Friend-Enriched Digital Life Stories
to Support People with Dementia

Master Thesis

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Abstract

Dementia and its most common form Alzheimer’s not only impairs the human capacity of remembering but also has a severe impact on the sufferer's personality and perceived well-being. Informal caregivers who can dramatically improve the patient's quality of life through their work often feel extremely burdened and frequently use ineffective coping strategies. Although various assistive software systems already exist supporting the sufferers and their families, many of the patients' needs are still unmet. The HCIM research team from the Department of Informatics at the University of Lisbon initiated a software project that uses automatic retrieved data of the patient's smartphone as input for an inference engine to indentify relevant life events in the patient's life. The collected data can then be used in various care scenarios. In a first version of the proposed system its gained knowledge is used to conduct digital-supported reminiscence therapy sessions. This thesis examines the possibility to use a friend-sourced mechanism through question-asking on Facebook and querying open available web services in order to enrich and validate the gathered knowledge of the system. The environment of the patients, their caregivers, and the disease itself are examined in this thesis. Crucial pre-conditions for the friend-sourced mechanism are studied and factors affecting the quality and quantity of the answers as well as ethical and psychological issues are discussed. Important requirements for a prototype that implements the suggested mechanism are derived from the findings and its development is described. The prototype and its enrichment component possess a flexible and easy extendable software architecture that allows fast and cost-efficient enhancements. A conducted expert interview supports the proposed system design regarding psychological and ethical considerations. Although the proposed system may support many patients dramatically through strengthening their social contacts and increasing their feeling of independence, not all sufferers may be willing to use a system that may invade their privacy. The system establishes a continuous interaction with the patient and his friends through his Social Networking Site that can prevent his isolation and moreover can unburden caregivers. The developed prototype will enable further research including all stakeholders in order to validate more intensively the system design, study the user acceptance, and examine the effects of the proposed system on the patients within a long-term study.

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1 Introduction

The number of people who are suffering from dementia and its most common form Alzheimer’s, increased significantly during the last years. According to Alzheimer's Disease International "4.6 million new cases of dementia (one new case every 7 seconds) [...]"[1] were registered in 2005. Care costs can be a towering financial burden for the family.[2] Costs for home health aide may arise even when the patient's family decides to nurse the sufferer at home. Besides the financial aspect, informal caregivers are often exposed to enormous stress situations which, in many cases, lead to emotional disorders or even depressions.[3] In the last decades, the disease that more likely affects elderly people has become a severe societal problem. Demographic changes, including the ageing of the population, even accelerate the trend. If no additional effective prevention methods are implemented in future, the number of new dementia patients will double every twenty years, so that in 2040 the existence of 81 million dementia patients can be assumed.[4] Unfortunately, for the dementia disease which is also referred to as the 21st century plague,[5] there is no cure[6] at this time. However, prevention as well as early diagnosis can "[...] play a huge role in delaying the onset of the worst effects of this severe disease."[7]

Assistive software systems for people with dementia can improve the sufferer's life quality dramatically and empower them to perform daily activities more independently which not only has a positive effect on the users but may also unburden the caregivers.[8] Although there are many technology-based approaches to serve people with dementia, most of their needs are still unmet.[9] Besides the desire of the patients to maintain their memory capacities as far as possible, people with dementia often wish to get support to perform daily life activities more autonomously and at the same time enhance their

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[1] (Ferri, Cleusa; et. al., 2005), p. 2112.

[2] cf. (Prince et al. 2013), p. 71ff.; (MetLife Mature Market Institute 2011); (Alzheimer's Association 2012).

[3] cf. (Tremont et al. 2013), p. 1.

[4] cf. (Ferri, Cleusa; et. al., 2005), p. 2115.

[5] cf. (Hall 2012).

[6] cf. (Mulvenna, Maurice; Nugent, C; 2010), p. 23.

[7] (Mulvenna, Maurice; Nugent, C; 2010), p. 23.

[8] cf. (Judd 2012), "What are the benefits?"; (Schröter et al. 2013), p. 1150.

[9] cf. (Armstrong et al. 2010), p. 492.

feelings of safety. However, since the disease sometimes makes persons forget e.g. the names of their friends or even the faces of their loved family members, one essential need of people with dementia is to reduce the risk of losing their social contacts and strengthen their existing social network.[10]

Unfortunately, most of the existing assistive software tools do not consider many of the already available mainstream technologies which may improve the patient's life quality.[11] Some recent projects can be identified which train the patient's memory[12] and try to help maintaining the sufferer's existing social contacts.[13] However, these approaches often lead to further work especially for informal caregivers since they mostly have to assist the patients constantly when using the software tools. Moreover, these tools require the responsible caregivers to constantly maintain the system and supervise the generated input data.[14]

1.1 Description of Overall Project and Objectives of the Thesis

This thesis is part of a larger research software project for people with a mild form of dementia. The project's overall goal is to provide a software system which helps sufferers to remember past events, reminds them on future events, and supports patients to maintain an active independent living by e.g. providing in-situ communication support, enhancing their (perceived) safety, and preserving their social contacts. The proposed software system will run on regular mainstream hardware to make it available to as many potential users as possible. Here, the system uses the patient's smartphone to automatically capture input data such as outdoor location, pictures the patient explicitly takes and activity recognition through the use of the phone's accelerometer. A server system that includes a semantic network as well as an inference engine will be implemented to detect routines in the patient's life. The gathered knowledge of the semantic network can then be enriched and validated through public available web services and moreover through question-asking on private social networking sites. This friend-enrichment process serves as a validation and personalization mechanism of the relevant patient's life events.

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[10] cf (Lou et al. 2010), p. 24.
[11] cf. (Kikhia et al. 2010), p. 163ff.
[12] cf. (Kikhia et al. 2010).
[13] cf. (Mulvenna, Nugent 2010), p. 25-26.
[14] cf. (Kikhia et al. 2010), p. 168ff.

The intention of sharing the workload among a trustworthy set of the patient's social networking site friends is to keep the process feasible for the caregivers and ensure more people engaged with the patient.[15] The enriched data can then be used in a variety of the mentioned care scenarios.

For now, the focus of this project will be to develop a software architecture and a first version of a prototype which enriched data can be used within a life logging web tool to support digitally reminiscence therapy sessions. This prototype should support further research and extensive trials involving the patients, caregivers and all other stakeholders. Long-term studies will be necessary to examine the effects of the provided software functions on the patient and adjust or extend the system if necessary. The goal of this thesis is to develop a prototype for a software system,

- that implements an enrichment engine using both, the web as well as the friend-enrichment mechanism as the sources, and is compatible with the other developed software modules within the project,
- which uses pervasive and affordable hardware (low-cost approach),
- that possesses a solid and easy extendable software architecture.

To be able to achieve this goal the following secondary objectives have to be considered:

- conduct research about dementia as well as typical user needs,
- discuss caregivers' motives and feelings to understand how the system can support them in their work,
- examine the viability of friend-enriched mechanism for the proposed system and analyze the factors which affect the use of the mechanism.

1.2 Structure of the Thesis

First of all the thesis will give a brief overview about dementia itself and discuss the unmet needs of the sufferers to examine important basic conditions. Secondly, the role of informal caregivers, their motives, as well the risks of their work will be discussed to get a general idea of the main stakeholders of the later presented system. Afterwards, current related

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[15] cf. (Martins et al. 2014), p. 1.

research work in the area of *Assistive Software* for people with dementia will be presented, important requirements of software tools in this area will be shown and yet unsolved problems will be discussed. Moreover, it will be shown that the use of *Social Networking Services* (SNS) such as *Facebook* can be adequate to enrich the data of the planned system and get answers about recent life events of a patient by presenting comparable approaches. After a brief discussion of the presented theoretical considerations, the developed prototype will be introduced. Here, especially the technical issues concerning the mechanism to enrich the existing data with the use of friend-sourcing methods and the data preparation for a context-based life logging tool will be introduced. Finally, all results of the work will be summarized and further research will be suggested.

2 Background Information

This chapter gives an overview of the disease dementia and its most common form, Alzheimer's. In this chapter some facts about the diagnosis and the stages of the disease will be outlined and typical challenges for caregivers as well as patients will be discussed. Finally, *Reminiscence Therapy*, a commonly practiced therapy method, will be briefly introduced. The information provided in this chapter is crucial to understanding the daily lives as well as the important needs of the proposed system's stakeholders, such as patients, their caregivers, family members and friends.

2.1 The Disease Dementia

The number of dementia patients has significantly increased in the last decades. According to the Alzheimer’s Association an estimated number of 5.2 million patients, including 200,000 people younger than 65 years, can be assumed in the US alone.[16] Worldwide, approximately 35 million people suffered from dementia in 2013.[17] Worrisome here is that there are reasonable assumptions that the cases will grow dramatically in future, so that the "[...] number of people affected will double every 20 years to 81.1 million by 2040."[18] In Europe, that would be around 10 million affected people in 2040.[19]

Alzheimer’s disease (AD) is the most common form (50% of all cases) of dementia. The disease causes

- brain atrophy (shrinking),
- small deposits which are called brain plaques,
- a decrease in the level of neurotransmitters (brain messengers),
- and a dramatic reduction of nerve fibers which can be recognized over time.[20]

The more the brain is affected from the described changes the more severe the symptoms of AD become. Until now, no single factor has been scientifically proven as a cause for AD, except age. However, it is "[...] likely that a

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[16] cf. (Thies, Bleiler 2013), p. 208.
[17] cf. (Prince et al. 2013), p. 1.
[18] (Ferri et al. 2005), p. 2112.
[19] cf. (EBC Brain Council 2011), p. 1.
[20] cf. (EBC Brain Council 2011), p. 1.

combination of factors, including age, genetic inheritance, environmental factors, lifestyle and overall general health, are responsible."[21] Severe dementia not only destroys the human brain and its memories but also affects the sufferer's personhood and identity which can be described as a "loss of self".[22] Depending on the state of the disease different symptoms can be identified.

2.1.1 The stages of dementia and its diagnosis

In many cases, dementia is diagnosed years after noticeable changes in the brain have already taken place: so called biomarkers that are characterized by changes in blood and brain functions can often be measured upwards of 20 years before the symptoms of the disease are recognized.[23] This initial stage of the disease is also referred to as Preclinical AD or Clinical Dementia Rating 0 (CDR-0). In this very early stage of the disease no impairments can be recognized.

A score of 0.5 on the CDR scale which is also referred to as *very mild dementia* represents minor impairments with memory inconsistencies. People in this stage usually struggle to solve challenging problems and have trouble with timing. Additionally, they may have difficulties at work or when engaging in social activities. However, at this stage they mostly can still manage their own personal care without the help of (informal) caregivers.[24]

Patients who suffer from a more recognizable stage of dementia are usually having *Mild Cognitive Impairments* (MCI) which is also referred to as *mild dementia* or CDR-1. In this stage of the disease, patients start to experience moments of confusion and very recent events tend to be forgotten easily. It can occur that sufferers feel disoriented and have problems finding their way back home, for example. Here, outside activities may sometimes be more challenging, housework may be neglected and patients may need to be reminded to insure their own personal hygiene.[25] People in this stage of dementia may

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[21] cf. (Alzheimer's Society UK 2011), p. 3.
[22] cf. (Lislerud Smebye, Kirkevold 2013), p. 1.
[23] cf. (Hope Dementia & Alzheimer Services Hyannis 2010).
[24] cf. (Washington University School of Medicine 2011), p. 10.
[25] cf. (Ellis, Krucik 2013).

> "[...] have trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, using poor judgment, and having some mood and personality changes."[26]

Moreover, the sufferers often lose their motivation for many activities and symptoms of depression can frequently be recognized.[27] In this stage of the disease, most of the patient's daily life activities can be conducted independently. However, more and more situations can occur in which the patient requires assistance.

Stage 4 of dementia is called CDR-2 or moderate form of AD. In this stage, the patients are more dependent on (informal) caregivers who can assist sufferers in situations where symptoms are experienced. This stage of the disease is characterized by frequently occurring situations of temporal and geographical disorientation. Patients suffering from CDR-2 often have trouble remembering new information, including places, objects and even new people, who they had recently met. Sufferers may have difficulties expressing themselves, sensory processing is impaired, illusions, hallucinations, delusions, paranoia and impulsive behavior may arise.[28]

In stage 5 of dementia, the patients suffer from severe impairments. Here, almost no activity can be conducted independently and help is needed to attend all personal needs. People in this stage of the disease cannot communicate and usually stay in bed throughout the day, since their body shuts down physically.[29]

Currently, the commonly practiced diagnosis procedure to identify dementia includes cognitive and behavioral tests, followed by reviews of the patient's psychiatric history, interviews of close family members as well as magnetic resonance image analysis to check for possible brain changes.[30]

The proposed system primarily addresses patients with dementia until stage CDR-1, since they are usually still capable of using technical devices and are aware of the system functions.[31] However, the use in later phases is

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[26] cf. (Alzheimer’s Disease Education & Referral (ADEAR) Center 2011), p. 3.
[27] cf. (Prince et al. 2013), p. 25.
[28] cf. (Alzheimer’s Disease Education & Referral (ADEAR) Center 2011), p. 3.
[29] cf. (Alzheimer’s Disease Education & Referral (ADEAR) Center 2011), p. 3.
[30] cf. (Thies, Bleiler 2013), p. 211.
[31] cf. section 3.1ff.

theoretically possible but may require more intensive consideration of ethical and psychological issues.

2.1.2 Dementia from the Patient's Perspective

Dementia often impacts the lives of sufferers significantly, from the point at which symptoms of the disease appear. Dementia and its most common form, Alzheimer's, not only affect the person’s recall ability but result in various emotional reactions.[32] This section will describe how the disease is usually perceived by the patient. Although in the past the patient's needs were often neglected in research,[33] nowadays the importance of acknowledging the patient’s view while planning new assistive technologies has been recognized.[34]

Losses and Changes

People suffering from dementia often gradually realize that something is “wrong” with them.[35] The greatest concern of the patient is mostly the loss of memory followed by a fear of not being able to communicate and verbalize properly with others, and the anxiety of losing orientation.[36] Additionally, many patients experience the feeling of losing control, autonomy and their independence; followed by the feeling of losing abilities to perform “normal” activities or work.[37]

Coping Strategies

Some people suffering from dementia are not able to accept their diagnosis: they often try to deny their symptoms, avoid the term “Alzheimer’s disease”, or just try not to think or talk about it.[38] Another coping strategy is a form of resistance where limitations are noticed but minimized or dismissed as normal.[39]

However, despite the impact of the disease, most of its sufferers try to live a

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[32] cf. (de Boer, Marike E. et al. 2007), p. 39.
[33] cf. (de Boer, Marike E. et al. 2007), p. 29.
[34] cf. (Dröes et al. 2010), p. 113.
[35] cf. (Clare 2003), p. 1022.
[36] cf. (Holst, Hallberg Ingalill R. 2003), p. 361-363; (de Boer, Marike E. et al. 2007), p. 33.
[37] cf. (de Boer, Marike E. et al. 2007), p. 33.
[38] cf. (Clare 2003), p. 1022; (de Boer, Marike E. et al. 2007), p. 37.
[39] cf. (Clare 2003), p. 1022-1023.

normal life to the fullest extent by sticking to daily routines and staying engaged in all sorts of activities to maintain control over their lives.[40]

Relationships

Relationships with others are of great importance for the sufferers. However, some patients realize that their own perception and the one of their family members or friends are not congruent.[41]

> "But aside from that I don't really have too much problem. At least I don't. Maybe other people do. You know, my wife and my kids, they probably find a big change or something."[42]

Many sufferers care a lot about the opinion of others and feel in many cases embarrassed to tell their friends and family about their diagnosis.[43] Patients often feel afraid of limitations on their experiences and increasing supervision (such as family members insisting they quit driving, or taking over responsibilities from the patient).[44] The well-being of people with dementia is often strongly dependant on how they are treated by their family and friends[45] as well as by medical personnel.[46]

Care, Assessment and Feelings

Patients experience care and assessment very individually. Some sufferers feel they lack information about their disease and that full disclosure of the diagnosis is important.[47] However, learning all information about the disease can be a destructive experience for the sufferer. Some people enjoy receiving care and hope that medication will help them while others feel constantly confronted with what they are not able to do anymore.[48] Sufferers of dementia typically experience a different set of emotions which can range from fear, insecurity, confusion, and disbelief to shock, sorrow or anxiety.[49] Some patients even feel they are "going mad":

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[40] cf. (de Boer, Marike E. et al. 2007), p. 38.
[41] cf. (Holst, Hallberg Ingalill R. 2003), p. 362-363.
[42] cf. (de Boer, Marike E. et al. 2007), p. 34.
[43] cf. (Harman, Clare 2006), p. 485ff.
[44] cf. (de Boer, Marike E. et al. 2007), p. 34.
[45] cf. (Lislerud Smebye, Kirkevold 2013), p. 2.
[46] cf. (Harman, Clare 2006), p. 484ff.
[47] cf. (Ostwald et al. 2002), p. 308.
[48] cf. (de Boer, Marike E. et al. 2007), p. 35.
[49] cf. (Holst, Hallberg Ingalill R. 2003), p. 359-360.

> “I’m mad as hell… [Alheimer’s] is constantly on my mind.”[50]

Other common feelings of dementia patients are frustration, discontent, anger, and annoyance but also embarrassment, humiliation, loneliness and isolation; followed by feelings of “being different”, feelings of disintegration or inadequacy.[51] Many sufferers feel uncertain about their future, which may even result in suicidal thoughts. Only a few patients feel little unconcerned about their health or relatively happy with their situation.[52] A study which involved 88 people with a mild or moderate form of dementia showed that general well-being and taking part in “normal” activities as well as maintaining friendships and the feeling of being attached are crucial factors for perceived quality of life.[53] The study concluded that for most of the patients the feeling of being useful and giving meaning to their life is a substantial concern.[54]

Unmet needs

Although dementia sufferers already have access to various kinds of support there are still needs which are unmet. These are:

- the need for general and personalized information (supporting daily activities),
- the need for social contact and company,
- the need for health monitoring and perceived safety,
- and the need for support with regard to symptoms of dementia (most frequently the loss of memory).[55]

Moreover, the need to do meaningful and purposeful activities, a perception of autonomy as well as the need to feel understood can be often observed.[56]

2.2 Informal Caregivers of People with Dementia

Informal caregiving can be crucial for the patient's well being.[57] Besides the fact that nursing the sufferer from home usually saves costs, many family

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[50] (de Boer, Marike E. et al. 2007), p. 35.
[51] cf. (Holst, Hallberg Ingalill R. 2003), p. 359.
[52] cf. (Holst, Hallberg Ingalill R. 2003), p. 363-364.
[53] cf. (Dröes et al. 2006), p. 542-543.
[54] cf. (Dröes et al. 2006), p. 551.
[55] cf. (Lauriks et al. 2007), p. 223.; (Lou et al. 2010), p. 24.
[56] cf. (Lunde 2012).
[57] cf. (Brouwera et al. 2005), p. 86.

members feel responsible for the care of their loved one. The next section will give an overview of who the most common informal caregivers are and what kind of motives they usually have. Furthermore, some potentials and risks of informal caregiving will be described.

