and obtain assistance. Following the current trend in the design of the Swedish sales environment – large scale, abundance of goods and Maslowian strategies for making people stay longer (and spend more money) – accessibility in the built environment is often an absent friend.

Keywords. Cognitive disabilities, older persons, shopping, dependency, architectural design

1. Introduction

Historically cognitive limitations have been treated and recorded as medical conditions and promotes the view of the person who experiences cognitive problems as an oddity. This is demonstrated by two compelling stories that give accounts of changed behaviors by the immediate family and the treating physician. In 1848, American construction foreman Phineas P. Gage (1823-1860) encountered an accident [1], which caused an iron rod to penetrate his head removing most of his left frontal lobe. Mr. Gage survived the injury, but had a completely different personality. He was considered not only a living miracle for medical science but also was for a period a touring exhibit in P. T Barnum's American Museum (ibid). Mr. Gage later became a stagecoach driver in Chile and resumed a structured living, which seemed to have promoted his recovery in terms of regained abilities and social skills, thus, suggesting a healing capacity of the human brain [1].

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The second story is about Auguste Deter (1850-1906) a wife of a railroad worker. In her early forties, she started to experience memory loss and confusion [2]. In 1901, she was examined by the neuropathologist Alois Alzheimer in München, who then followed her case and noted her frequent states of deliria, shifting moods and agitated crises. It was at her death that Alzheimer first discovered the characteristic plaques in the neural tissue of the brain that have become associated with the symptoms of Alzheimer's disease. Little is known about Mrs Deter's strategies for coping in daily life before her admittance to a mental institution in Frankfurt, Germany.

Common for both cases, the brain conditions caused long-term medical conditions with personal changes that stretched from 15 to 22 years. It is probable that Mr. Cage and Mrs. Deter experienced anxiety, when they realized that the everyday life they were accustomed to would never be the same again, and that they would slowly become an outsider beyond sanity and social order, poignantly described as becoming an *horla*, an opposite to the ordinary human being [3].

Today, cognitive limitations are considered within a health-related domain, i.e. the World Health Organization's International Classification of Functioning, Disability and Health, in the following ICF [4]. This framework addresses disability in relation to health condition, the physical and social environment and participation in everyday life [4]. The United Nations Convention on the Rights of People with Disabilities [5] asserts the rights of persons with disability, including those with cognitive disability, to enjoy the basic rights and freedoms that everyone is entitled to and sets out measures that states should take to remove any obstacles that hinder persons with disability to be active citizens.

1.1. Aims and Purposes

This paper is an explorative study focused on difficulties encountered and strategies used by older persons diagnosed with dementia and their immediate family when shopping groceries. It is part of a Swedish governmental assignment entitled 'Living conditions for persons with dementia', in the following LCPD (in Swedish 'Levnadsvilkor för personer med demenssjukdom'). The assignment was entrusted to the Swedish Agency for Participation, in the following MFD after the Swedish abbreviation (Myndigheten för delaktighet). The assignment targets approaches for improving living conditions for older people with dementia. Shopping groceries is usually regarded as a simple everyday activity. However, in combination with a cognitive limitation, the interviews in this study reveal shopping to be a cognitive challenge for a great number of the older persons. This paper maps strategies that older persons with dementia and immediate family construe in order to overcome factors that inhibit their access to shopping. In addition, some advice concerning the reshaping of sales environment is discussed.

1.2. Theory

According to the ICF framework disability represents the negative aspects of the interaction between an individual and contextual factors, both environmental and personal factors. Environmental factors refer to aspects of the external world that form the context of the individual's life and as such impact on that person's functioning. Such factors can improve functioning and reduce disability or be barriers that limit functioning and aggravate disability [6], and life experiences. The natural aging process

often involves the loss of agility in functional properties and yields a decreased adaptability to respond to internal or external stress [7]. In addition, aging includes an increased vulnerability to disease and subsequent mortality [7]. The frail aging process is a geriatric syndrome that is characterized by weakness, weight loss, and low activity that is associated with adverse health outcomes [7]. As a consequence, the frail older person is sensitive to environmental stress that causes inflammatory reactions and pathologies.

Dementia is “a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement” [8]. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation [8]. This syndrome occurs in Alzheimer disease, in cerebrovascular disease, and in other conditions that primarily or secondarily affect the brain [8]. However, the older person’s consciousness remains unclouded and active. Dementia often results in stress filled reactions of fatigue or despair when the affected person is submitted to a too high level of stimuli. However, the cognitive problems, which the affected older person experiences, constitute an increasingly more acute disability. This group of people are often misunderstood by other people, especially in contact with care services [9].

