



Making the case for innovation to support  
informal caregivers:  
An exploratory study on the most relevant  
characteristics of a mobile technology  
solution from the particular case of The Weal  
Life

Athina Radoslav

Dissertation written under the supervision of Prof. Susana  
Frazão Pinheiro

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## Abstract

### **Title**

Making the case for innovation to support informal caregivers: An exploratory study on the most relevant characteristics of a mobile technology solution from the particular case of The Weal Life

### **Author**

Athina Radoslav

The goal of this dissertation is to investigate how a mobile technology solution can support the needs of informal caregivers. The objective of this research was dual: first to understand how a mobile technology solution can be used to answer the major issues of informal caregiving related to modern living and second to determine the features of a caregiver mobile solution that can support the informal caregiver with their care responsibilities. With these objectives in mind, a case study was explored, on the San Francisco based start-up The Weal Life. The Weal Life is a pioneer mobile technology solution in the informal caregiving industry which aligns its mission with the objectives of this dissertation. The Literature Review explored the main challenges of the caregiving industry, alongside informal caregivers' concerns and needs.

Through the case analysis on The Weal Life and the examination of two "holistic" cases, critical mobile features were presented in order to advance better technology solutions for informal caregivers.

Keywords: informal caregivers, caregiver needs, mhealth, caregiving innovation.

## Resumo

### **Título**

Hacer valer la innovación para apoyar a los cuidadores informales: Un estudio exploratorio sobre las características más relevantes de una solución de tecnología móvil del caso particular de The Weal Life

### **Autor**

Athina Radoslav

O objetivo desta dissertação é investigar como uma solução de tecnologia móvel pode suportar as necessidades dos cuidadores informais. O objetivo desta pesquisa foi duplo: primeiro entender como uma solução de tecnologia móvel pode ser usada para responder às principais questões de cuidados informais relacionados à vida moderna e em segundo lugar para determinar as características de uma solução móvel de cuidador que pode apoiar o cuidador informal com os seus cuidados. Com esses objetivos em mente, um estudo de caso foi explorado, sobre a start-up The Weal Life baseada em San Francisco. A Weal Life é uma solução pioneira de tecnologia móvel na indústria de cuidar informal, que alinha sua missão com os objetivos desta dissertação. A Revisão de Literatura explorou os principais desafios da indústria de cuidados, ao lado das preocupações e necessidades dos cuidadores informais. Através da análise de caso em The Weal Life e do exame de dois casos "holísticos", características móveis críticas foram apresentadas a fim de avançar melhores soluções de tecnologia para cuidadores informais.

Palavras-chave: cuidadores informais, necessidades dos cuidadores, mhealth, inovação na prestação de cuidados.

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## List of Acronyms

**AARP** – American Association of Retired Persons

**ADLS** – Activity of Daily Living

**FCA** – Family Caregiver Alliance

**IADLS** – Instrumental Activity of Daily Living

**NAC** – National Alliance of Caregiving

**NCDs** – Noncommunicable diseases

**WHO** – World Health Organization

## 1. Introduction

Chronic diseases are currently the main cause of mortality worldwide, with 38 million deaths each year (WHO, 2015). Globally, premature death from Noncommunicable Diseases (NCDs) has declined between 2000 and 2012, however the number of individuals affected by a chronic illness is expected to grow, due to the development of the main drivers of these diseases.

The main drivers: an aging population, caused by fallen fertility rates and substantially increased longevity (ONU, 2015), and the globalization of unhealthy lifestyles (e.g. air pollution, physical inactivity or unhealthy diets), explain the systematic increase of individuals affected by NCDs (WHO, 2016). An estimate of individuals who are expected to need assistance with one chronic disease or more was of approximately 177 million people in the USA by 2020 (Ward, Schiller, & Goodman, 2014). Consequently, as the demand for health care increases, the number of individual caregivers whose assistance is needed in order to provide ongoing care is expected to increase as well. Recent reports indicate that due to gaps in the health care system and preference, caregiving is mostly provided by family and friends (Anderson, 2010), with a forecast of 45 million unpaid caregivers by 2020 (American Association of Retired Persons, 2016). The trend of unpaid caregivers is known in academic literature as “informal” caregivers, defined as any “relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (FCA, 2014).