2.2.1 Profile of Informal Caregivers

According to the U.S. Census Bureau most people with dementia live in their communities. In the U.S. for example, this number ranges from 70% to 80%.[58] In the EU approximately 100 million people currently provide some type of informal care.[59] 75% of people with dementia receive care from family members. Typical groups of informal caregivers are spouses, children or children in-law of the affected person. In developed countries, more than 60% of those caregivers are female.[60] In average, the informal caregiver is 46 years old and working.[61] However, according to a study from the Alzheimer's Association, the share of male informal caregivers, currently 40%, has been slowly increasing over the last years.[62] Carol Levine, director of the Families and Health Care Project at the United Hospital Fund mentioned:

> "It used to be that when men said, 'I'll always take care of my mother,' it meant, 'My wife will always take care of my mother. But now, more and more men are doing it."[63]

2.2.2 Informal Caregivers and their Work, Motives and Feelings

One of the earlier defined goals of this thesis was to discuss how an assistive software system for people with dementia could be implemented without increasing the burden of the caregivers. Therefore, it is crucial to get some insights into the work of informal caregivers as well as obtaining a better understanding of what aspects of their duties are perceived as burdensome and how these situations can be avoided. Since the sufferers' well-being is strongly dependant on the care provided,[64] the motives as well as the feelings of the caregivers can also be relevant to an understanding of the sufferer's environment while planning assistive software systems for them.

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[58] cf. (He et al. 2005), p. 35ff.
[59] cf. (Llena-Nozal et al. 2011), p. 43f.
[60] cf. (Brodaty, Donkin 2009), p. 217.
[61] cf. (Family Caregiver Alliance 2003).
[62] cf. (Leland 2008).
[63] cf. (Leland 2008).
[64] cf. section 2.1.2.

There are many possible motives for informal caregivers to provide their unpaid support. Often, caregivers are motivated by their love to their family member; they feel guilt or a sense of duty. Even spiritual fulfillment can be a possible motive for informal caregiving.[65] Conversely, in some instances reasons such as social pressure or culture norms, complex family structures, the greed for future bequests or current informal caregiving provisions can be drivers for caregivers.[66]

The typical duties of caregivers for people with dementia are:

- providing practical help with cooking, cleaning, washing and shopping,
- taking them to and from and arranging appointments,
- providing emotional support,
- making sure they are safe,
- assistance with finances and paperwork,
- provision of physical support such as assistance with bathing, washing, dressing, lifting and mobility.[67]

Dementia is a condition that typically demands, depending on the state of the disease, many hours of care. In developing countries 3 to 6 hours of daily care are spent on average with people suffering from dementia.[68] Besides many required care hours, massive care-giving expenses usually arise. These costs include direct costs for medical consultations, investigations, pharmaceuticals, provision of personal and nursing care, and often residential care in the later stages.[69] Additionally, in many cases massive indirect costs arise because patients and caregivers relinquish or reduce their employment. About two thirds of all employed informal caregivers reported "[...] that they missed work, 8% that they turned down promotion opportunities, and up to 31% that they had given up work to attend to caregiving responsibilities."[70] These costs often mean a substantial financial setback for families that they sometimes are hardly able to cover.[71]

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[65] cf. (Eisdorfer 1991), p. 238-247.
[66] cf. (Lundborg 2006), p. 4.
[67] cf. (Bletso 2013), p. 5.
[68] cf. (Brodaty, Donkin 2009), p. 218.
[69] cf. (Brodaty, Donkin 2009), p. 220.
[70] cf. (Brodaty, Donkin 2009), p. 220.
[71] cf. (Prince et al. 2013), p. 71ff.

The majority of informal caregivers who find their work beneficial feel less stressed and often find positive aspects of care giving. The positive aspects most often mentioned are improvement of the relationship between caregiver and sufferer, fulfillment or reward, enjoyment, and the provision of a higher quality of life.[72] However, caregivers who are driven by more negative reasons tend to feel easily burdened by their caregiving duties. Many studies have shown that especially those caregivers whose charges have dementia perceive a higher level of burden than other groups of informal caregivers.[73] There are many possible negative effects of caregiving that can be identified. Many informal caregivers suffer from extreme fatigue, burn-out syndromes and even depression. Moreover, about a quarter of all caregivers of people with dementia suffer from significant clinically anxiety.[74] The perceived psychological and emotional pressure can sometimes experienced as unbearable by the caregivers.

> "I think it can only be described as nightmarish. It has no rationale […] I've got to the stage now, where I think I'm almost beyond the crying. I've cried so much, I've cried an ocean I think."[75]

Sometimes, the almost intolerable burden as well as the use of unhelpful coping strategies can even lead to abusive behavior towards the patient.[76] However, the objective burden of the dependency of the person with dementia on the caregiver often does not correlate to the perceived subjective burden of the caregiver.[77] In many cases it is not the hard facts, the objective load itself, which is the reason for those negative effects. Instead, it is rather soft facts, such as the former relationship between caregiver and sufferer, the caregiver's self-efficacy as well their confidence in their role as caregiver that are most important to the level of the felt burden.[78] It has been earlier shown that informal caregivers can be effectively unburdened by providing them with useful information and strengthening them in their role as caregivers.[79] For example, caregivers often feel less stressed about their duties when they are secure about their responsibilities and obtain constructive and practical advice

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[72] cf. (Cohen et al. 2002), p. 186.
[73] cf. (Campbell et al. 2008), p. 1078.
[74] cf. (Cooper et al. 2006), p. 15.
[75] (Aggarwal et al. 2003), p. 193.
[76] cf. (Cooper et al. 2010), p. 141.
[77] cf. (Brodaty, Donkin 2009), p. 219.
[78] cf. (Gonyea 2005), p. 276ff.
[79] cf. (Campbell et al. 2008), p. 1083; (Gaugler et al. 2008), p. 8ff.

in difficult situations.[80] Informal caregivers often do not accept the offered help or feel awkward about asking for support. However, crucial coping strategies to avoid stress while taking care of people with dementia include spreading the responsibility and making use of all available resources.[81] Helping hands cannot only lower the caregiver's objective burden but also the subjectively perceived burden, since caregivers will not feel "left alone" with their duties.

Consequently, the proposed system has great potential to lower the perceived burden of the caregivers if the system helps to spread responsibilities by keeping friends up-to-date of current activities in the life of the patient. This can make friends feel more involved and may indirectly invite them not only to provide data on the SNS but also step forward and support the caregivers with their duties.

2.3 Reminiscence Therapy

Reminiscence Therapy (RT) is an often practiced treatment for people with dementia. According to Woods *et. al.*,

> "Reminiscence Therapy (RT) involves the discussion of past activities, events and experiences with another person or group of people, usually with the aid of tangible prompts such as photographs, household and other familiar items from the past, music and archive sound recordings."[82]

Tsai et al. give a more constructivist definition as they describe RT as a form of mild confrontation between the current self and the patient's past self.[83] Although the positive effects of RT have yet to be sufficiently explored and evidence in this area is lacking, Woods' meta study on RT argues that the following list of therapy outcomes are viable at the current state of research:

> Improvement of well-being, mood and quality of life, communication and interaction, cognition (particularly autobiographical memory) as well as positive impact on caregivers e.g. caregiver strain or staff.[84]

Despite its lack of scientific exploration this type of therapy is frequently

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[80] cf. (Aggarwal et al. 2003), p. 193ff.
[81] cf. (Smith, Kemp 2014).
[82] (Woods et al. 2005), p. 3.
[83] cf. (Tsai et al. 2013), p. 2.
[84] cf. (Woods et al. 2005), p. 6.

practiced and well accepted.[85] Bohlmeijer's work demonstrates that *Reminiscence Therapy* that is mostly perceived by patients as pleasant can reduce depressions significantly.[86]

The media used in the therapy session is essential to enable the patients to remember important past events and also to support the communication between caregivers and sufferers. Here, the relationship between both parties is usually strengthened while sharing and valuing past competencies, failures, achievements, emotions and feelings of the patients.[87]

Reminiscence Therapy sessions allow the patients, together with their caregivers, to review their life on a more abstract meta level. This perspective makes it possible to value certain life events, compare past experiences, identify relations between them and see positive developments in their life more clearly. Here, it is important to carefully select the material for the therapy sessions together with people who have a good knowledge of the patient and their life. Exposure to material pertaining to memories that the patient has already forgotten can lead to emotional upset or, even worse, to depression in the patient. Family members can also be affected, if for example, the patient cannot remember photographs of close relatives or important events like their own wedding.[88]

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[85] cf. (Gowans et al. 2004), p. 826.
[86] cf. (Bohlmeijer et al. 2003), p. 1092.
[87] cf. (Gowans et al. 2004), p. 827.
[88] cf. (Gowans et al. 2004), p. 828.

3 Related Work

There is a wide variety of organizations and companies in Europe which provide support to people suffering from dementia. Besides many informational websites for caregivers, there are various institutions which develop technologies and software systems to support the sufferers to get through their daily work routines and to improve their quality of life.[89] In this chapter a short overview about the existing technologies available for people suffering from dementia will be given and a digital form of the earlier outlined *reminiscence therapy* (RT) will be introduced. After presenting a current project which implements a software system to perform digital RT sessions, the possibility to enrich the input data through question-asking on *Social Networking Sites* will be addressed and its viability for the proposed system will be discussed. Here, important pre-conditions of friend-enrichment and factors influencing the quality and quantity of online question-asking will be illustrated. Finally, specific data privacy and security issues regarding assistive software for people with dementia will be mentioned.

3.1 Assistive Software for People with Dementia

Assistive Technologies (AT) is "[...] any item, piece of equipment, software or product system that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities."[90] There are many assistive software systems, also referred to as adaptive software systems, which serve the needs of people suffering from dementia mentioned in section 2.1.2.

Software projects like *NeuroPage*, *MemoJog* or *COGKNOW* implement automatic reminder tools, e.g. to take medication, offer context-aware activity prompting for upcoming events and include functions for enjoyment and to support sufferer’s independence.[91] Other software systems help the patients to keep in contact with their family, friends or other sufferers to stay social. These systems typically utilize very easy to use software phones, intercoms or communication and memory wallets.[92] Other software systems which usually

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[89] cf. (Lou et al. 2010), p. 24.
[90] (Assistive Technology Industry Association 2013).
[91] cf. (Lou et al. 2010), p. 25.
[92] cf. (Armstrong et al. 2010), p. 488.

require specific hardware, mostly sensors, are used to guarantee the patients safety. There are activity monitors and alarm systems that can protect the sufferer from a flood in the bathroom, fire in the kitchen or detect when the patient falls. Moreover, there are systems like *DigitalAngel* that informs caregivers when patients start to wander outside the house.[93]

Although various research projects in the area of assistive technology and assistive software systems have been conducted most of the needs of people suffering from dementia are still unmet. It has been discussed earlier that pervasive technologies, such as smartphones, can provide various functions that may meet the sufferers’ most urgent needs inside and outside their homes.[94] Additionally, studies have shown that people suffering from mild or moderate dementia are usually still capable of handling simple devices properly and even can benefit from it in terms of acquiring more confidence and feeling more positive.[95] However, up to now, none of the existing systems covers all functions adequately.[96]

3.2 Computer-Supported Reminiscence Therapy through Life-logging

In the past, reminiscence therapy sessions were often conducted by using labeled photographs or other types of media like newspapers, music records, videos, etc. However, the advantages of technology-supported sessions have been recognized in various recent studies: studies have shown that patients as well as caregivers often find reminiscence therapy sessions which are conducted using electronic devices to be more pleasant than traditional methods.[97] Devices like tablets or laptops make it possible to review different types of media in only one handy device. Moreover, well-designed software on these devices can empower patients to utilize the programs without any external support, which can also improve the patient's self-esteem noticeably.[98]

One possible approach to implement a software system to support

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[93] cf. (Armstrong et al. 2010), p. 489.
[94] cf. (Armstrong et al. 2010), p. 492.
[95] cf. (Lauriks et al. 2007), p. 223; (Lou et al. 2010), p. 24; (Kikhia et al. 2010), p. 169.
[96] cf. (Armstrong et al. 2010), p. 492ff.
[97] cf. (Sarne-Fleischmann et al. 2011), p. 1.
[98] cf. (Mulvenna et al. 2010), p. 12.

reminiscence therapy sessions is to utilize a *life-logging* application.[99] *Life-logging* applications are software tools which capture past life events and allow the users a closer look into their daily routines, often with very little effort required. The concept of *life-logging* is often referred to as "passive journaling".[100] Life-logging tools usually provide functions to store different types of media reflecting important life events which occurred during the day. There are two main classes of life-logging tools: *total capture* and *situation-specific capture* systems.[101] The goal of *total capture* life-logging tools is to record the complete record of everyday life of a subject, including as many different kinds of data as possible. These can be documented using cameras, sensors, audio-capture devices or devices that combine a variety of these functions such as smartphones. In contrast, s*ituation-specific capture* life-logging systems are less widespread and their scope is rather limited. Usually, the capturing is restricted to specific places or situations such as conferences, meetings or conversations. Typically, the existing systems in this area are more work-related and include detailed and complex information from many different sources, utilizing, for example, a technology-enhanced meeting room with different cameras and microphones.

Life-logging systems offer several benefits to the user. Sellen & Whittaker call those benefits the "five Rs" which are *recollecting, reminiscence, retrieving, reflecting*, and *remembering*.[102] Here, *recollecting* describes the activity of mentally reliving certain past life events. *Reminiscing* stands for a more specific form of recollecting for emotional or sentimental reasons or, as mentioned earlier, for therapeutic purposes. Life-logging systems that support reminiscence functions need to provide optimized data sharing mechanisms and their databases are usually individual and user-centered. *Retrieving* includes the possibility of using life-logging tools to access media which is not present anymore and of which only certain attributes can still be remembered. For example, a picture of a situation about which only place or time is still known. *Reflecting* in the context of life-logging systems describes the possibility of obtaining a more abstract representation of personal data that

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[99] cf. (Caprani et al. 2005), (Kikhia et al. 2010), (Astell et al. 2010), (Sarne-Fleischmann et al. 2011).
[100] cf. (Frankhauser 2013).
[101] cf. (Sellen, Whittaker 2010), p. 72-73.
[102] cf. (Sellen, Whittaker 2010), p. 73-74.

enables the user to identify the patterns and routines of someone's life over time. Moreover, this meta perspective may also allow the drawing of conclusions about personal well-being and emotional states. Finally, life-logging tools help *remembering intentions*. This can help the users to remember important appointments or double check, for example if medication has already been taken. Beside the mentioned benefits, people suffering from dementia can profit from digital memory aids since they usually stimulate communication and can alleviate their feeling of loneliness effectively.[103]

Nowadays software and memory systems are frequently used, and a shift of responsibility can be recognized from human to digital devices (e.g. saving a phone number instead of learning it by heart).There are different types of life-logging tools available on the market. However, there are only very few applications which support reminiscence and most of these existing tools do not fulfill important requirements for people with dementia. The ones available do not possess an incentive through design to the user to take more responsibility for remembering information.[104] Moreover, they do not provide "[…] memory triggers that have the capability of shaping participants' reminiscence behavior."[105] For example, an overview menu in those tools including some pictures representing life events that fade out after a certain time frame may encourage the user to take the responsibility and to memorize those moments instead of relying on the system's capabilities. At the same time, those systems should allow the communication of the personal significance of the past life events.[106] This can be realized through a function that neglects pictures which have never been selected by the user within a certain time frame or a mechanism that allows the rating of the importance of certain events.

Devices for people with dementia should be easy to use and consider visual and auditory impairments.[107] As already described in section 2.3, people suffering from dementia often feel upset or even depressed when being confronted with media which they cannot remember. Tira *et. al.* observe these

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[103] cf. (Caprani et al. 2005), p. 2073.
[104] cf. (Tsai et al. 2013), p. 331ff.
[105] cf. (Tsai et al. 2013), p. 335.
[106] cf. (Tsai et al. 2013), p. 336.
[107] cf. (Mulvenna, Nugent 2010), p. 24ff.

possible conflicts within technology-based reminiscence therapy sessions and propose in their work a *contextual exploration* mode to avoid these situations.[108] Here, instead of directly confronting the patient with memories of their past life, more explorative tasks are suggested where the patient can chose between a set of media freely and the system neglects media which the patient does not find interesting. This mode requires that the tool stores the behavior of the user while reviewing the media and eventually provides additional information about the author or the source of the media. Besides the non-existence of the mentioned adjusted functions of *life-logging* applications for people with dementia, usually possess different requirements regarding the data gathering process. Ordinary life-logging tools often collect data by making use of implicit user interactions with e.g. their smartphones. In contrast, life-logging tools for reminiscence therapy sessions need to be able to capture input data automatically, in case the impaired user is not capable of collecting, or simply forgets, the relevant data.

Finally, one of the challenges when designing applications to support reminiscence therapy sessions are designing reasonable rules to filter out non-meaningful, and capture meaningful information for its users.[109]

3.2.1 Building Digital Life Stories for Memory Support

Previous work has already been undertaken in the area of assistive software for people with dementia to support reminiscence therapy sessions. In this section, a context-aware life-logging tool will be presented which is used for reminiscence therapy sessions and embodies a memory aid for past, current and future activities.[110]

The main goals of the proposed prototype were to provide a semi-automated system, which includes real-time support for daily life activities as well as a media enriched life-log to perform RT sessions. The most significant design requirement here was to implement a highly intuitive user interface that would enable the patient to use the software, as far as possible, without a caregiver's assistance.

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[108] cf. (Tira et al. 2005), p. 1301.
[109] cf. (Shi, Setchi 2013), p. 47.
[110] cf. (Kikhia et al. 2010), p. 161.

Two different types of logs were suggested to collect useful data for the proposed context-aware life-logging system: a context log which captures location changes via GPS and nearby persons via Bluetooth, as well as a content log to record related images, audio, or video files.[111] All entries from both logs can then be linked to build up a rich semantic memory. Here, the location information serves as a base to create new contextual knowledge. A new location can then be enriched by linking media entities from the content log to it.