Living conditions for older persons with dementia have attracted a large interest in Sweden, either as research studies on care, medication and therapies [10], or as governmental initiatives that have focused on living conditions and the potential positive effects of assistive technologies (the programs ‘Technic for older people’ [11] and ‘Growing old, living well’[12] The MFD has previously carried out work concerning the living environments for persons for dementia, which has resulted in guidance documents with information on how color and color contrasts, lighting the sound environment can be used to facilitate orientation and make the environment less confusing and cause less agitation and anxiety, for example:

- a subdued background color scheme can reduce unnecessary stimuli with stronger color used as signals for attention,
- adaptive lighting can be used so as to give good general lighting with stronger lighting in certain areas,
- the sound environment can be managed so that it is not perceived as foreign and unfamiliar to avoid creating confusion [13].

Some of these factors can be applicable to other types of environments, although representatives of sales organizations and the Swedish Consumer Agency (Konsumentverket) mostly have collaborated in similar projects that focused on physical accessibility in the sales environment [14]. When consideration is taken to the needs of persons with cognitive problems, cues for wayfinding and personalized shopping aids can be seen as the most important features that may reduce barriers in different types of sales environment [14]. However, the current trend in the development of Swedish sales environment suggests large-scaled grocery stores in the outskirts of urban areas, which generates increasingly larger distances between population in residential areas and access to basic groceries [15].

2. Methodology

This study used an explorative approach in order to describe coping strategies. The study was conducted as a case study that involved two senior officials of the Swedish Agency for Participation, (MFD, Myndigheten För Delaktighet) [16]. The research material consists of field notes and observations by the two officials. Both officials are trained occupational therapists with about 15 respective 25 years of clinical experience that includes working with people with cognitive disability. The Swedish Association for People with Dementia, in the following DF (in Swedish Demensförbundet) acted as advisor to the LCPD project and recommended appropriate group activities organized for people with cognitive problems in different Swedish municipalities. The weekly group activities were organized by the local eldercare authority in close collaboration with the DF.

The research material for this study originates from three such group activities. The MFD officials were invited to inform about the LCPD during a meeting that was organized in spring 2016. In addition, the officials informed about the quite new authority that the MFD is, formed in 2014 after a merger between two other organizations active in the field of assistive technology, care and people with disabilities. The meetings were held under agreeable conditions and coffee and cake were served. The attendees were asked if they were interested in participating in the small explorative study to gather information for use in the governmental assignment. Those who agreed to participate were promised full anonymity and confidentiality [17]. The officials used the following question to animate a discussion: *How do you shop for groceries or other basic products?*

In some cases, this question was repeated by care staff members, who assisted at the meetings. This simple question generated an avid response from the attendees at the three meetings. GP-1 had six members. Group 2, GP-2 had eight members. GP-1 and GP-2 were older persons with dementia who took part in weekly group activities for people with cognitive disability. All of the members of GP-1 and GP-2 were between 65 and 80 years and lived in their own houses with assistance from family and formal home care services. Group 3, GP-3, was composed of close family members to a person with dementia, and counted 15 members. Most of the members of the GP-1 and GP-2 were women, while GP-3 was mixed. GP-1, consisted of older persons with dementia who lived in a medium size municipality with about 43000 inhabitants. GP-2 and GP-3 consisted of older persons with dementia and immediate family of persons with dementia who lived in municipalities in a large city region with about 200000 inhabitants.

3. Results

This section is divided into four sections. The first part presents shopping strategies used by two older persons in GP-1, who lived in a medium size municipality. The second and third parts present strategies used by two older persons with a dementia diagnosis in GP-2 and two relatives in GP-3, who all lived in a large city region. The fourth section summarizes conclusions on the relationship between strategies and layout of shops.

In order to anonymize the interviewees and their strategies for shopping groceries, the information has fictionalized and collated into short stories, which include a brief

background to aid understanding the coping strategies. Behaviors and strategies have been aligned with six fictional characters of older persons with dementia, who are based from a study on patterns of spatial usages at two units in a residential care home for residents with cognitive and/or somatic diagnoses [18].

3.1. Shopping in a Medium Size Municipality

Beth and Fleming are members of GP-1. They will be briefly introduced in order to provide a logical background to their shopping strategies.

3.1.1. Beth and Her Shopping Strategies

Beth is a healthy looking woman in her late 60s who lives alone in a large house located close to the city center. She only uses the kitchen, bedroom and living room. Her husband died ten years ago, and her son has moved to Stockholm. She smokes, and was diagnosed with dementia three years ago. Beth has minor memory loss: cannot remember addresses, telephone numbers nor find her way.