The prototype's system architecture consists of two main components: a smartphone and a desktop application. The smartphone application feeds both of the logs mentioned earlier by automatically taking photos, recording GPS information, and searching for nearby Bluetooth devices,[112] and allows the patient to see a preview of the captured data of the day. The smartphone application is connected to a storage entity that is usually installed on the patient's home computer. As soon as the patient arrives at his house, all the data captured by the smartphone is automatically transferred via Wi-Fi connection to the storage entity. All retrieved data will then be analyzed by the desktop application, filtered and clustered by time. The prototype also provides two web views: One of those is used to tag the gathered data with additional information. The visited locations or a friend on an automatically taken photo can be named. Since this interface can be difficult to use Kikhia *et. al.* suggested that a caregiver should support the patient while using it.

3.3 Data Enrichment and Validation Using Friend-Sourcing Techniques

As described earlier in section 2.2.2, especially informal caregivers, are often overburdened with their caregiving duties. For this reason it is fundamental that assistive software systems do not increase their feeling of stress by burdening caregivers with additional responsibilities. In section 3.2.1 an assistive software system was presented which can be used for reminiscence therapy sessions. This system provides many functions which have been well accepted by the patients in first trials. The proposed system, however, also

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[111] cf. (Kikhia et al. 2010), p. 6.
[112] cf. (Kikhia et al. 2010), p. 186.

shows disadvantages. Caregivers are forced to constantly annotate the input data gathered for the system. Since here the well-being of the informal caregivers is put at risk through excessive workload, while the well-being of the patient is highly related to the caregivers' psychological state,[113] an alternative to enrich and validate the system's data using friend-sourcing methods will be explored within the next sections.

Friend-sourcing has recently become a more prominent method to solve a task by asking friends for help and, moreover, has already been implemented in several applications.[114] Friend-sourcing techniques are especially useful when "[...] the problem to be solved either requires data that is available only to friends (and not the public at large) or when friends are more likely to help [with a] problem compared to random strangers."[115]

Before going into more details as to why the friend-sourcing techniques, according to Benkler’s theoretical framework, can be suitable methods to enrich and validate the input data of the planned software system, the need for the enrichment process will be briefly discussed. Once this need is established, Benkler's framework, supported by McClelland's motive framework, will be applied to the proposed system to argue why friends will probably contribute and what might motivate them to do so. Subsequently, how a friend-sourcing mechanism can be implemented with the use of S*ocial Networking Sites* (SNS) will be described. Here, some examples of existing applications that use SNS to enrich data will be given and finally known issues related to those kinds of applications will be addressed.

3.3.1 Motivation for Friend-Enriched Input Data

Before discussing an alternative approach to enriching and validating input data using friend-sourcing methods in more detail, it is essential to get a better understanding as to why a more sophisticated enrichment mechanism for a system supporting reminiscence therapy sessions is necessary in the first place. As described earlier,[116] reminiscence therapy sessions usually include a variety of personal media like photographs, music or written material which

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[113] cf. (Brouwera et al. 2005), p. 85-86.
[114] cf. (Bernstein et al. 2010), p. 6.1.
[115] cf. (Shankesi 2013), p. 19.
[116] cf. sections 2.3, 3.2.

are relevant to the patient's past life. Reminiscence therapy can have a great impact on the patient's communication behavior and well-being. This requires that the material showed in the sessions is relevant for the patient and fits to the patient's current emotional state.[117] This very personal data cannot, however, be retrieved completely automatically in all scenarios. For example, if the patient's place cannot be identified because the results retrieved from the location service are ambitious. Here, human help is needed to select the correct place name and to be able to identify exactly where the patient has been during the day. The exact location of the patient at a certain time during the day is still very abstract information. The information itself will probably not be sufficient to stimulate the patient's memory and arouse deeper sentimental feelings. Media that is provided in reminiscence therapy sessions should be appealing and invite recall from the patient.[118]

Therefore, it is necessary to enrich the gathered information with other media. In this example, it would be advisable to search for available online pictures or, if the web search is not successful, friends on an SNS could be asked to provide additional media. Surely, the system can then learn over time so that important life events of patients will be identified after time and hopefully get enriched by friends with additional media and validated.

3.3.2 Preconditions and Characteristics of Successful Friend-Sourced Systems

Friend-sourcing has many similarities to *commons-based peer production*.[119] Benkler, who in 2002 published the, to this point, most prominent and substantial work on this mode of labor, has already pointed out many characteristics of peer production and the conditions under which it can be a successful approach. In this section it will be shown that the main characteristics described in his theoretical framework can be applied to friend-sourcing as well as friend-enrichment.

Commons-based peer production is a model of labor in which people produce goods or services in a decentralized manner, usually without remuneration and

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[117] cf. (Woods et al. 2005), p. 3.
[118] cf. (Tsai et al. 2013), p. 232ff.
[119] cf. (Shankesi 2013), p. 22.

then share the outcome among the producers. In most cases the goods or services are part of a larger project and its coordination is handled with the help of the internet.[120] Commons-based peer production can be distinguished from friend-sourcing since contributors of commons-based peer production projects mostly have an interest in the project's results, and the amount of available contributors is rather high compared to friend-sourced projects. However, significant similarities can be identified when comparing both models: Contributors of both labor models are not motivated by monetary factors since there is no financial reward. Another similarity between both models is that the work setting differs in both cases highly from a traditional work environment and is usually organized without hierarchies and with the help of the internet where the contributors can choose the task they would like to execute. Since Benkler's basic ideas about peer production are very general and abstract, in this work it will be assumed that the application of Benkler's framework to the current approach can give some valuable insights about the feasibility of the planned friend-enriched approach. Moreover, his framework will be used to discuss what motivates people to contribute to those unpaid projects to see if sufficient contributions can be expected. These theoretical findings will then be supplemented by results of research projects where similar friend-sourced techniques have already been implemented.

Benkler mentions three important characteristics that are of importance when defining the project tasks. These characteristics are: high *modularity*, small *granularity* (possibly including heterogeneous task sizes), and low-cost *integration*.[121]

Modularity here means the possibility to break down a project into "[...] smaller components, or modules, that can be independently and asynchronously produced before they are assembled into a whole."[122] A modular task then enables prospective contributors to decide when and what to contribute. Applied to the proposed system, a task would be an enrichment or a validation request, e.g. the request to provide a picture of a certain life event of the patient. The prospective contributors here would be the patient's

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[120] cf. (Gries et al. 2013).
[121] cf. (Benkler 2002), p. 68-69.
[122] cf. (Benkler 2002), p. 68.

SNS friends. Consequently, a request task as described would be modular and could be executed independently; the patient's friends can choose what task they want to perform and when.

A *fine-granularity*, including heterogeneous task sizes, means that the smallest possible contribution only requires a low personal investment regarding time and effort. This low investment then also leads to a low level of motivation needed so that consequently many friends can contribute. Heterogeneous task sizes are important to address people with different levels of motivation and qualification: Friends who are willing to spend more time and effort to contribute need suitable tasks. The system described by this work will include different kind of questions. For example, an easy task could be to simply select from a list the correct name of the location where the patient has been located at a certain time during the day. Every task requires a certain level of qualification; in this particular scenario, the knowledge about the patient's location. A larger and more time-intensive task could be providing a song or a picture file, for example, to enrich the data of a certain life event.

The last mentioned characteristic, the *low-cost integration*, means that after a successful processing every single task can be easily brought together. In this context, not only should the integration time and cost itself be low, but the contributor's effort needed to utilize the integration system should be moderate. The proposed system can sustain this criterion in addition to the others. When using an SNS in combination with a server application, the integration of the processed tasks can be performed using the internet. SNS are widely used nowadays,[123] so the expected amount of learning necessary for the patient's friends to use the contribution system is rather small. Here, the internet allows a very fast integration for a very low price.

Besides those three characteristics of successful peer production projects, Benkler mentions that it is essential that the contributors possess a significant level of *motivation* and have an interest in contributing to the project. The motivation of an individual can derive from many different incentives and is often complex to understand. However, Benkler's work, along with

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[123] cf. (Shankesi 2013), p. 17.

McClelland's motive system from psychology, illustrates some factors which usually lead to higher motivation. One important characteristic of peer production, which also applies to friend-sourced projects, is the self-identification of tasks by the contributors, which usually provides incentives. Humans prefer to choose tasks that fit to their personal abilities and interests. This freedom usually also leads to a higher level of creativity when performing the tasks and can improve quality dramatically.[124]

Two different classes of motivation can be identified to move someone to perform a certain action: intrinsic and extrinsic motivation. A person who possesses intrinsic motivation performs a certain task because they find it enjoyable, interesting or profit personally and directly from the action. In contrast, a person possessing extrinsic motivation is driven by a separable expected outcome, e.g. monetary incentives.[125] Both classes of motivation can possibly drive prospective contributors of the proposed system. A friend who provides a photo of a recent life event of the patient can be lead by intrinsic motivators such as the perceived feeling of pleasure when helping a close relative or friend to remember certain events, for example. Other intrinsic factors, which move online users on SNS in particular to answer, is the perceived ownership of information, the visibility of expertise and the feeling of making a unique contribution.[126] An extrinsic motivator here could be the expected recognition by other family members or friends when helping the friend.

McClelland, who published a motive system in 1961 that still serves as a basis of present motivation research and has been adopted extensively, describes three types of needs which motivate high or improve performance. All these three described needs are also possible intentions of prospective contributors of the proposed friend-sourced enrichment system. These are:

- *Need of Achievement*, or the simple "intrinsic satisfaction of doing something better"
- *Need for Power*, which is the desire to be in charge and the

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[124] cf. (Benkler 2002), p. 8.
[125] cf. (Ryan, Deci 2000), p. 2.
[126] cf. (Morris et al. 2010), p. 3.

- *Need for Affiliation*, or the need to have harmonious relationships with others.[127]

As described earlier, all characteristics of Benkler's framework can be identified in the system, and motivation theory also supports its basic concept. Consequently, commonly known preconditions of the system are fulfilled which at this point allow a closer look into existing projects in the area of friend-sourcing mechanisms, their technical details as well as recognized problems of present projects.

3.3.3 Viability of Friend-Enrichment Using Social Networking Sites

Social Networking Sites (SNS) such as Facebook, Google Plus, or Twitter are online services that allow their users to interact with each other and share content. SNS have become very popular in recent years, especially Facebook with a market share of 92%. At the beginning of 2013 the number of registered active online users at Facebook was 1.1 billion. Currently, among American Internet users "[...] 70% of 30-49 year-olds, 51% of 50-64 year-olds, and 33% of those 65 or older now have a profile on an SNS."[128] Especially older users over 55 years are the largest growing group on SNS.[129]

SNS were originally intended to be a place to catch up on personal information and talk about current activities. However, there is a noticeable trend that SNS are used more frequently for other purposes such as gaming, business-related networking or question asking.[130] *Social Search* describes the process when online users use their social resources to find information online. This may include the search through existing online databases, e-mails to friends, questions on Q&A sites or, as often practiced nowadays, the use of status updates of social network sites to find answers for current questions.[131] Since many people have more trust in answers provided by their friends rather than results of search engines, social search is currently an often practiced method for question answering. Especially when answers require personal opinions or advice people prefer to ask their social network rather than consulting search

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[127] cf. (McClelland 2010), p. 36ff.
[128] (Lampe et al. 2012), p. 1.
[129] cf. (Bullas 2013).
[130] cf. (Morris et al. 2010), p. 1.
[131] cf. (Morris et al. 2010), p. 2.

engines or online forums.[132]

Current studies have shown that Facebook's status message, which is up to 423 characters long and visible to one's connections on the network, has become one of the most prominent forms to conduct *Social Search*.[133] Question-based SNS status updates can serve various purposes such as "[...] creating social awareness, encouraging the asker to reflect on a current information need, building social ties, and, of course, finding answers."[134]

In a survey about SNS question asking, 73.4% participants answered that they had seen friends posting questions using their online status. Of those 73.4% participants 93.4% said that they had at least once provided an answer to those questions using the comment function.[135] Consequently, the results of the study lead to the assumption that there is a general acceptance of this form of question-asking.

3.3.4 Factors Affecting Answer Quantity, Quality and Response Time on SNS

It has been shown that questions posed on SNS which require contextual knowledge are less likely to receive responses than requests that can be answered without any background knowledge.[136] However, different studies demonstrated that certain factors have a great influence on the likelihood of receiving a response to an online request.

<u>Amount and structure of SNS friends and frequency of question asking:</u>

A study involving 614 members of a larger American university has shown that Facebook users who possess many diverse friends on their SNS are more likely to receive non-redundant answers through SNS question asking. Joeng *et. al.* could not identify any correlation between the amount of friends or followers and the chance of receiving a positive reply.[137] However, a more detailed study about favor-asking on Facebook argued that chances of receiving responses on SNS increase the more someone’s friends are

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[132] cf. (Morris et al. 2010), p. 6.
[133] cf. (Lampe et al. 2012), p. 1.
[134] (Teevan et al. 2011), p. 1.
[135] cf. (Morris et al. 2010), p. 7.
[136] cf. (Jeong et al. 2013), p. 5.
[137] cf. (Jeong et al. 2013), p. 4ff.

motivated by individual benefits.[138] Moreover, it has been shown that SNS users tend to rely more on answers that are provided by actual friends. That usually has the effect that the more actual (real life) friends a user possesses, the more trustworthy questions are usually posed on their SNS.[139] SNS users who receive an answer to their SNS questions usually experience a quick answer times, with a median answer time of only 471.5 seconds (less than 8 minutes).[140] Surprisingly, question seekers who consult their SNS on a regular base have better chances to receive an answer as the likelihood to get answers increases significantly for frequent posters.[141]

Phrasing of questions:

Burke *et. al.* analyzed the impact of different phrasing when conducting online questioning and investigated how the quantity of responses changes when implementing certain rhetorical strategies. For example, questions that people ask can range from:

> *"Any recommendation for a nice museum in Lisbon?"*

to more detailed:

> *"I am on vacation in Lisbon with some friends from work. We wanted to explore the city by foot today but since it is raining we would prefer to do some indoor activities instead. That is why, we need some advice for a nice museum, preferably in the city center."*

The study suggests that posed online questions should consist of two parts, an introduction part and a request part. The intention of introductions is to signal legitimacy, show commitment and demonstrate the author's relationship to the group. "Disclosure also signals a willingness to be vulnerable; an act that fosters the building of close relationships."[142] Online posts without short introductions however, are often perceived as too impersonal, "data queries" that are less likely to receive a response. Within the introduction sentence the use of first-person pronouns can reinforce disclosure and the use of third-person pronouns usually indicates knowledge of a commonly known third person. Burke *et. al.* demonstrate that both types of pronouns can increase

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[138] cf. (Jung et al. 2013), p. 7.
[139] cf. (Lampe et al. 2012), p. 3ff.
[140] cf. (Jeong et al. 2013), p. 5.
[141] cf. (Jung et al. 2013), p. 7.
[142] (Burke et al. 2007), p. 3.

the amount of response whereas second-singular pronouns usually create distance. The second part of the question, the request, which shouldn't include indirect questions, is supposed to explain in clear words how potential answer givers can be helpful. The results of the study show that 57% of all messages received an answer. Here, questions including an introduction sentence increased the likelihood of receiving an answer by 7%. Moreover, a doubling of pronouns in those sentences increased chances by 8%. Clear requests also increased the likelihood of receiving a response by 6%. A question mark in the end of the sentence leads to a 3% higher response rate.

Punctuation	Sentences	Scoping	Example
Question	One	None	Should I watch E.T.?
		Anyone	Does anyone think I should watch E.T:?
		Movie buff	Do my movie buff friends think I should watch E.T.?
	Two	None	Taking it easy. Should I watch E.T.?
		Anyone	Taking it easy. Does anyone think I should watch E.T:?
		Movie Buff	Taking it easy. Do my movie buff friends think I should watch E.T.?
Statement	One	None	I wonder if I should watch E.T.
		Anyone	I wonder if anyone thinks I should watch E.T.
		Movie Buff	I wonder if my movie buff friends think I should watch E.T.
	Two	None	Taking it easy. I wonder if I should watch E.T.
		Anyone	Taking it easy. I wonder if anyone thinks I should watch E.T.
		Movie Buff	I wonder if my movie buff friends think I should watch E.T.

Table 1 The different question phrasings studied, cf. (Teevan et al. 2011)

Teevan *et. al.*, inspired by social psychology theories, conducted another study in the area of online question asking. Here, it has been analyzed how different phrasing not only affects the quantity of responses but also the quality and speed of the given answers.[143] The study, which involved 282 diverse participants, showed that three different factors relating to the phrasing have the biggest influence: the punctuation, the amount of sentences used to describe the problem and the scope to whom the question was addressed to.

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[143] cf. (Teevan et al. 2011), p. 4.

Table 1 gives an example of a question which was posed by the study's participants using different phrasing.

The results clearly show that the questions posed on SNS that end with a question mark and consist of little text which addresses a very specific group of friends are more likely to be answered. Beside the fact that the quantity of the responses increase through this type of phrasing it has been shown that response time and quality improve dramatically.[144]

Motives for answer givers:

A study which analyzed the motivation of answer givers on SNS showed that the intrinsic and extrinsic motivation factors[145] described earlier illustrate the incentives of answer givers appropriately. Moreover, the study demonstrated that the strongest motivation for commonly asked questions on SNS is altruism: In 37.0% of all cases the participants of the survey answered that they wanted to be helpful, friendly or they acted out of a sense of social duty.[146] 31.9% of all participants answered that they felt they had specialist knowledge in the area of the question and liked to receive acknowledgment for it. Two other important factors that usually drive answer givers to answer were the properties of the question (15.4%), for example if the question was addressed directly, and the nature of the relationship (13.7%).[147] These three mentioned factors explored in the study allow assumptions of the possible system's acceptance which can be expected. The family members and friends of people with dementia feel often insecure about how they can provide help, are overstrained with the new situation, and often keep their distance or resist keeping in touch.[148] A friend-sourced approach using an SNS with clearly structured requests might be a possibility to give these friends a chance to still offer their support without being in direct contact with the patient. This may even help them strengthen their relationship with the patient again by being informed on a regular base though the requests about recent events of the patients. The desire to get more information about the patient to get closer again can be seen, from the friend's perspective, as a personal benefit.

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[144] cf. (Teevan et al. 2011), p. 3-4.
[145] cf. section 3.3.2.
[146] cf. (Morris et al. 2010), p. 8.
[147] cf. (Morris et al. 2010), p. 8.
[148] cf. (Alzheimer's Association 2013).

Personal benefit is considered as the strongest incentive for people to provide their help on SNS.[149] Consequently, this could also affect the participation of the friends providing answers positively. An extrinsic incentive that could be provided by the application itself could be a point system that posts regularly, a monthly summary on the SNS to show the friends who contributed the most, for example. A similar point system has been already suggested by Bernstein *et. al.*[150] This could moreover fulfill the need for acknowledgment mentioned earlier.

3.3.5 Examples and Results of Current Friend-Sourced Applications

Social Search does not necessarily have to be conducted directly by a person. Instead, several projects can be identified where social search is performed with the help of a software system.[151] These projects often use social search to implement a friend-sourcing approach where a server system processes the provided answers for use within a wider context.[152]

Brady *et. al.* have developed a prototype, called VIZWIZ Social, which allows blind people to post questions to their SNS to gather information about their environment that they are unable to answer without support.[153] For example, with this prototype blind people are able to ask for the color of an object by posting a photo of it via VIZWIZ Social to their Facebook page. Additionally, as an alternative source the prototype provides the possibility to ask anonymous web workers. VIZWIZ Social demonstrated well that an assistive software system using a friend-sourcing mechanism to implement a visual prosthesis is technically viable. However, the results of the research project indicated that most of the participants preferred to ask anonymous crowd workers rather than friends on their SNS, even if financial costs for crowd workers arose.[154] One reason seemed to be the inaccessible design of many SNS for blind people as well as slow response times if the answers were needed immediately.[155] Another issue mentioned in the project was that the perceived social costs for blind people were too high; the participants preferred avoiding

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[149] cf. (Jung et al. 2013), p. 8.
[150] cf (Bernstein et al. 2010), p. 6:5.
[151] cf. (Bernstein et al. 2010), (Shankesi 2013), (Jeong et al. 2013).
[152] See section 3.3 for more information on friend-sourcing.
[153] cf. (Brady et al. 2013), p. 1ff.
[154] See also section 3.3.6 for a more detailed discussion of the issue.
[155] cf. (Brady et al. 2013), p. 11.

asking their friends, especially since their type of questions did not require any contextual knowledge and was easy for anonymous staff to answer. Brady *et. al.* address the problem of high social costs and suggest the possibility of posting SNS questions only to a very small amount of friends (e.g. close family members). Further research in the area of SNS question asking as a resource for blind people using VIZWIZ Social is planned.

Another software tool in this area is *Collabio,* which was developed at Massachusetts Institute for Technology in cooperation with Microsoft Research to investigate friend-sourcing methods in the course of a game.[156] The game was implemented with the use of an ASP .net application server and a Facebook application was created to provide a user interface.[157] The game asks its users to tag their SNS friends with individual descriptive attributes to generate useful information about each other. For example, a friend who is a computer expert could be tagged with the label "computer science". The information generated by the game is accessible through the so-called *Collabio QnA* component and allows the user to search for friends who possess certain skills or knowledge.[158] *Collabio* stimulates motivation in many users with the help of virtual credit points to tag people. Contributors to the tagging game provided 4,000 tags describing SNS friends. The study's evaluation showed through usage log analysis and survey data that the gained data is accurate and reliable and the level of vandalism and abusive use is almost equal to well-known crowd-sourced projects such as *Wikipedia* (1-2%).[159] Moreover, the game *Collabio* even realized high data quality for unpopular data that hasn't been available elsewhere.

3.3.6 Challenges When Using Friend-Sourced Techniques

Studies in the area of question-asking on SNS have shown that there are some common challenges when designing software systems that implement friend-sourcing mechanisms.[160] Within this these challenges will be outlined in order to raise awareness of common design errors and to be able to create avoidance strategies for them while planning the system architecture for the

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[156] cf. (Bernstein et al. 2010).
[157] (Bernstein et al. 2009), p. 3.
[158] cf. (Bernstein et al. 2010), p. 6.20.
[159] cf. (Bernstein et al. 2010), p. 6.23.
[160] cf. (Bernstein et al. 2010), (Brady et al. 2013), (Lampe et al. 2012), (Teevan et al. 2011).

proposed system.

As mentioned earlier in section 3.3.5, asking friends for help using SNS can be perceived as unpleasant for the information seeker. Obviously, there is a need for data enrichment and data validation for different purposes,[161] however, another conflicting need of people with impairments is to stay independent as long as possible.[162] The *VizWiz Social* research project showed that blind people who seek information prefer to ask anonymous crowd workers than their SNS friends. Social or psychological costs were perceived as high, especially when the required information is commonly known.[163] However, the friend-enriched approach of the proposed system would be implemented to receive information that is only known to a small amount of people: the ones who are in close contact with the patient. Brady *et. al.* address the conflict of social costs in friend-enriched systems for people with impairments and suggest that questions only be asked on SNS to a small subset of friends (e.g. family members and close contacts).[164] This could be realized by the proposed system, by creating a separate profile page where only friends are added who are supposed to see the questions posed for example.

Lampe *et. al.* mentioned another problem regarding asking questions on SNS sites through status updates: which friends see the status update in their feed is not predictable or controllable. Posed questions may not show up on the SNS of a potential answerer because they are not considered relevant for the SNS friend.[165] Here, it could be useful if the caregivers provide some instructions to the helping friends in person or on the patient's SNS profile to raise the friend's awareness of the system. This may motivate the contributing friends to visit the patient's site frequently without any prior notification needed.

Another danger when asking questions on SNS is called *social loafing*. Social loafing describes the effect when people feel less responsible for a collective task because they believe that others will also contribute. *Diffusion of responsibility* describes a similar effect where many people share a common

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[161] cf. section 3.3.1.
[162] cf. (Brady et al. 2013), p. 10.
[163] cf. (section 3.3.5).
[164] cf. (Brady et al. 2013), p. 10.
[165] cf. (Lampe et al. 2012), p. 9.

responsibility and each person "[...] feels less cognitive dissonance when he or she does not act individually."[166] Both described effects in online communities can lead to the *bystander effect*. The bystander effect describes the phenomenon in computer-mediated communication when someone asks a question in a chat but nobody is willing to take the first step and answer. To avoid these effects in the proposed system, additional incentives through a point system, as discussed earlier,[167] can be provided. A point status message posted by the system can motivate prospective answerers through competitions, and also remind all contributors of the uniqueness of their knowledge.[168]

Social interactions in computer-mediated environments can be more uninhibited than in traditional setups.[169] That is why there is a risk that answer givers provide answers that embarrass or "flame" the patient. A possible approach for the proposed system is that a caregiver, who possesses special permissions on the SNS, deletes those unwanted contributions. A so-called "silent" deletion strategy for all unwanted contributions has the additional positive side effect that answer givers will not get discouraged to contribute in future.[170] Hopefully, considering the sufferer's health status and their need for protection, those incidents will occur only rarely. Another challenge mentioned in the literature when asking questions on SNS is the process of finding new contributors. According to Bernstein *et. al.* 63% of all Facebook invitations to new applications are ignored.[171]

The proposed system provides contacts with the opportunity to approach friends suffering from dementia in a more indirect way and supports them while getting used to the new – and often very difficult – situation. Hence, it will be assumed that the level of acceptance of the friend-enriched approach in the context of dementia will be high. To find suitable friends who provide answers and enrich the data of important life events of the patient, a personal consultation of potential candidates is suggested. This can be done by the informal caregivers who have intimate knowledge of the patient's social

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[166] cf. (Bernstein et al. 2010), p. 6.6.
[167] cf. section 3.3.4.
[168] cf. (Bernstein et al. 2010), p. 6.6.
[169] cf. (Bernstein et al. 2010), p. 6.6.
[170] cf. (Bernstein et al. 2010), p. 6.11.
[171] cf. (Bernstein et al. 2010), p. 6.13.

contacts.

3.4 Ethical Issues and Other Crucial Considerations

Some authors have previously criticized software systems that automatically capture various impressions of a person's daily life, such as tracking the person's locations, recording background sounds, taking pictures of the environment or similar contextual data. These systems have been described as being spies that plant a "bug" in every object people use, or as a violent technical penetration of daily life.[172]

Data capture and enrichment via the web, as well as through friends using SNS, is conducted to retrieve more valuable and meaningful information about the patient. This information can then serve as input for computer-supported reminiscence therapy sessions, notify caregivers when the sufferer is in danger or help clinical staff to evaluate the patient's health status more extensively. All these fields of application may aid the sufferer in many daily life situations, and there is a great potential that the system improves the perceived quality of life noticeably for its users.

In contrast, retrieving information automatically and publishing parts of it to close friends and family on SNS for data enrichment may lead to certain undesirable effects for the user and his environment: People suffering from a mild form of dementia are generally vulnerable since they may experience the feeling of being lost or have sudden mental blackouts. However, most of the time patients with mild dementia can carry out their daily life without any help needed.[173] People with dementia usually want to sustain independence, are afraid of being too much supervised by their family or sometimes just feel ashamed and exposed in regards to their symptoms.[174] That is why people suffering from dementia may not feel comfortable sharing certain life events on their SNS, even if this information is only accessible to close friends. For example, the patient may not want to publish certain locations where they have been during the day or feels embarrassed about a situation where they were wandering.

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[172] cf. (Kikhia et al. 2010), p. 171.

[173] cf. section 2.1.1.

[174] cf. section 2.1.2.

Consequently, certain ethical and privacy issues have to be considered while planning the system. Bjørneby *et. al.* suggest the investigation of available alternative technologies and analyze constantly which ethical dilemmas and problems may arise and how they can be solved while planning a new assistive system. Here, all living circumstances and the needs of the person with dementia have to be taken into account.[175] It has to be ensured that data containing personal information is stored in secure locations, eventually encrypted and only kept if there is a reasonable expectation that the person with dementia will benefit from it in future.[176]

A policy that ensures that all ethics and privacy issues are respected and information security is not harmed should be created over time.[177] Since ensuring security and privacy policies can be seen as a continuous process it can be useful to create a sub-group of different stakeholder who observe this process and ensure its completeness.[178]

Since the user's consciousness for his actions can decrease during the course of the illness, balancing privacy and gain is an individual non-trivial task while planning assistive software for people with dementia. While the technology items itself are "neutral" devices the applications running on those can generate various care scenarios that are complex.[179] Therefore, it is very important to educate the sufferers and caregivers about the software’s mode of operation and possible risks adequately in time.[180] Although full disclosure and providing complete and truthful information is a suggested practice in medicine, this process does not need to be brutal: An appropriate sensitivity is important while educating the patient.[181] For example, the main target group "dementia patients" and the patient's need for help do not have to be emphasized while educating the patient. Instead, the benefits of the system as a useful application to aid recall of important life events and master everyday

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[175] cf. (Bjørneby et al. 1999), p. 5ff.

[176] cf. (Martin et al. 2010), p. 67ff.

[177] Further information concerning the topic ethical, privacy, and security issues for assistive technologies for people with dementia is provided by official institutions and is not part of this thesis. Alzheimer Europe published in 2013 a guideline including a list of criteria that is recommended to be considered when creating security and privacy policies for assistive software for people with dementia (cf. Alzheimer Europe 2013). A model of an efficient process that implements privacy and security issues was provided by Bjørneby et. al. (cf. Bjørneby et al. 1999).

[178] cf. (Martin et al. 2010), p. 68.

[179] cf. (Kikhia et al. 2010), p.171.

[180] cf. (Martin et al. 2010), p. 71.

[181] cf. (Braddock 2010), "How much do patients need to be told?".

life should be highlighted. This may strengthen the patient's feeling of self-determination and at the same time improve the patient's acceptance for the system.

Typically, the education process also includes intensive tutorial sessions in the first weeks of use where the patient slowly explores the system’s functionalities and learns how to handle the equipment without any help. It has been shown that 45-min sessions of individual training, conducted twice a week, can be an efficient practice.[182]

3.5 Discussion

It has been shown that people suffering from mild dementia are in most cases still able to cope with their daily life routines to a high degree and only suffer infrequently from sudden mental blackouts.[183] Many patients feel scared of losing certain abilities, no longer being an active member of society, and being over-controlled by their families. Often, sufferers do not accept their diagnosis, feel embarrassed, or avoid using the term “Alzheimer's”.[184] In this work, it has been discussed that potential costs occurred through the treatment of the illness can be a towering burden for the families. Additionally, caregivers are often overstrained with their duties which in many cases can even lead to serious diseases such as extreme fatigue or depressions.[185] At the same time, many caregivers use inadequate coping strategies and often do not ask others for help. It has been shown that reminiscence therapy is a commonly practiced therapy form for people suffering from dementia. Although evidence that memory capacities can improve through this therapy form is lacking, it has been recognized that the patients usually become calmer, their self-confidence improves, and therapy sessions can lower their symptoms of depression.[186] Computer-supported sessions have been conducted successfully in past studies[187] and it has been shown that many patients prefer computer-supported sessions compared to traditional sessions since devices are often perceived as more handy and provide a better

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[182] cf. (Armstrong et al. 2010), p. 490.
[183] cf. sections 2.1.1f.
[184] cf. section 2.1.2.
[185] cf. section 2.2.2.
[186] cf. sections 2.3, 3.2.
[187] cf. section 3.2.1.

overview. Moreover, patients feel confident of handling those simple devices.[188]

An existing project has been presented where data was automatically retrieved through different hardware components and then validated and enriched manually by a caregiver.[189] First user studies showed that the system was capable of retrieving data and has been used, after an annotating process, to support reminiscence therapy sessions. However, the required annotation process of the approach is very work-intensive for the caregivers. Moreover, the proposed system provides neither a function that allows highlighting the relevance of certain life events, nor incentives to remember past events – although their importance has been discussed by various authors.[190]

Shankesi demonstrated in his work that friend-sourcing is a viable approach to spread the task of receiving information to friends if required knowledge is not available to the public at large.[191] By using a friend-sourcing mechanism, the system's necessary enrichment and validation task can be performed by friends on a SNS. This thesis has demonstrated that important pre-conditions for the use of friend-enriched techniques are fulfilled; given that the planned enrichment process possesses a high modularity including different task sizes and a low-cost integration of the contributions.[192] Additionally, a general acceptance for question and favor-asking on SNS has been recognized in literature.[193] It has been shown that the phrasing of the SNS questions can affect the answer speed and answer quality dramatically. Short, precise questions including a brief introduction and addressing the question to a specific field of people can increase the chances to receive answers significantly.[194] Various challenges regarding SNS question-asking have been revealed which can be avoided if potential contributors are briefed adequately and are aware of the possible impact of their contribution.[195] It has been discussed that it can be beneficial for the proposed system to motivate

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[188] cf. sections 3.2, 3.2.1.
[189] cf. section 3.2.1.
[190] cf. sections 3.2, 3.3.6.
[191] cf. section 3.3f.
[192] cf. section 3.3.2.
[193] cf. section 3.3.3.
[194] cf. section 3.3.4.
[195] cf. section 3.3.6.

contributors through e.g. a point system.

It is important to educate patients about the possible publishing and opening of their data sufficiently. While educating the patient about the system and its benefits as a useful application to remember important life events more easily and master everyday life should be highlighted. This may strengthen the patient's feelings of self-determination and at the same time improve the patient's acceptance of the system.[196]

There is great potential benefit for patients and caregivers from the proposed system, if the question-asking mechanism on the SNS invites friends to support the patient online and eventually even with additional “offline” support. This can improve the patient's well-being by enabling them to stay engaged in "normal" daily activities. Moreover, the situation for caregivers may improve since their actual workload decreases, through the bettering of the patient's wellness as well as their perceived burden through a strengthening of their confidence in their caregiving duties.[197]

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[196] cf. section 3.4.

[197] cf. section 2.2.2.

4 A Software Prototype to Build Friend-Enriched Digital Life Stories

In this chapter important requirements for the proposed system which result from the earlier described related work as well as the background information on the dementia disease are described. First of all, some details about the project formation and the project's method of work will be given. Afterwards, the main non-functional requirements are listed followed by the system's functional requirements which are described as a user story. In addition, a brief overview of the complete system will be given. Finally, more detailed characteristics of the two main components which are developed as part of this thesis – the *Enrichment Component* as well the *Central Software Layer (CSL)*–are described in more detail.

4.1 Project Initiation and Method of Operation

The project was initiated in 2013 by Luís Carriço, Tiago Guerreiro, Carlos Duarte, and Francisco Couto who are professors at the University of Lisbon at the Department of Informatics and members of the *Human-Computer Interaction and Multimedia* (HCIM) research team together with three master students José Carilho, João Martins, and Oliver Schnell. Since then, the project has been developed in collaboration with an association for people with dementia in Portugal, Alzheimer Portugal, and meetings are conducted together with the institution's spokesman for psychological matters regarding the disease.

The first results gained from literature studies showed that no project could be identified where friend-sourced techniques were used to enrich and validate the input data of an assistive software system for people with dementia. Yet, evaluating a system design which uses a friend-sourced mechanism is complex and various psychological factors can affect the user acceptance.[198] At the same time, the state of health and the environment of the potential users of such systems, the patients, can be varying and complex to observe.[199] Consequently, defining all requirements from the beginning was not productive in this project. Instead, a more explorative development methodology was

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[198] cf. section 3.3.4ff.

[199] cf. section 2.1.1ff.

required which allows constant validation of the current stage of development and ensures a fast and flexible adaption to changing requirements. That is why an agile software development methodology was chosen for the planned software system. Therefore, since the initiation phase of the project, weekly meetings are conducted with the professors of the department and the master students. They are frequently accompanied by a psychologist.

In these meetings the current state of the project is reviewed together with all parties; typically including a demonstration of the current version of the prototype. Here, the role of the "customer", the patient, is played by the psychologists as well as the professors. In every meeting new goals are stated mostly from the user’s perspective in form of user stories or expected functionality. After every meeting the developers discuss technical details in a smaller developer group meeting where the whole workload of a week can be broken down into smaller tasks and divided up. After dividing up the tasks the group members usually work very closely together. The three developers’ workplaces which are located side by side in a laboratory allow intense communication during the project. While developing the software the developers discuss their ideas on a daily base and keep the other developers constantly informed about their software components. Drawings on big posters are updated regularly to visually describe architectural decisions and to provide a base for discussions among the developer team. Intensive tests are conducted after single tasks are completed. In case an error occurs, the whole developer group feels responsible and a collective code ownership is present. Additionally, pair programming sessions help the developers to get more insights of the different components and lead to more understanding even outside of each developer’s own area of focus.

4.2 Non-Functional System Requirements

Several non-functional system requirements for the proposed system have been identified. In this section various requirements which are crucial for the system's software architecture will be summarized and briefly explained.[200]

Low-cost approach

One design goal was to provide a system which is affordable and uses pervasive technologies to avoid the need to buy expensive additional hardware components.[201] Moreover, possible license costs and the costs of operation should be kept as low as possible. Therefore, open source and free technologies should be preferred. This includes the programming language, additional tools which are used within the development process, as well as any other third-party services which are needed.