Beth has shopped at the local grocery store since 1970, so the environment is familiar and safe. She says that the store has always had the same spatial configuration and that she does not have difficulty shopping. She tries to find products herself, the staff usually helps her when she appears to have difficulty. She experiences this positively, and she enjoys talking to the staff. Beth shops before lunch, when the store is not crowded. She usually talks with the staff when checking out especially when she is unsure. She always pays in cash and the staff helps her to count the bills and coins.

3.1.2. Fleming and His Shopping Strategies

Fleming is a 70-year-old athletic man diagnosed with dementia two years ago. He lives in an apartment located close to the city center with his ten-year younger wife. Despite his strikingly good physical vigor, he has an aggressive form of dementia, so that he has severe memory loss, decreasing ability to speak and is highly dependent on his wife. Three times a week he goes to a senior center which organizes social activities and serves lunch.

Fleming enjoys his long daily walks with his wife, when they communicate without words, admiring a view, a flower or a bird's song. Fleming has problems in expressing his feelings about shopping. His wife says that they shop groceries in two stores; one in a mall in the outskirts of the city as well as a small local store. Most often Flemming and his wife form a splendid shopping team, she finds and pays for the items, while he organizes them in the cart. His wife says that when Fleming has a bad day, he waits outside.

3.2. Shopping in a Large City

Augustine and Felix are two members of GP-2, and live in large city. A backdrop gives some cues to understanding their shopping.

3.2.1. Augustine and Her Shopping Strategies

Augustine, a retired interpreter, is a well-dressed lady with urban habits. She lives alone in a 19th century apartment building in a fashionable city district. Augustine has

minor memory loss that she hides by saying the missing word in a foreign language. She was diagnosed with an unknown type of dementia four years ago, but she has not applied for help from the municipal eldercare. She attends meetings organized by the local church that she helps organize but never takes part in the discussions.

Augustine shops in a shopping mall. Recently, the grid of interior streets and passages that delimited different shops was replaced by a meandering pathway that connects the mall to the surrounding streets. She does not like the new setting. Augustine experiences great stress when she shops groceries. Leaning on her cart to calm her nerves, she looks for suitable cues to find her way: young mother equals basic food products, young man equals ready-made food products, filled carts and a large group of people equals checkout counters. She always pays with a credit card, and has embroidered the code as part of the overall pattern of her wallet.

3.2.2. Felix and His Shopping Strategies

Felix, a retired shipping engineer, was diagnosed with dementia two years ago, when he started to experience problems with producing technical drawings. Felix lives alone in a suburb of a large city in a two-room apartment for seniors. Felix was divorced 15 years ago and has no contact with his ex-wife.

It takes him about 20 minutes to get to the center which has a grocery store, bank and post office. He feels insecure walking in the park-like way to the center, especially when he sees young men with shaved heads. He shops groceries daily at the local petrol station. He finds some of the products he needs, since the selection is limited. The staff is friendly and helpful and he enjoys helping them with technical terms. The petrol station offers meals with coffee and a large variety of cakes, so that he often eats a simple meal when he is there. He is aware that the prices are approximately 25 per cent higher than those at the local supermarket. He uses his credit card with his year of birth as code. He worries that the credit card will be refused.

3.3. Shopping in a Large City Region with a Relative with Dementia

Laura and Eugene belong to GP-3. They have no individual dementia diagnosis, but their spouses have a diagnosed brain disease. The backdrop gives some cues to their shopping behavior.

3.3.1. Laura and Her Shopping Strategies for Herself and Her Husband

Laura is 69 years and retired four years ago. She spends a good part of her time taking care of her 85-year-old husband, who was diagnosed with dementia eight years ago. They live in an apartment in a suburb of a large city. Her husband has significant memory difficulties and goes regularly to an activity center for persons with dementia, a 25-minute walk from their apartment. He usually finds his way to the center, but cannot find his way back home. He cannot use a mobile telephone or any other assistive equipment. Laura attends meetings for informal caregivers. Both types of meetings are provided by the local eldercare office.

Laura and her husband shop at two markets in the local shopping center. They both enjoyed shopping together until a year ago when he started to get frustrated and angry when he could not find his way in the stores. Laura talked with the manager of one of the markets and asked for extra help for older people. The manager improved signs and began to offer special shopping hours for older people. The staff also began to wear

shirts in bright colors. The signs and staff gave him sufficient support to continue shopping for a while. However, he developed increased memory difficulties and could not remember the product he was looking for nor recognize his own wife. Today, Laura shops on her own several times a week while her husband stays at home alone, either sleeping or watching television. Laura has to be quick because after about one hour he starts to search and call for her.