Flexibility and Maintenance

Since research in the area of assistive software for people with dementia and its effects for the patients can only be analyzed over several years of clinical research[202], the system itself has to be highly flexible and easily expandable. This may allow fast and cost-saving changes as well as extensions if results of clinical research require it even if there is a change of developers over the course of time. Three criteria should be defined here to help to achieve this goal: Firstly, a commonly used programming language should be used to allow possible future developers fast familiarization with the developed system. Furthermore, the prototype of the proposed system should possess a clear and well-defined object-oriented software architecture. This helps developers to understand the system more easily and the perceived system complexity can be reduced. As a last criterion, the prototype and its source code should be well-documented. Only well-documented source code allows future enhancements rapidly and makes bug-fixing possible, even after many years.

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[200] This thesis includes the state of research and describes the version of the planned system in its version of the beginning of March 2014. The research activities at University at Lisbon are still ongoing and more functionalities and new findings from research can be expected in future. However, a description of this would go beyond the scope of this thesis and therefore will not be part of it. Instead, all recent activities will be included in related work of the research team.

[201] cf. sections 1.1, 2.1. Although pervasive technologies such as desktop computers or smartphones can possess high purchase prices, these costs will be accepted for the proposed system. Marginal costs will be unavoidable in order to make use of the software. However, to make the software available to as many people as possible, these costs should be kept as low as possible in the proposed system.

[202] cf. (Alzheimer's Association Research Center 2014).

4.3 System Functionalities Described as a User Scenario

In this section the current results of the system's planning phase will be described in brief. Since the project is developed by the use of an agile software development methodology, the common form of a user story is used in this section to illustrate the aspired functionalities of the system. The user scenario includes some additional information about the patient's background in order to characterize a typical usage environment. Afterwards, a short list will summarize all important functionalities.

Paul, who is a 75-year-old widower, has been recently diagnosed with a mild form of Alzheimer's. Since his diagnose he lives with his daughter Sally who takes care of him. Paul has a big family and is father of five children. Paul recently experienced some sudden mental black-outs. Some weeks ago, his youngest grandsons went to visit him. When they arrived at his house he had great difficulty recognizing their faces. This situation was very uncomfortable for him and put him under enormous stress. His daughter, who realized what was happening, took care of the situation and quickly reminded Paul of his grandson's name and tried to calm down her stressed-out father. This situation was very painful for Paul because he realized that his mental abilities are decreasing. During the next few days, whenever he received phone calls from his family he felt very insecure and was worried about mixing up names, for example, or saying something which disclosed his state of health. He was afraid of not been taken seriously and losing his role as a strong member of the family; changing to a position of being dependent on his children. Consequently, Paul tried more and more to avoid situations where he might disclose his state of health and communicated less.

During his next doctor appointment he talked about the situation he experienced. Dr. Smith, Paul's doctor, suggested trying out a new software system which may help him to stay more connected with his family and which allows him to review past situations with his family. Sally encouraged her father to use the system and scheduled an appointment with a representative from the local Alzheimer's initiative to receive more detailed information about the software system. Here, both have been educated about the system's functionality and about the fact that some information may also be sent to a selected group of friends on his Facebook site for further validation and enrichment. Back at their house, Sally follows the instruction guide and installs the server system on their desktop computer as well as the corresponding app on Paul's smartphone. Paul never used Facebook in the past, so Sally creates a profile together with Paul and sends some "friend requests" to family members and close friends of Paul who use Facebook frequently. After some friends accepted the invitation, Sally *and Paul send them a message and inform them that Paul's Facebook page is connected to his new application. In the message they provide them with more information how they can support Paul and briefly describe the purpose of the system-posted requests on his Facebook site.*

The next day, Paul starts to use the application which is installed on his smartphone. On that day, Paul meets his friend Adam and they visit the nearby technical museum together. At this museum they run into their mutual friend Peter who already accepted Paul's friend's request on Facebook. During Paul's stay at the museum he takes some pictures of the exhibition as well from his friends.

Later, back home, Sally and Paul try out the web application which is part of the system. Paul starts the web application without any help from Sally. He is happy that the font is very easy to read and the application is very easy to handle. The system shows a picture of the museum where he had been that day and tells him that it was the technical museum. Then, the software tool shows the pictures Paul took during his stay at the museum. The system already knows that Paul has been there with his friends Peter and Adam. Peter, who is Paul's Facebook friend, even added some pictures of the exhibition which are shown by the system as well. Afterwards, the system shows some pictures of the park he passed on his way back home. Paul rates the museum visit as an important life event and is very happy to be able to use the system without any help and looks forward to using the system in the coming days.

During the next few days he continues using the system and starts the RTW tool every night to support his reminiscence sessions. Over time, the system gathers more and more pieces of information about people of importance, significant life events, locations he usually visits and his daily routines. Paul enjoys using the system and he likes to review his last few weeks. He likes to be able to choose which events he wants to see and being able to ignore the others. It makes him feel more involved in daily life again and he feels more secure when having conversations.

The user story showed many of the system's possible functionalities. These require the existence of various system-wide functions. In summary, the most important functions which are needed for the Central Software Layer (CSL) and the enrichment component and which are required in the first version of the prototype are:[203]

- a mechanism to automatically detect unknown places and seek for places which are located nearby
- a function to search for pictures of visited public places and link them to the

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[203] The listed functions contain all important features which are required to be able to experience the scenario described in the user story and beyond. Functions of the components which are not developed within this thesis will not be listed here in order to provide a better overview.

locations

- a mechanism to ask for pictures of a life event to illustrate it via the SNS

4.4 Overview of System Design and Project Distribution

The complete system consists of several components which are developed separately and are combined within a central software layer. The central software layer (CSL) was developed within this thesis and its main function is to provide communication methods between the separate components (cf. figure 1). Additionally, this layer provides a persistence component which allows storing different kinds of system data in a simple way through a centralized module. The central software layer also includes all system-wide needed tool classes.

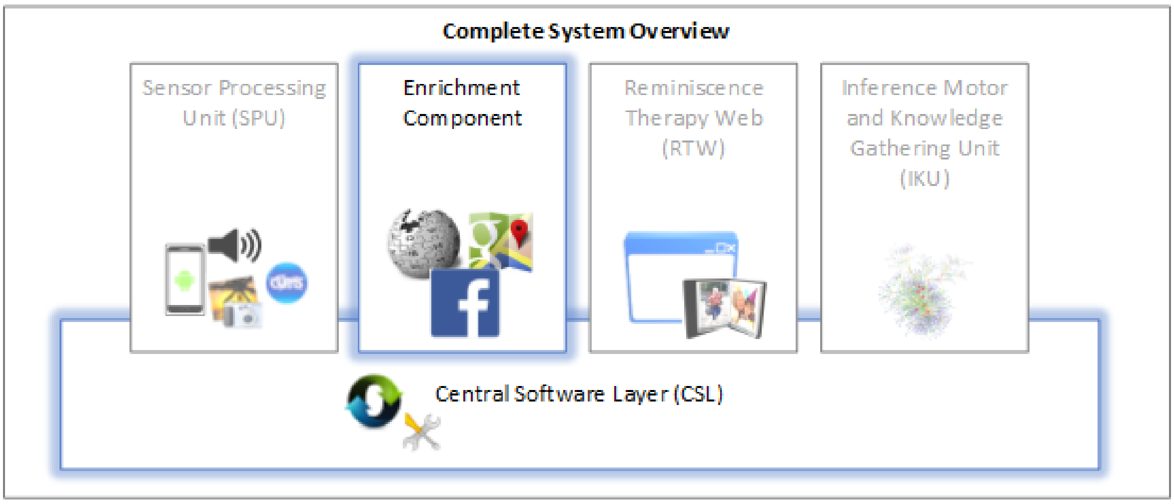

Figure 1 Complete System Overview

The sensor processing unit (SPU) which is developed by João Martins automatically retrieves different kind of data from the smartphone such as photos which have been taken, audio, and outdoor location, or accelerator data and logs new available resources via the CSL's persistence component in a database. This data serves as input for the inference motor and knowledge gathering unit (IKU) which is developed by José Carilho. This complex unit, which comprises a knowledge base, implements artificial intelligence techniques to build classifiers which are trained with previously gathered data from the patient. The IKU constantly monitors its knowledge base and tries to complete the missing information. To accomplish that, the IKU makes use of the enrichment component.

The enrichment component is also part of this thesis. It implements the earlier discussed enrichment mechanisms to widen and validate the IKU's semantic network by using open available web sources as well as SNS question-asking.

The Reminiscence Therapy Web component (RTW) which is developed by João Martins is a web application that allows patients and caregivers to review important life events of the patients and supports reminiscence therapy sessions. The RTW uses the available knowledge and media objects provided by the IKU and its semantic network.[204] The next two sections will discuss important requirements for the technical implementation of the two components which were developed within this thesis: the Central Software Layer and the Enrichment Component.

4.5 Central Software Layer

The Central Software Layer is designed to provide all system-wide tool classes that

- simplify the communication with web services,
- allow accessing different internet sources,
- realize configuration loader classes,
- and simplify the communication between the different system components or are required from an architectural point of view.[205]

Additionally, the CSL provides a system-wide and easily accessible persistence mechanism to be able to store data in a database if necessary. In the proposed system, a database can be useful for different scenarios. For example, the providers which are used for the enrichment process mostly require login data and sometimes issue temporary keys to retrieve the results of a former transmitted query. The data, which is provider-dependant and only used for e.g. the enrichment process itself, does not semantically belong to the data describing the patient's life events. Consequently, it makes sense to store this data separately in the CSL's database to also keep the knowledge base handier.

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[204] For more information about reminiscence therapy see also sections 2.3 and 3.2.1.

[205] In section 5.2 the concrete classes which realize those functions will be listed and a simplified class diagram will be provided.

The IKU's semantic network which possesses important information about the patient's life event can be queried easily from other parts of the system. However, in some scenarios querying the semantic network directly can lead to poor performance. In those scenarios, caching copies of some information of the semantic network can be recommendable. Here, the persistence layer of the CSL can also be used.

This database should be easily exchangeable if, for example, the amount of data grows in future and a change of technology is required. Additionally, writing and reading operations should be expressed on an abstract level so that a change of the database technology does not require changes of the database manipulation methods. It is important to make the data storing process easy and allow storing new data classes easily if, for example, additional service providers or new sensors will be used in a future version of the system.

4.6 Enrichment Component

The IKU manages and constructs its semantic network. Usually, the input data is provided by the SPU (reflecting the patient's actions) which is in most cases incomplete and low-level data (e.g. GPS coordinates). However, in section 3.3.1 it has already been argued that rich, meaningful, and understandable information is of great importance to trigger the user's reminiscence. Therefore, the IKU monitors the semantic network constantly. If the IKU detects some missing information, the enrichment component can be used to gather more data from external sources with the intention to fill the knowledge gaps.

Since the enrichment component serves as an additional information provider for the IKU, its structure is also partly dependent on the IKU. As already mentioned, the IKU consists of a semantic network to represent its knowledge. In semantic networks "[...] new knowledge may change the old network by adding and deleting nodes and arcs or by modifying numerical values, called weights, associated with the nodes and arcs".[206] The knowledge of the semantic network includes certain information about the patient's environment

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[206] cf. (Sowa 2013).

and important life events. For example, the semantic network can represent knowledge including information about his daily routines, his friends and the relationship among them or events and their location, including details about the participants and media characterizing this event. Consequently, a request from the IKU to the enrichment component can:

- semantically relate to diverse data objects representing very different things (data about e.g. real life objects, past actions, people, or relations between them can be requested) and
- may be available in various data formats such as textual information, images, audio files, etc.

This shows that the enrichment component has to be a software unit which is very flexible and can be adapted easily to possible new data objects and formats.

Besides the handling of different data types which semantically can relate to very different things, the enrichment component has to allow querying different online information providers and making the process of adding new service providers very simple. The next sections will give an overview about the data objects which should be considered by the enrichment component in the version described in this thesis. Afterwards, some additional information about the online information providers which the prototype uses will be given.

4.6.1 The System's Enrichable Data Entities

This section provides a brief overview how the life events experienced by a patient can be represented digitally. Figure 2 shows a simplified model of a class diagram which defines objects that are related to a life event. The object-oriented approach used to express important life events of the patient is connected to the structure of the IKU's semantic network. As the diagram shows, a life event is defined as an event which occurred at a specific time, at a specific place – possibly together with friends of the patient. A life event can be illustrated through a list of *comments*. A *Comment* object includes information that enriches the corresponding life event and usually describes the already automatic retrieved low-level data about a life event more detailed. A *Comment* object can be seen as one data entity (e.g. an image) that provides the user with more descriptive and meaningful information. A comment always includes a short text, has an author, and can include media objects. Media objects are, in the current version of the system, pictures. However, different media object types such as audio or videos can be added easily in the future. A comment can be indirectly created through different sources. In the current version of the system, possible sources are the enrichment component (an enrichment request was successful and retrieved new data) or the SPU (the patient e.g. has taken a picture). After the IKU was informed that additional information is available the IKU evaluates the input data and e.g. considers if its author is trustworthy. After a successful evaluation of the data, the IKU creates a new *Comment* object including the gathered data and links it to the corresponding life event.

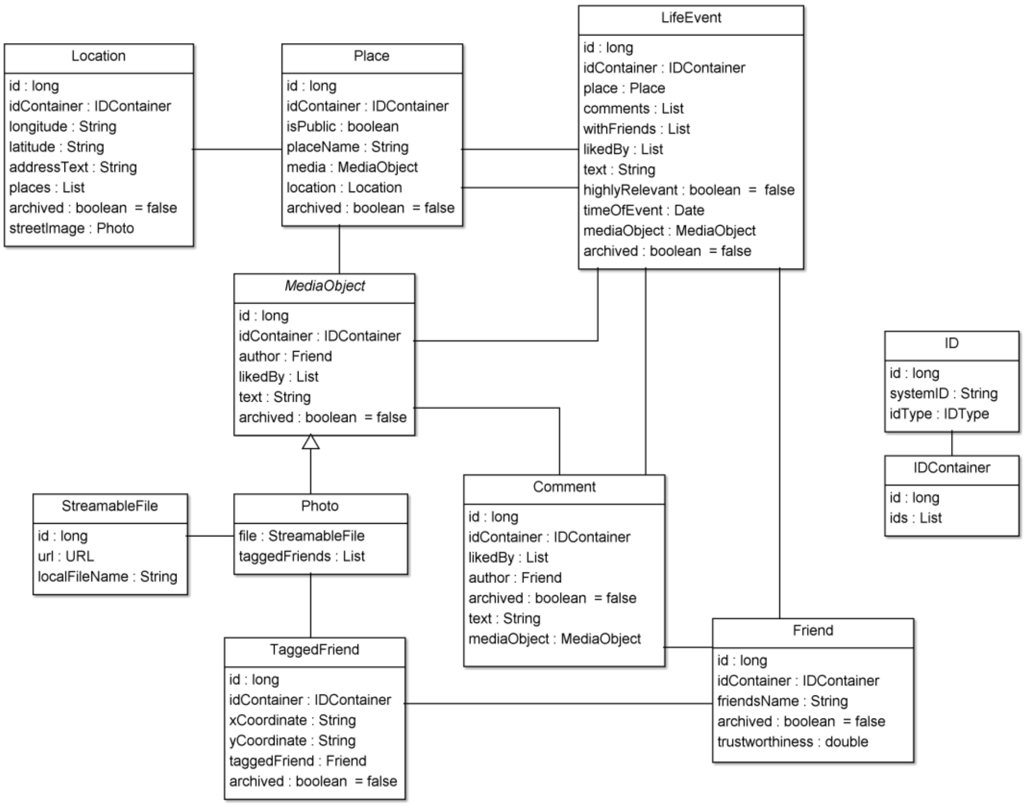

Figure 2 Simplified class diagram of enrichable classes[207]

Trustworthiness in the proposed system is a value that represents how reliable

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[207] Figure 2 shows a simplified class diagram of all enrichable classes of the system. For a better clarity, operations and multiplicities have been removed from the diagram. Additionally, only important relations between the classes are shown.

a friend or source has been in the past and is computed by the IKU. This value can help to ensure data quality and may prevent misuse of e.g. the SNS.[208] For example, if a certain author repeatedly provided pictures on Facebook that upset the patient and a caregiver had to delete those, the IKU can use this information to decrease the friend’s value of trustworthiness accordingly. A friend object which is defined in the diagram (cf. figure 2) usually represents a real life friend of the patient. Yet, a friend can also stand for any person in the environment, such as the patient's doctor, or a system such as a smartphone or an internet source which is related to a patient’s life event or the media object representing it. By storing the authors of all comments, it is also possible to implement the suggested point system[209] and provide additional incentives for the contributors on the patient's SNS.

As it can be seen in the diagram, almost every enrichable class owns an attribute of the type *IDContainer*. An *IDContainer* manages different ids which an object may have in the existing subsystems. For example, an actual real life friend of the patient may be known by the smartphone since there is an entry in the patient’s contact list. At the same time, the friend may be known on Facebook and belongs to the patient’s Facebook friends list. An *IDContainer* can help here to keep the information closely together. By this, only one object of the friend class has to be initiated for every real life friend or system and all IDs which this friend may have in any subsystem, e.g. a Facebook ID, can then be stored in the corresponding friend’s *IDContainer* object. Another advantage of the *IDContainer* concept, besides its function to avoid redundant data entries, is to be able to bring together information which is available on different sources. For example, a friend's phone number can be collected from the smartphone but his birth date from Facebook.

In the proposed system, a differentiation can be made between two main types of data which can be used by the IKU to widen its knowledge:

- data which is publicly available and requires no or only very little contextual knowledge, or
- data which is only available to the patient's friends and usually requires

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[208] cf. chapter 3.3.6 for more information about possible misuse on SNS.
[209] cf. section 3.3.5f.

the knowledge of a context.

The first listed type of data, the public available data, should be, if possible, retrieved by freely available online sources in order not to burden the friends[210] providing the data. Here, sources should be selected which are free of charge in order to keep the system's operation costs as low as possible.[211] In this section, different kinds of data objects were presented which can be enriched. In the next section, it will be shown how these data objects can be enriched by making use of public web sources. Afterwards, the enrichment process of the data objects which require knowledge of the patient's friends will be discussed in more detail in section 4.6.3.

4.6.2 Enrichment of Public Available Information

The current version of the proposed system already enriches many of the described data classes. In this section a short overview of suitable internet sources will be given and how the available information can be used to enrich the system.

Geographical Enrichment

Google provides a range of different APIs which can be used, among other things, to query map-based information. As figure 2 shows, the proposed system can capture the places where a life event of a patient has taken place. A location in the proposed system is defined by its geographical coordinates and can include an address text, a media object of the location and may include various places which are nearby. The Google Map API as well as the Google Places API can help here in different scenarios. For example, if the smartphone captures the coordinates of the patient's location the APIs can be used to firstly retrieve the address of the visited location and secondly to retrieve a list of possible places where the patient might have been located. Moreover, a reverse function is provided by the Google API. That means an address text can be used to determine the corresponding coordinates. Another useful function of Google's services which can be beneficial for the proposed system is the possibility to retrieve photos of a location through Google's

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[210] cf. section 3.3.6, "Social costs".

[211] cf. section 1.1, Description of Overall Project and Objectives of the Thesis.

Street View function. Additionally, a picture of the street where the patient has been located during a life event can be easily downloaded through Google's API and can be attached to the location as a media object. Rich information about the location is helpful to provide more detailed RT sessions and can help the IKU to extend its network and detect redundancies in its knowledge.

Many of Google's online services are accessible through web service calls. This means hypertext transfer protocol (HTTP) requests including parameters specifying the information requested are used to retrieve the server results which are described using the extensible markup language (XML). Most of the available API requests on Google only require passing a so-called API key which can be created after a free signup procedure on the Google developer's page.[212] For free use of Google's web service, the daily request limit of 2,500 requests must not be exceeded.[213]

Consequently, the proposed system has to possess three important characteristics to efficiently implement requests to Google. These are in particular:

- providing an easy mechanism to perform web service calls,
- promptly retrieving the results and make them available to other system components via the CSL,
- and ensuring that request limits are not exceeded and deadlock therefore is avoided.

Image Provider

In a small experiment, different available online web sources, in particular, Wikipedia, Bing, flickr, and Google Image Search, were compared. The intention of this experiment was to observe which of the providers delivers the most suitable results for images of well-known locations in a city. A retrieved image was in particular suitable if it characterized the location well and presented the location entirely (and not only parts of it). Therefore, all providers were queried for pictures of various locations in the city center of Lisbon in Portugal. First results showed that the best images were given by

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[212] cf. (Google 2014), section "API Key".
[213] cf. (Google 2014), section "Usage Limits".

Wikipedia using its MediaWiki query API. The results of this experiment are not representative since sufficient control samples were not taken. Moreover, only places in Lisbon have been used in the experiment, although other cities in different countries may deliver divergent results. Nevertheless, the first results of the experiment helped as a point of reference. This lead to the MediaWiki API being investigated in more detail as a possible additional enrichment source for the proposed system. However, additional image providers can be easily added in future.

M*ediaWiki* is an open-source PHP-based wiki software which is currently widely used by many wiki systems such as *Wikipedia*, *Witionary* or *Commons*.[214] MediaWiki provides a query API which allows developers to retrieve data from wiki pages. MediaWiki's API uses HTTP requests including parameters specifying the requested information to transmit the query. The server answer of an API request is sent in the form of a XML document and consists of the typical elements of a wiki page and can include links to external sources such as images. Wikipedia, which is using the WikiMedia software, has become a widely utilized encyclopedia and provides plenty of information, including images. Wikipedia contains more than 13 million articles in 271 different languages.[215] The content of Wikipedia pages is peer-produced and is open for everybody who wants to contribute information.

Although the retrieved data from Wikipedia is peer-produced and may not be accurate, it has been argued that most of its content usually possesses a high quality and only around 2% of its content is on average incorrect.[216] Consequently, Wikipedia as an additional source to enrich the IKU's knowledge will be provided in the current version of the system. However, the proposed system has to ensure that there are mechanisms implemented which allow the caregivers or the patient to remove unfitting or improper retrieved data by that source.

Finding suitable web sources for the proposed system can be seen as a continuous process. It is complex to test different combinations of the existing web sources. It is essential to observe the patient's feedback over time as part

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[214] cf. (MediaWiki 2014).
[215] cf. (Fletcher 2009).
[216] cf. (OnlineDegrees.org 2010).

of a long-term study into which enrichment methods deliver the best results for the patient. Additionally, there are constantly new providers available in an area of fast changing technologies. Thus, the flexible and easily extendable software architecture of the enrichment component will allow adding or removing new enrichment providers over time without much technical effort.

4.6.3 Enrichment Requiring Contextual Non-Public Available Knowledge

It was previously discussed that the proposed system may benefit significantly from an enrichment and validation mechanism with the use of an SNS and when important pre-conditions for the use of friend-enriched techniques are given.[217] Currently, there are different SNSs available. However, Facebook is the most dominant provider:[218] Facebook and its web interface is widely known and has the highest number of registered users. This is why Facebook has been chosen as the provider to implement the application's friend-enriched mechanism. However, the enrichment component is designed to be implemented modularly and allows a quick change of provider if in future another SNS becomes more popular.

Facebook provides an application programming interface (API) which, instead of accessing their website, enables developers to directly communicate with their servers to read and modify pieces of Facebook pages after its owner has granted permission. However, Facebook restricts certain actions that are possible to perform via the website but not through their API. Additionally, the daily amount of API calls is limited: Facebook allows 100M API calls per day.[219] Besides Facebook's official limits for their developer API, in various online forums developers point out that there is probably another limit of 600 calls per 600 seconds.[220] Some first tests calls with the Facebook API using a dummy application confirmed these assumptions. Those findings lead to the requirement that the proposed system needs to follow possible restrictions of the online information providers. That means that the proposed system has to

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[217] cf. section 3.3.1 f.

[218] cf. section 3.3.3 ff.

[219] cf. (Facebook 2014).

[220] Various discussions by developers have been found in different forums where it has been criticized that Facebook uses an additional limit of 600 calls per 600 seconds. One representative source can be found here: http://webapps.stackexchange.com/questions/41137/limit-on-use-of-Facebook-api.

be able to distribute its accumulated queries so that an optimal utilization is given without running into deadlocks due to provider restrictions. Since provider restrictions are often changing and are sometimes not very transparent, the system has to quickly adapt to new possible limitations.

Additionally, the system should provide a function that allows prioritizing all requests so that requests which are more important get processed promptly in case the provider's limits have been almost reached. Finally, a mechanism has to be implemented that ensures rapid notification of the IKU, whenever data has been retrieved by the enrichment component. The enrichment component has to ensure that all retrieved data is passed to the IKU. It is important that the enrichment component does not filter any of the retrieved data. Instead, the IKU decides which data is used to extend its knowledge or if e.g. other enrichment requests are necessary.

4.7 System Categorization According to Bigham et. al.

Based on the requirements which have been described in the previous sections, a classification of the system according to Bigham *et. al.* will be conducted in this section. The application of the framework, that classifies technologies for people with disabilities enlisting others to help, makes the proposed system more transparent and easily comparable with other approaches.[221] The framework analyzes 13 different dimensions of technologies in this area. Those dimensions will be presented briefly and the proposed system will be classified correspondingly.

Initiative

The dimension "Initiative" describes who requested the assistance of the community. This can usually be end users, workers or organizations.[222] In the proposed system the assistance requests are usually driven (indirectly) by the end user who can be the patients themselves or caregivers by using the system. Contrariwise, the end user can decide to not ask for assistance, for example by disabling the enrichment component or shutting down the whole system.

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[221] cf. (Bigham et al. 2011), p. 1

[222] cf. (Bigham et al. 2011), p. 2.

Source of Human Workers

The contributors in the scenario of the proposed system are *volunteers*. In comparison to crowd workers, professionals or organized volunteers, they provide their work for free, are not anonymous people and usually provide their help during a longer time frame.

Motivation

The incentives which drive friends to contribute to the proposed system can be, as already described[223], very versatile. The incentives which may describe well the motivation of possible contributors are *intrinsic*, societal *status*, or *enjoyment*.

Financing

The financing for the proposed system and its required hardware will be *privately* funded by the user or his family although public funding may be available in future.

Worker Competence

The workers or more specifically the contributors on the SNS will typically be *non-experts*. The SNS friends of the patients do not require specific expertise except the requested knowledge.

Latency

The proposed system and especially its enrichment component expect an *undetermined* delay. Since some missing system knowledge will be requested via a SNS, it cannot be clearly defined if or when contributors may provide their help.

Accuracy Guarantees

Humans may provide poor quality assistance for various reasons such as misunderstandings, laziness, unspecified questions, etc.[224] The proposed system ensures data quality through two mechanisms: *Redundancy* and

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[223] cf. section 3.3.4.

[224] cf. (Bigham et al. 2011), p. 5.

human mediation. Redundant data which may occur through different input sources will confirm the knowledge of the IKU. If a caregiver deletes unwanted contributions on the SNS the IKU will be informed and wrong information can be corrected.

Reliability

The system's enrichment component possesses an *undetermined* reliability: Although potential contributors can be motivated by certain factors to provide answers on the SNS, these contributions cannot be taken for granted.

Assistance Provenance

The system is in some situations not able to show who specifically provided the required information and therefore is *opaque*.[225]

Confidentiality, Privacy, and Anonymity

In some cases, the system provides *user feedback* through the smartphone application so that the user can decide which information is published to the contributing community and which not.[226]

Consideration of Broader Context

The friend who provides the answer on the SNS has to be aware of possible effects on the patient and has to ensure not to offend the patient with his contribution. According to the framework a *worker consideration* is prevalent in the proposed system.

Broader Applicability of Human Work

Contributions by friends to the SNS may be *reused individually* if, for example, the answer provider uses the patient's SNS as a location to access mutually experienced events.

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[225] Although the sources and answer providers of every single data entity is known and its trustworthiness can be even ranked by the system, the IKU uses complex methods to gain new knowledge from the retrieved data. These methods make it in some cases hard to identify the crucial answer provider or source which leads to the resulting knowledge. However, whenever the author or the source of the won knowledge is identifiable unambiguously this information can be made available to the user.

[226] Besides the notification mechanism, the user will be educated adequately and be made aware of certain privacy issues. For more detailed information see also section 3.4.

Target Disability

The system's main target group are people with a mild form of dementia.

5 Technical Aspects of the Prototype's Realization

This chapter will describe how the earlier listed requirements have been realized technically in the first version of the system's prototype. First of all, the technology selection process will be commented upon, followed by a short overview of the overall system’s software architecture, which was developed as part of this thesis. Afterwards, some details about the technical realization of the CSL and finally the enrichment component will be given.

5.1 Technology Selection

The system was developed using Java’s Enterprise Edition (JEE). Several factors which lead to the decision to use JEE as the system's base technology. In particular, these were:

- the free availability of JEE technology
- existing knowledge of Java as well as JEE within developer group
- high compatibility with other technologies required to implement artificial intelligence techniques as well as to realize the communication with the smartphone
- the existence of many freely available JEE extension frameworks such as Hibernate, Spring, IceFaces, etc.
- the extensive documentation available for JEE on the internet as well as in print media
- the availability of numerous functionalities for web and distributed systems including the powerfulness of the classic pure Java "world"
- the high level of diffusion of JEE and high degree of popularity may address more potential prospective developers.

An Apache Tomcat server was set up in the laboratories of the Department of Informatics at the University of Lisbon to use as JEE's web server and servlet container. This server was supplemented by *Apache Axis* to extend the tomcat servlet container with web service functionality. Additionally, the open source Hibernate framework has been configured on the web server. This powerful framework for object-relational data mapping (ORM) possesses various useful functionalities for the system’s CSL. In particular, Hibernate:

- allows exchanging the underlying database technology easily through the use of the abstract Hibernate Query Language (HQL) instead of standard SQL,
- provides annotations in Java entity classes which allow a simple mapping to relational database so that the database structure can be generated automatically,
- can work as an JPA provider,
- is the standard ORM solution,
- works independent from the database and only requires a compatible JDBC driver,
- provides methods for validation.

Since JEE has already been selected as the system’s base technology the use of Android for the smartphone application has been chosen. Android's developer API is available for Java and is currently widely used; in 2014, Android, which is the largest and fastest growing mobile platform, is used on hundreds of millions mobile devices in more than 190 countries.[227]

The IKU uses Apache's *Jena* framework as well as the *Weka* framework to realize machine-learning techniques. The enrichment component uses *RestFB* to simplify the communication with Facebook, and the open source framework *dom4j* to parse XML documents.

5.2 Realization of the System’s Software Architecture and CSL

In this section an overview of the system’s software architecture as well as its basic components belonging to the CSL will be given. As figure 1 shows, there are five main components in the proposed system: the SPU, the enrichment component, the RTW, the IKU and the CSL. One design goal was to create a clear and well-structured software architecture.[228] That is why the single components were designed to be highly modular and the communication between them is only performed through provided interfaces. Here, the number of relations between classes is kept as low as possible to reduce complexity. The system possesses a three-tier architecture which makes use of the model-view-controller (MVC) pattern. In the next paragraphs some

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[227] cf. (Android 2014).

[228] cf. section 4.2.

more details of architectural decisions will be given followed by some technical details of the CSL.

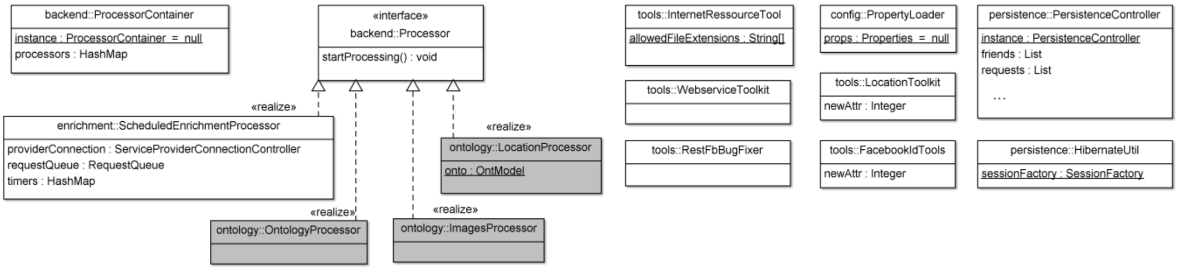

Figure 3 Simplified class diagram of the CSL's classes

Processors and the ProcessorContainer class

Currently, every existing component processes parts of its logic within a time-based recurring thread. Those time-based logic parts are separated from the event-driven logic parts to provide a better overview and keep the system easier to maintain. The separated recurrent logic parts implement the defined *Processor* interface. All concrete instances which implement the interface can then be collected in the so-called *ProcessorContainer* class (cf. figure 3). This singleton class manages all system-wide instances which implement the *Processor* interface. This allows an easy adjustment of the single thread instances if the time interval has to be changed or a specific thread has to be stopped or started, for example. As a result exception handling can also be centrally realized. In the system’s current version the container class manages the following instances of the *Processor* interface:

- the *ScheduledEnrichmentProcessor* which contains all enrichment processes[229],
- the *ImageProcessor* which detects new pictures taken with the smartphone,
- the *LocationProcessor* which detects new locations of the patients and
- the *OntologyProcessor* that contains regular processes to enhance the semantic network of the IKU and detects routines.

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[229] More detailed information about the process will be given in section 5.3.

The persistence layer

The CSL's persistence layer, which communicates with classes of the *Hibernate* framework, provides the so-called *PersistenceController* class. This class allows all clients to store any object in a very simple process: The state of any entity class can be easily made storable by annotating it according to the specified notation of Java's Persistence API (JPA). Moreover, Hibernate's configuration file has to be extended with an entry specifying the package of the entity class.[230] The *PersistenceController* then allows a very easy storing mechanism for all storable entity classes. For this, the instantiation of an entity class only has to be conducted via a provided method of the *PersistenceController* that uses Java Reflection. Hereby, the new instance of the entity class will be registered in the controller and unsaved data can be stored simply by calling the corresponding storing method of the *PersistenceController*. The controller class abstracts the persistence process to a great extent and all required reading and data manipulation methods are defined centralized. The simultaneous use of Hibernate's query language makes all implemented queries universally valid so that the controller does not have to be changed even if the database technology is exchanged in future.

The CSL's tool classes

Aside from the persistence layer the CSL contains various tool classes. Some important tool classes are, for example, the *WebserviceToolkit*, the *InternetRessourceToolkit* and the *StreamableFile* class. The *WebserviceToolKit* makes requests to web services very easy and provides plain Java objects as results instead of unhandy XML files. Java's built-in JAXB library can be used to generate data output classes for new web services if any should be added in future. For every web service call through the toolkit class, only the address and optional parameters as well as the type of the generated output class have to be specified. The web service call, the exception handling and the wrapping of the XML response to the result class is then realized by the toolkit class.

The *StreamableFile* class, together with the *InternetRessourceToolkit,* provide

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[230] A very detailed documentation of the JPA'a annotation is online available (cf. JBoss Community 2011).

some functions to enable easy download of internet sources, and make them available in the system without much effort. For example, if an image file is available online an object of *StreamableFile* can be created by just passing the Uniform Resource Locator (URL) of the image. The *StreamableFile* object then allows download of the picture to the system's picture directory through a simple method call. *StreamableFile* objects can include references to local or remote files and make a differentiation between both sources from a technical point of view irrelevant.

Another powerful tool class which is provided by the CSL is the *PropertyLoader* class. The singleton class allows a very simple access to all system settings; regardless of whether the system is started locally or in a server environment. The corresponding configuration file is added to the catalina server directory or local project directory and can include various system settings such as settings for Facebook and other service providers, paths to required file directories, time intervals for the enrichment providers, etc. The configuration file allows execution of the system with different settings, in different environments, without needing to recompile the source code.

5.3 Realization of the Enrichment Component

In this section an overview will be provided of the technical realization of the earlier described requirements regarding the enrichment component.[231] Regarding the enrichment component, various technical concepts are introduced in this thesis such as enrichment requests, enrichment agents, adapters and enrichment helper classes. More details about these will be provided in the following sub-sections.

5.3.1 Enrichment Requests

This section will describe the concept of the enrichment component's request types. A request in the proposed system is commonly created and initiated by the IKU if certain information in the semantic network is missing. For example, the name of a visited location is unknown or there are no pictures available for the detected life event of a patient. This request can then be transmitted to the enrichment component which will communicate with the enrichment

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[231] cf. section 4.6.

providers to retrieve the requested data. An instance of a request type always represents the need for one unit of information and moreover can contain the retrieved data from a service provider after a successful request execution.[232] Generally, any type of data defined by the system's "enrichable" data types can be requested (cf. figure 2). That means it is possible to represent the need for information with a concrete request object which does not necessarily refer directly to a life event. For example, a request could be created because some contact information of a patient's friend is unknown. This makes the system very flexible and allows requests of any type of data, to e.g. ensure the data quality and eliminate unwanted redundancies. However, in the current version of the system the available requests are strongly related to life events.