3.3.2. Eugene and His Shopping Strategies for Himself and His Wife

Eugene lives in a single-family house in a suburb to a large city with his wife who was diagnosed with dementia five years ago. Eugene is three years younger than his wife, and spends a good part of his time taking care of her. His wife experiences memory problems; gets lost easily, roams about without a goal and cannot use any type of household equipment. She has medication, but it has little effect. Eugene has acquired stress-related problems; with resulting fatigue and sleeping problems. Their two daughters have advised him to apply for municipal home care, but he hesitates believing that caring for his wife is part of their marriage vows. He is aware of the progressive nature of his wife's condition, and has applied for adjoining rooms at a nearby residential care home.

Eugene and his wife shop at two local supermarkets. He drives their copper-colored C70 Volvo, their last purchase before his wife's condition was diagnosed. He parks their car and his wife remains in the car with a stuffed animal in her hands, admiring the great view from the car. She can wait calmly for about 25 minutes so he quickly enters the shop, grabs products and vegetables, pays and hurries back to the car. He sits with her for about ten minutes, and then goes on to the next errand. Eugene has tried to have his wife sit near the customer help desk and asked the staff to keep an eye on her and call him on his cell phone if she became anxious or agitated. They declined, saying they could not supply this service.

4. Conclusions on Shopping with Dementia

This paper has focused on how older people with dementia create strategies for being able to interact in a sales and purchase situation. Also, the absence of individual coping strategies or strategies among relatives have been explored by asking close family members of persons who have dementia. In order to meet ethical issues for research that involves frail persons, who might not fully grasp the consequences of participating in a research study, this paper has used narration techniques to anonymize the informants. These narratives provide an explicatory backdrop in order to explain probable motives for how an individual with cognitive disability copes in a sales environment. The narratives reveal that the main driving force behind different strategies can be seen as profoundly human:

A personal and strong wish to maintain individuality and independence.

For all of the interviewees with dementia, coping strategies were invented and used to attenuate or mask an experienced difficulty to interact with the surrounding environment. The strategies were linked to the overwhelming demands from the surrounding environment, which comprised complex situations that require high

perceptual control. In line with most theories on human ageing, the individual response to an overload of environmental stimuli was confusion and nausea [7] that called for sitting down and relaxing for a moment. The narratives supply some shreds of advice for adjusting the sales environment. These suggest that the following aspects should be enforced in order to meet cognitive problems:

- a spatial configuration with a main path that connects the entrance with the exit through the check-out counters,
- intersection points between the main path and side pathways,
- places to sit down for a short rest,
- clarity and legibility in signage and exposure of goods.

However, the most important feature was the presence of staff to ask for help and guidance. In addition, clear or bright colors of aprons and shirts that the staff wore made them more visible in a crowded shop. In that aspects, cognitive problems forward the need for a type of 'cognitive accessibility' in the sales environment that instill:

- a feeling of being at ease and allowed to ask questions,
- a feeling of being in a safe and secure environment.

5. Concluding Remarks

This paper is a small study on coping strategies among 29 older persons, who strived to maintain their individuality and independence by constructing ways of overcoming stress and fatigue in a shopping situation. The study is explorative, which calls for some caution with regard to the results. However, the study confirms existing research on the need for limiting environmental demands on the older person with dementia and providing cues or other support within the environment. Hence, cognitive accessibility is relevant, especially in a purchase situation when a series of decisions have to be made regarding brand, price and number.

Based on the experiences of the persons in this study, cognitive accessibility converges with a built environment of small-scale and small-size, but becomes increasingly difficult to address in large-scaled and mega-sized buildings and districts. Also, given the permanent detrimental effects of a dementia disease, the study suggests that cognitive accessibility is an interaction between individual coping strategies and different types of supportive sales environments.

Hence, cognitive accessibility has an ephemeral character that depends upon moods, setting and individual strategy to address cognitive problems. The ultimate aim is to create an environment which facilitates a feeling of wellbeing and fight the inner worry that Maupassant describe as the outsider:

-What is my problem? It's that thing, that thing the outsider, who haunts me and makes me experience these disillusion! It is inside of me, it is eating my soul.²

² Translation by author, Qu'ai-je donc? C'est lui, lui, le Horla, qui me hante, qui me fait penser ces folies! Il est en moi, il devient mon âme (G. Maupassant, Le Horla, Folio classique, Paris, 1991, 74)

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