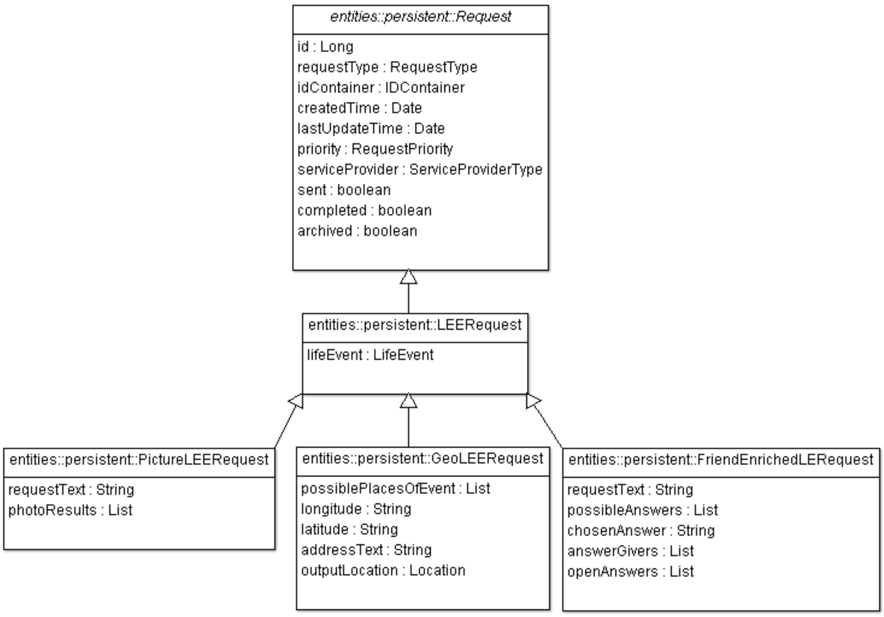

Figure 4 The request classes (without methods)

Figure 4 provides an overview of the currently available request classes. The abstract class *Request* contains an attribute of the *RequestType*. For example, the request type *RequestType*.ADDING_PICTURE_REQUEST can be used if a life event was detected by the IKU but there are no pictures in the system available which illustrates the life event. Besides the request type a request object contains the date of creation, a priority, the last time the enrichment component performed the request and other information necessary during the

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[232] More information how requests will be retrieved by the enrichment component from the IKU and how every single request is performed will be given in section 5.3.4.

enrichment process.

Currently, three request classes are defined in the system:

- PictureLEERequest, which can be used to retrieve pictures that illustrate a life event,
- GeoLEERequest, which is used for all request types related to geographical information (e.g. address text of GPS coordinates) and
- FriendEnrichedLERequest which specifies requests which are sent to the SNS.

Those request classes can specify the request with provider-specific information if required. For example, as discussed in section 3.3.4, the wording of the questions posed on Facebook is very important. The attribute *requestText* of the *FriendEnrichedLERequest* class allows specification of an individual question text for every posed question on the patient's SNS, to increase the likelihood of valuable answers.

As figure 4 shows, the request classes separate noticeably the already existing information in the semantic network within the *LifeEvent* attribute from the request process information and the retrieved data entities, which are expressed as attributes. The enrichment component does not update directly the semantic network after retrieving result data from the service providers. Instead, the IKU is informed through the use of the *Observer Pattern* when new information is available and the IKU will then decide which information will be updated in its semantic network.[233] Sometimes, if more than one result has been retrieved by the enrichment component the IKU needs to use the power of its semantic network, or use an additional enrichment process to choose the best provided answer. Here it is of importance to provide sufficient data to the IKU for the reasoning process. That is why the enrichment component will always provide the complete retrieved dataset to the IKU without eliminating or pre-selecting given results.

5.3.2 Enrichment Agents, Adapters, and Helper Classes

The enrichment component introduces the concept of the so called “agents”.

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[233] cf. section 5.3.4.

An agent is an interface which defines how requests will be executed and transmitted to a specific service provider type. An agent defines its methods in a non provider-specific way. For example, a *LocationInfoAgent* defines requests that a service provider for geographical information can answer (cf. figure 5).

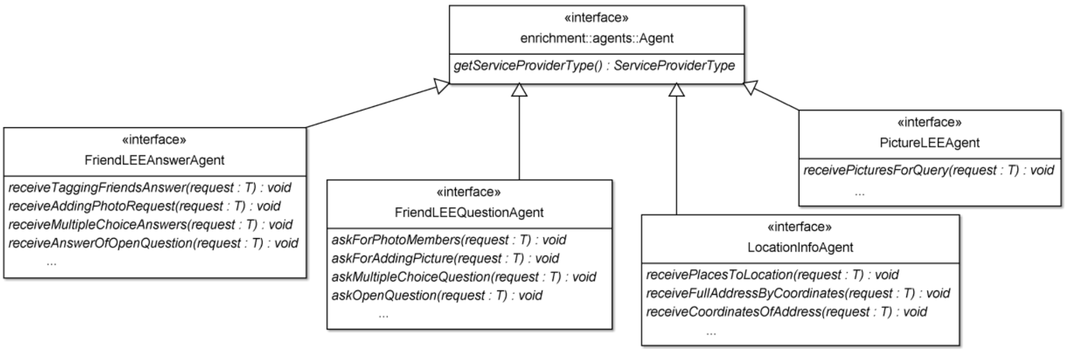


Figure 5 Shortened class diagram of agents

The concrete realizations of those agents are called enrichment adapter classes and contain the provider-specific logic (cf. figure 6). For example, if, along with *Facebook,* also *Google Plus* should be used for the enrichment process, an additional adapter class has to be implemented for Google Plus that implements the *FriendLEE* answer and question adapter classes.

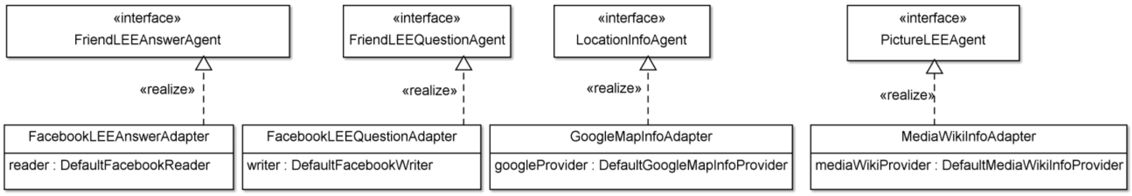
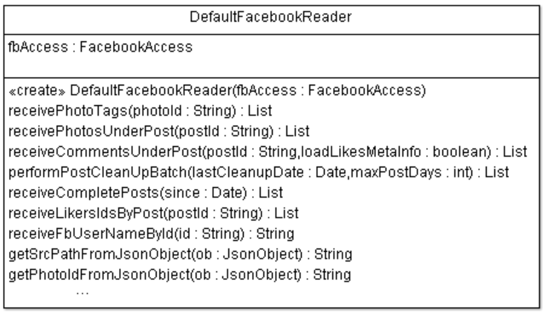


Figure 6 Enrichment adapter classes

The methods of an agent usually contain multiple (complex) calls to the service provider. These calls can be combinations of connection establishment procedures and read or write actions addressed to the service provider. To avoid code redundancies the adapter classes usually only call methods of an additional helper class, which provides all needed provider-specific actions. For example, the *FacebookLEEQuestionAdapter* contains methods to retrieve the given answers on the patient's SNS. If for example the provided post is a picture, there is usually significant meta-information available about the picture or possible likes and comments of other friends on *Facebook*. To retrieve all pieces of information and to be able to forward it to the IKU, various calls through the Facebook API are required. The helper class *DefaultFacebookReader* (cf. figure 7) provides all those methods and deals with the connection establishment to the service provider so that the adapter class only has to combine the calls of the helper class methods. Another advantage of the helper classes is that they make the concrete provider access code highly exchangeable since the adapter class only calls methods of the corresponding helper class interface.



```
DefaultFacebookReader
fbAccess : FacebookAccess
«create» DefaultFacebookReader(fbAccess : FacebookAccess)
receivePhotoTags(photoId : String) : List
receivePhotosUnderPost(postId : String) : List
receiveCommentsUnderPost(postId : String,loadLikesMetaInfo : boolean) : List
performPostCleanUpBatch(lastCleanupDate : Date,maxPostDays : int) : List
receiveCompletePosts(since : Date) : List
receiveLikersIdsByPost(postId : String) : List
receiveFbUserNameById(id : String) : String
getSrcPathFromJsonObject(ob : JsonObject) : String
getPhotoIdFromJsonObject(ob : JsonObject) : String
          ...
```

Figure 7 DefaultFacebookReader as a class diagram

5.3.3 The Service Providers and the Connection Handling

There are different service providers which are considered in the current version of the system such as Wikipedia, Google, and Facebook. Each of those requires a more or less complex login procedure including temporary keys or the transmission of a pre-registered user account. The *ServiceProviderConnectionController* contains a concrete implementation of the interface *ServiceProviderAccess* for every existing service provider. This implementation defines various functions which are usually needed to establish a connection and maintain it. The *ServiceProviderConnectionController* is the location in the system where possible errors regarding the service providers can be handled. This connection controller provides a better overview of all existing connections and shifts the responsibility to perform necessary actions, like temporary key renewal mechanisms, away from the concrete helper classes to one centralized location.

5.3.4 The request queue and request tasks

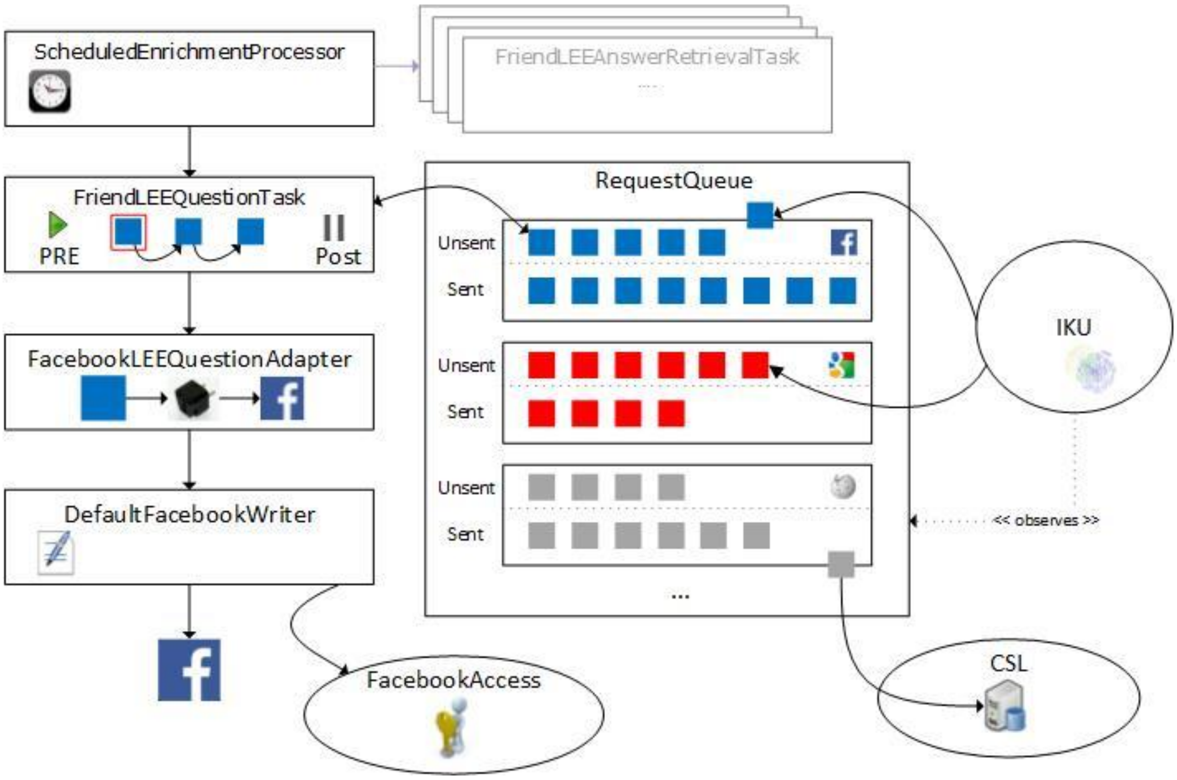


Figure 8 The RequestQueue (simplified)

The *RequestQueue* is a data structure that contains all requests which exist in the system. For every service provider the *RequestQueue* data type generates a list for all requests that are unsent and another list for all sent requests. The prioritized list of unsent requests contains all requests which were created by the IKU but have not been transmitted to the corresponding service provider yet. The other list of sent requests stores all requests which have already been transmitted to the provider but its request process has not yet been completed by the provider (cf. figure 8). The IKU can prioritize through the request's priority attribute a newly created request object and just has to call the according *RequestQueue* method to place the request in the queue.

The so-called request task (a concrete subclass of the superclass *AbstractRequestTask*) specifies details of the request execution process. The superclass *AbstractRequestTask* which is "runnable" extends *java.util.TimerTask* and automatically supplies its concrete request task subclasses with the subsequent request from the *RequestQueue*.

It is advisable to create a subclass of *AbstractRequestTask* for every created agent so that logically different enrichment processes can be performed within separate *Java* threads. That allows an individual timing for every thread. In this way e.g. a request to Facebook and its wall posts can be created in a first step within the *FriendLEEQuestionTask* thread, but possible answers, eventually provided by the patient’s Facebook friends, are retrieved within the second *FriendLEERetrieveAnswerTask* thread. Both threads can be performed repeatedly in a different time period which allows a high flexibility.

Request tasks also allow the creation of certain pre and post execution behavior for the request process. A possible pre-execution behavior can be the implementation of an algorithm that checks if more complex API call restrictions of an external service provider are followed and the execution of the request process can be delayed if required. A typical post-execution behavior which can be specified in such a request task class would be to check whether the enrichment process is completed or not. The identification of the completion of an enrichment process can be trivial, if e.g. only one result is expected and the service provider retrieved a dataset in the expected format (e.g. address text of GPS coordinates). However, requests transmitted to the patient's SNS do not, in some scenarios, possess unambiguous criteria of completion. For example, if the SNS friends are requested to provide pictures to illustrate a life event multiple pictures can be possibly provided from different friends during an undetermined time-frame. In these scenarios the enrichment's post-execution behavior typically includes a time-based condition which is modifiable in the system's external configuration file[234] (e.g. 30 days after request creation) to complete the request processing after a reasonable time.[235] Whenever a task has been executed and new information has been retrieved the IKU which observes the *RequestQueue* through the *observer pattern* will be notified.

Once a request has been determined as completed the *RequestQueue* marks the request respectively and it will be archived through the CSL in the

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[234] cf. section 5.2.

[235] It is important to determine especially the requests which were transmitted to Facebook after a certain time-frame. Facebook's developer API does not provide a mechanism which can inform the proposed system actively about new provided answers by friends. Instead every posed question has to be checked for possible answers through separate API calls. However, every single API call increases the chance to exceed Facebook's call limitations.

database. By this, a log of all transmitted requests is realized. This allows a future assessment of all requests which have been created by the IKU and the accuracy of all retrieved answers can be validated.

The earlier mentioned class *ScheduledEnrichmentProcessor* can be seen as the starting point for all enrichment processes. This class creates an instance of every task class and manages those threads. The thread interval for every task class can be also edited in the external configuration file.

5.3.5 Example of Friend-Enrichment from a User Perspective

In this section a short example will be provided to illustrate the (friend-) enrichment process from the user's perspective.

Joao Garcia
April 23 via RememberMe_LOCAL

Some help is needed, friends. Joao visited a location in Berlin this morning. Does anyone know which of the listed places it was? (Please select the correct answer by liking it!) [ID=223a32fa23]

Joao Garcia Technisches Museum Berlin
about a minute ago · Unlike · 1

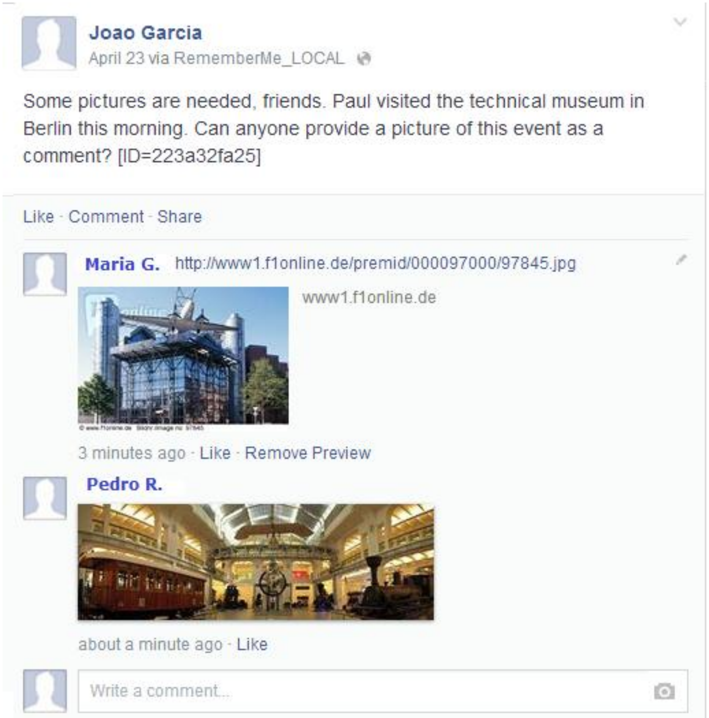
Joao Garcia Gleisdreieck Berlin
a few seconds ago · Like

Joao Garcia Kühlhaus am Gleisdreieck
a few seconds ago · Like

Joao Garcia Premium Exhibitions Berlin
a few seconds ago · Like

Figure 9 Facebook question to specify patient's location

In the example the IKU detected a life event on patient João's system. The IKU detects that the patient has never been at that location before. In a next step the IKU initiates a request to the Google API to find some possible places which are near to the detected location. The result of the request is a list of several possible places. The IKU now uses a Facebook request to ask the patient's SNS friends to choose the correct place from the list (cf. figure 9).



Joao Garcia
April 23 via RememberMe_LOCAL

Some pictures are needed, friends. Paul visited the technical museum in Berlin this morning. Can anyone provide a picture of this event as a comment? [ID=223a32fa25]

Maria G. http://www1.f1online.de/premid/000097000/97845.jpg

www1.f1online.de

Pedro R.

Figure 10 Providing pictures of a life event through Facebook

After the correct place has been chosen from the list the IKU creates another request to Facebook to ask the patient's friend for pictures which illustrate the event. As figure 10 shows, two of João's friends have provided a picture. The first picture which was provided by Maria was inserted as a hyperlink; the second picture from Pedro was provided through uploading a picture. Both pictures will be retrieved by the system and forwarded to the IKU. If the pictures are liked by friends or a caregiver with special page permissions deletes a provided picture, the IKU will be informed. Likes of friends can be used by the IKU to determine the relevance of a certain life event and may allow conclusions about the quality of certain answers or even their trustworthiness.

6 Validation of the Proposed System

The validation of a system in the area of assistive software for people with dementia is a non-trivial task. The effects of such applications and their suitability can only be examined adequately in long-term studies.[236] Moreover, many different interest groups such as patients, caregivers, psychologists and engineers are usually involved in the development, which can slow down the process. However, in this chapter the validation process of the application will be initiated and a first validation of the system will be presented. Therefore, in the next section it will be shown how the earlier defined requirements have been realized through the system design. Moreover, further steps necessary to validate the system more extensively in further research will be described. Afterwards, an expert interview will be presented to start a discussion of psychological and ethical aspects of system design.

6.1 A First Technical Validation

Low-cost approach

One goal defined as a requirement was to develop a system that is affordable, and uses pervasive technologies.[237] The choice to use Java EE, an Android-based smartphone together with the powerful Hibernate framework allows the system to be run on diverse hardware and makes it highly scalable, even if the available hardware performance is limited. The use of the free and open available online services such as Google, Wikipedia or Facebook keeps the system's operating costs low.

Highly flexible and extendable enrichment component

One requirement was to provide a highly flexible system that is easily extendable. The enrichment component's design which introduces the concepts of agents, requests, request tasks, service provider handling classes and enrichment adapter classes not only allows the easy request of any type of data related to the IKU's semantic network but also allows to query very different kind of service providers while respecting possible service provider limitations. Here, further request types can easily be added and the concept of

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[236] cf. (Alzheimer's Association Research Center 2014).
[237] cf. section 4.2ff.

the presented request queue allows clients to conduct new requests very easily. Clients such as the IKU which use the request queue can create new requests in an abstract manner without knowing the provider type, required connection establishment procedures or provider-specific query notations. This makes the underlying provider communication easily exchangeable (similar to the Hibernate concept) and simplifies the request procedure for all clients dramatically.

The CSL as well as the enrichment component has been documented entirely through the Java Doc notation. Moreover, the provision of a manual which explains in detail how to extend the framework will support prospective developers if changes are necessary in future.

Implemented functionalities

Some of the system's functionalities have been specified through a short user scenario. Here the possibility of conducting three types of requests has been specified:

The mechanism to automatically detect unknown places is realized through the use of the request type "RECEIVE_POSSIBLE_LEE_PLACES" that can be answered through the Google Maps API using the *GeoLEERequest* class. The function to search for pictures of visited public places is implemented by the request type "PICTURES_BY_REQUESTTXT". This request type can be used in combination with the *PictureLEERequest* class and provider Wikimedia. The last requested function to ask friends of the patients to provide pictures of a life event is provided through the request type called "ADDING_SNS_PICTURE_REQUEST" using the request class *FriendEnrichedLERequest*. Additionally, the current version of the prototype already includes various other request types such as

- TAGGING_FRIENDS_ON_PICTURE_REQUEST, which helps to identify people on taken pictures through SNS question-asking,
- ANSWER_MC_QUESTION that poses a question and a set of possible answers on the SNS (possibly including media) and returns the rating of the friends,
- ANSWER_OPEN_QUESTION, which poses a question (eventually including media) on the SNS and returns all provided answers including the rating through the number of likes of the SNS friends, for example

- ADDRESSTXT_BY_LOCATION_COORDINATES which uses coordinates to return a formatted address text,
- LOCATION_BY_ADDRESSTXT, which uses an address text to deliver its coordinates,
- AUTOMATIC_RETRIEVED_LIFEEVENT, which can be used to check the SNS for new posts which were initiated by the patient's friends and include enough information to describe a life event of the patient.

For all listed request types various tests have already been successfully conducted through the developed testing suite within the application's *test* package. More detailed information about those request types is available within the application's documentation.

Further crucial actions for validation of the system design

Further steps will be necessary in future to validate the proposed system design adequately.[238] Those steps will typically include standardized questionnaires to examine the user's system acceptance. Here, the selected group of test users should include people suffering from a mild form of dementia, their informal caregivers, clinical staff, as well as friends who are willing to contribute answers on Facebook. Beside questionnaires some more intensive live tests have to be conducted to evaluate the collected data together with the users. An instructed test user group should use the system for a specified period of time. Simultaneously, the test users should be asked to keep a diary where they describe all important events which were experienced during the test period by the patient including their locations and other information which they find relevant. Afterwards, the retrieved data from the enrichment component must to be analyzed together with the test user's diaries. Regarding the validation of the enrichment component, it has to be ensured that the retrieved data, such as pictures or geographical information as well as the contributions of the friends on the SNS, match descriptions of the event by all parties in the diaries. The use of the reminiscence therapy web tool can support this process by presenting the collected material directly to the caregivers and patients in an easy and illustrative manner. If the retrieved data does not match the expectations of the test users the system

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[238] Extensive further validation procedures are necessary but would have exceeded the scope of this thesis. However, they will be conducted through members of the research team in future and their results will be published in related work.

must be responsively adapted. Those changes can include, among others, the mechanism that retrieves the raw input data, the IKU's routine reasoning or changes of query parameters used by the enrichment component.

6.2 Expert Interview for a First Validation of Psychological Concerns

The proposed system requires an intense examination of psychological and medical conditions which are connected to the symptoms of people suffering from dementia. It is of importance that the system does not compromise the patient's health status but provides opportunities to improve the perceived life quality instead. Therefore, an interview with Prof. Dr. Maria José Azevedo de Brito was conducted during a consultation on 2nd May 2014 in Berlin to get another expert opinion from a medical, and importantly, a psychological perspective. Before the interview was conducted, Maria José Azevedo de Brito received this thesis to allow inspection.

> Maria José Azevedo de Brito holds a medical science degree as well as a PhD in psychology, and is a professor at the universities *Universidade Federal de São Paulo* and *Universidade do Vale do Sapucaí*. She is an experienced researcher in various areas of psychology that require a strong medical background and demand an intense examination of the patient's perceived life quality. Currently, she researches neurocognitive aspects of body dysmorphic disorder (BDD)[239] that are present in the areas of Psychiatry and Plastic Surgery. BDD is a common mental disorder, yet still underdiagnosed. The uncertainty of identification of the diagnosis that can be also seen in types of dementia, led her to develop a model based on fuzzy logic, which evaluates the level of suffering of these patients. She is currently involved in the process of developing a software system that applies her model for decision support on the patient's selection for Plastic Surgery and Psychiatry.

Q: *In this thesis it has been discussed that people suffering from dementia often feel embarrassed and exposed regarding to the symptoms of their disease. They mostly feel uncomfortable when dependant on others and sometimes even try to repress thoughts about their diagnosis. The innovation of the proposed system to use Facebook to enrich and validate its obtained data can support the patient in various scenarios e.g. by providing rich digital reminiscence therapy material. The question-asking mechanism on Facebook should typically only be visible to a chosen set of the patient's friends. However, those questions can sometimes include personal information about*

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[239] BDD manifests itself in severe degrees of body dissatisfaction and can be confused with their own comorbidities, such as depression and social anxiety, interfering dramatically on the disease's course and on the patient's treatment. Individuals with BDD have extreme concerns and clinically significant distress when it comes to physical appearance. High rates of suicide are part of the clinical picture.

the patient such as his former location during the day. How would you assess the overall patient's acceptance for the proposed system?

M.J.A. de Brito: "Throughout the thesis, I identified that all care and ethical principles were respected concerning the development of the new tool. Moreover, many variables related to the disease and its perception have been considered both from the point of view of the patient and of the environment which surrounds it. The fact that the patient can count on and manage by itself this feature can be more valued in terms of autonomy and consequent psychological well-being, in that the system reveals the value of dignity to its current condition. There is still some exposure, but decreased, since it is through a system. On the other hand, inhibition and denial of symptoms afflict the patient more than the exposure of their own vulnerability. This vulnerability can actually strengthen relationship bonds in a more human way or condition, as it was well cited in the thesis (p. 34). I believe that through this tool, Alzheimer's patients, their caregivers, family and friends, may exercise and better understand humanity itself. Being able to interact, given their current condition, will be the biggest gain in terms of acceptance of the system in their lives."

Q: *One design goal of the proposed system was to use pervasive technologies which are commonly used and affordable. Nevertheless, some costs may arise to use the system such as acquisitions costs for a smartphone and a desktop computer as well as possible internet provider fees. Additionally, it has been shown that intensive introductive training sessions and educating of all users is important. Do you think the patients and especially caregivers will nonetheless see the system as beneficial?*

M.J.A. de Brito: "With no doubt. In terms of cost-benefit, the system can improve the quality of life of patients and their caregivers. Nowadays, both the training and the equipment have values/prices that are more accessible to the population in general. Such technology tools are extremely valuable and can combine degrees of effectiveness and efficiency of their actions on health."

Q: *It has been noticed that some patients feel lonely and often less friends keep in contact with the patients over time. How likely do you think it is that* *the patient's friends use the social network site mechanism to provide their help?*

M.J.A. de Brito: “As it comes to a specific population (close friends), they will, in principle, be motivated. This motivation will be fed by the behavior of the other, whether by imitation, or even by a certain kind of healthy competition (quantity and quality of information posted), or by the longings and desires of each of themselves and also by human solidarity. The fact that there is a specific tool for this purpose serves as motivation for approximation (getting in touch, getting closer) and identification, since it functions as a memory. It is as if this system encouraged communication and language itself, that are increasingly scarce due to the disease.”

Q: *Another design goal of the system was to not increase the perceived burden of caregivers. Caregivers are usually overstrained with their duties and in most cases many caregiving hours are necessary every day. At the same time informal caregivers often use ineffective coping strategies and do not ask for help from others. The question-asking mechanism through Facebook will not only serve the enrichment and validation process of the system but will also inform friends through the generated questions about current life events of the patient. This may give friends who are insecure about how to deal with the disease a chance to help and can sensitize them to the current state of the patient. How would you assess the system's impact on the friends of the patient?*

M.J.A. de Brito: “It is a form of interaction that without this system would not be possible. By making use of tools that are known to them, people who are not used to dealing with patients suffering from these diseases would feel more comfortable to establish communication and bounds. The proposed system establishes a long lasting and continuous interaction and thus prevents isolation of the patient. In the medium- to long-term, this would ease the burden of the caregiver, which as a consequence would increase the patient’s well-being.”

7 Conclusion

Many people who are suffering from dementia commonly express various unmet needs, including the need for social contact, as well as the need for memory support. It has been shown that patients are usually still capable handling simple electronic devices. Yet, most of the existing assistive software tools do not consider many of the already available mainstream technologies that may improve the patient's quality of life. Informal caregivers can have a great influence on the patient's well-being. However, their caregiving duties are often perceived as highly stressful and the use of ineffective coping strategies along with their common refusal of asking others for help can lead to serious diseases such as clinical anxiety or depression.

In this thesis, a system was presented which uses automatic retrieved data of a smartphone as input for an inference engine running on a server system to identify routines and relevant life events of the patient. This thesis examined the possibility of querying open available web services as well as using a friend-enrichment mechanism through question-asking on a SNS to validate and enrich the gained knowledge of the system. The gained knowledge can then be used to conduct reminiscence therapy sessions, a commonly practiced form of therapy, by using a provided web tool of the system. Benkler's framework of peer production was applied together with studies of similar approaches to examine the viability of a friend-sourcing mechanism for the proposed software system. It was shown that the proposed system follows important characteristics and a general acceptance for friend-sourcing is present; yet an appealing question phrasing is of great importance to motivate contributors. Moreover, it was shown that patients need to be adequately educated about the system and its functions to follow existing psychological guidelines. Additionally, extensive introductive training sessions must be conducted in time. An interview with Maria J. Azevedo de Brito, an experienced researcher in psychology, showed that important psychological and ethical issues seem to be followed through the suggested system design. Maria J. Azevedo de Brito believes that the system will be well accepted by the patients and their caregivers and provides adequately incentives attracting friends to contribute on Facebook.

Even though the system may strongly support many sufferers in their daily life, it is neither a "universal remedy" nor suitable to all types of patients. Although the system's data accuracy will be improved through the use of artificial intelligence and friend-enriched techniques, some inappropriate material may still be presented in the reminiscence therapy web tool which could upset the patient. For example, although being comprehensively educated about the system’s functionality, a patient may unconsciously use the system and unwanted information about a visited location is posted on Facebook. Some patients, who are very conscious and protective about their privacy, have trouble accepting their diagnosis, or are not comfortable using modern technologies, may not be willing to use such a system.

Using the proposed software system only requires affordable hardware, a desktop computer and a smartphone. Moreover, the system’s operating costs are kept as low as possible through the use of free open available service providers. The system may encourage communication and language itself between patients, their friends, and caregivers. Furthermore, the software has a great potential to improve the patient's perceived quality of life by enhancing his feeling of self-determination, strengthening his social connections, and motivating his friends to offer their support beside their contributions on the patient’s SNS. This cannot only improve the patient’s well-being, but may also help to unburden the caregivers.

The prototype developed in this thesis can query open available web services, as well as realize a friend-enrichment mechanism through a server communication with the patient’s Facebook page. This enables the software system to execute various enrichment requests that can personalize and validate the system’s knowledge gained about the patients’ life events. These are, for example, requests to retrieve additional geographical information about visited locations, or images illustrating life events, as well as requests that can validate the reasoning of the inference engine. The introduced architectural concepts in the enrichment component such as adapter classes, enrichment agents, the request queue, and request tasks, all grant the component a solid architecture that allows future adjustments to be easily made. Future long-term studies, including all stakeholders, will allow validating the system’s design, extensively studying the user acceptance, as well as examining the system’s overall effectiveness on the patient’s perceived quality of life.

8 Suggestions for Further Research

The proposed system justifies various further research topics. In this chapter some suggestions will be provided for possible research areas regarding the system's friend-enrichment mechanism which was a focus area of this thesis.

A possible focus for e.g. a potential master thesis could be examining the use of additional providers which also implement the friend-enrichment mechanism. This may expand the group of contributors through an enhanced technical diffusion. Moreover, the examination of additional request types can be conducted to empower the IKU performing more diverse information requests using the existing providers. The prototype's software architecture allows an easy inclusion of further service providers and the adding of request types can be implemented rapidly. Besides Facebook, e.g. Google Plus could be used as another SNS. Even the implementation of an e-mail service or text messaging service might be feasible. This service could send questions to potential contributors (friends) of the patients via e-mail or text messages and include a link to an online form where the contributions can be provided. A survey could be conducted with test users to study their preferences.

Another focus area which could continue the work of this thesis is to analyze if the implemented service providers are also suitable to use them in supplementary care scenarios. For example, Facebook or the earlier mentioned e-mail and text messaging system could be used to enhance the patient's safety by informing friends if the patient e.g. is leaving his usual routes and starts to wander. Those service providers could also be used to strengthen the contact with the patient's friends. As mentioned earlier, friends of people with dementia often do not know how to deal with the disease and sometimes distance themselves from the patient.[240] Here, for example, Facebook could be used to contact friends individually and inform them about current life events of the patients. Moreover, the system could be used to suggest activities the friends could participate in with the patient. This would require working closely together with psychologists and specialist in the area of dementia. Also this focus area could include some surveys examining the test user's preferences and observe if the suggested extensions are beneficial.

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[240] cf. section 2.1.2ff.

List of Figures

List of Tables

List of Abbreviations

AD	Alzheimer's disease
API	Application Programming Interface
AT	Assistive Technology
BDD	Body Dysmorphic Disorder
CDR	Clinical Dementia Rating
CSL	Central Software Layer
HTTP	Hypertext Transfer Protocol
JEE	Java Enterprise Edition
IKU	Inference Motor and Knowledge Gathering Unit
JPA	Java Persistence API
MCI	Mild Cognitive Impairment
MVC	Model-View-Controller
ORM	Object-relational Mapping
RT	Reminiscence Therapy
RTW	Reminiscence Therapy Web
SNS	Social Networking Site
SPU	Sensor Processing Unit
URL	Uniform Resource Locator
XML	Extensible Markup Language

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Appendix A: Abstract Translated to German

Demenz reduziert nicht nur die kognitiven Fähigkeiten des Menschen, sondern hat auch einen starken Einfluss auf die Persönlichkeit und empfundene Lebensqualität der Betroffenen. Pflegende Angehörige können einen großen Einfluss auf das Wohlergehen der Patienten haben, jedoch belastet sie ihre Arbeit oft stark. Gleichzeitig benutzen sie häufig unwirksame Bewältigungsstrategien. Obwohl bereits eine Vielzahl von Softwaresystemen existiert, die die Betroffenen unterstützen, bleiben viele ihrer Belange unerfüllt. Das HCIM-Forschungsteam des Instituts für Informatik der Universität Lissabon startete ein Softwareprojekt, bei dem automatisch erhaltene Daten von einem Smartphone des Patienten als Eingabequelle für eine Inferenzmaschine benutzt werden, um relevante Ereignisse im Leben des Patienten zu identifizieren. Die gesammelten Daten können dann in unterschiedlichen pflegeunterstützenden Einsatzgebieten Verwendung finden. In einer ersten Version des vorgestellten Systems wird das gewonnene Wissen genutzt, um digital unterstütze Reminiszenztherapie durchzuführen. In der vorliegenden Arbeit wird die Möglichkeit eines Friend-Sourcing-Mechanismus, der durch automatisierte Fragen auf Facebook und Nutzung von Online-Webservices das gewonnene Wissen anreichert und validiert untersucht. Hierzu werden die Lebensumstände des Patienten und der pflegenden Angehörigen sowie die Krankheitssymptome näher untersucht. Anschließend werden wichtige Voraussetzungen für die Nutzung eines Friend-Sourcing-Mechanismus geprüft und Faktoren, die die Qualität und Quantität der Antworten beeinflussen können sowie wichtige psychologische und ethische Betrachtungen diskutiert. Wichtige Anforderungen an einen Prototypen, der diesen Mechanismus implementiert, werden aus den Ergebnissen der Literaturrecherche abgeleitet und die Entwicklung dieses Prototypens wird erläutert. Obwohl das vorgeschlagene System Betroffene gravierend unterstützen kann, indem es ihre sozialen Kontakte sowie deren Gefühl von Unabhängigkeit stärkt, werden nicht alle Patienten bereit sein ein System zu nutzen, welches ihre Privatsphäre einschränken kann. Das System kann eine fortlaufende Interaktion zwischen dem Patienten und seinen Bekannten durch die Nutzung eines sozialen Netzwerkes etablieren, was seine soziale Isolation verhindern und die pflegenden Angehörigen entlasten kann. Der leicht erweiterbare Prototyp wird weiterführende Forschung erlauben, um den Systementwurf umfassender zu validieren, die Nutzerakzeptanz zu erforschen und die Effekte auf den Patienten innerhalb einer Langzeitstudie zu untersuchen.

Appendix B: Eidesstattliche Erklärung

Hiermit erkläre ich, dass ich die vorliegende Arbeit selbstständig und eigenhändig sowie ohne unerlaubte fremde Hilfe und ausschließlich unter Verwendung der aufgeführten Quellen und Hilfsmittel angefertigt habe.

Berlin, den

(Oliver Schnell)