Providing care leads to physical strain, high emotional stress and financial distress for caregivers when supporting individuals along the care continuum (Reinhard, Feinberg, Choula, & Houser, 2015). The current market value of the care provided by unpaid caregivers to ill and disabled adults is estimated to be at \$470 billion in 2013 (Reinhard et al., 2015). Therefore, leveraging technology to deliver services and support that can help to address this range of needs is critical in this health care sector.

The aim of this research is to evaluate how The Weal Life, seeks to close the gaps in caregiving and develop significant solutions to support patients along the care cycle and improve their overall quality of life.

In this dissertation The Weal Life, a pioneering mHealth company is introduced in the form of a case study in order to answer the following Research Questions:

1. *How a mobile management solution can improve a caregiver's psychosocial well-being to manage day-to-day treatment and better cope with the emotional and physical stress?*
2. *Which are the key factors that a mobile caregiving support tool can consider in order to provide an individualized approach, tailored to meet individual healthcare environments?*

Specifically, the main goal is to differentiate between two main chronic diseases and their respective healthcare environment: metastatic Breast Cancer patients and Parkinson patients.

Firstly, Chapter 3, *Literature Review*, is based on secondary sources, mainly academic articles and websites, through the use of search engines, in order to create a base for the case study. We will present an overview of *The Caregiving Sector* in the first sub-chapter, followed by a second sub-chapter in which we will explore the key needs of the “informal” caregivers. The third sub-chapter will consider the *Leading Chronic Diseases* and their implications. Furthermore, we will discuss the important role of *Innovation in Caregiving Support*.

Secondly, in Chapter 4, *Case Study*, we will explore the management tool developed by The Weal Life. First of all, in the sub-chapter *Technology to care for one another* we will present the company in detail. In the second sub-chapter we will address the first research question, identifying the main caregiving dimensions that The Weal Life aims to improve and exploring how it will deliver value. The last sub-chapter is dedicated to a qualitative analysis on how the mhealth company The Weal Life can deliver tailored approaches to patient care and the main challenges it faces.

The Chapter 5, *Teaching Notes*, is written for classroom practice and it offers an illustration of the learning objectives and the respective teaching questions.

Finally, conclusions and further implications will be discussed in Chapter 6.



## 2. Methodology

In order to address the previously presented Research Questions a qualitative approach is used, in the form of a single case study. The case study approach is suitable in this research because “(a) the focus of the study is to answer “how” and “why” questions;” (Baxter & Jack, 2008). Moreover, the aim of this research is to investigate a single case and to understand what can be learned about this particular case (Baxter & Jack, 2008), exploring The Weal Life mobile application and its characteristics, in order to help corroborate to existing literature or advance best practices for future digital solution for the caregiving industry.

The case study will be holistically prepared, focusing on The Weal Life information and secondary resources, including personal communication. Therefore, weekly meetings with The Weal Life founders were developed to help with the analysis of this case. Firstly, a research will be performed to identify sources that guide/inform on caregiver journeys (Meta and specific) in order to understand a caregiver’s needs and wants.

Secondly, these sources will be mapped to help create a framework for a holistic structure of guiding principles/best practices for The Weal Life mobile application, which will address emotional/physical well-being of the caregiver. Afterward, implications of this framework for The Weal Life features and functions will be considered (informing not only content type/structure of presenting resources along the journey for The Weal Life users, but also informing which filters/views The Weal Life tool can have for better outcomes).

Finally, the framework will be applied to two specific caregiving stories, of breast cancer and Parkinson treatment, to help illustrate the framework.

## 3. Literature Review

### 3.1 The caregiving Sector

#### 3.1.1 Demographics and Prevalence

Current population aging has been influenced by the recent trends in fertility and mortality, which have decreased significantly globally. Fertility has fallen to 2.5 children in 2015 from 5 children in 1950 and all regions have improvements in life expectancy (ONU, 2015). These developments indicate that almost every country should expect a significant growth in the number of persons at age of 60 years or over (ONU, 2015).

In addition, chronic diseases cases are progressively increasing in the United States with nearly 50% of the population suffering from at least one chronic disease and evidence suggests that the number of individuals affected by multiple chronic diseases is increasing as well (N3C, 2014). Therefore, these trends of rapid aging and prevalence of chronic diseases are accompanied by an increase in the number of elderly individuals requiring ongoing care. And, with the increasing numbers of individuals who require care, costs of health care raise as a result of increased health care expenditure. However, the health care system has not evolved to provide effective care coordination and affordable health care coverage to people with lower income or little family support (WHO, 2015).

The health care system relies on unpaid caregivers to provide most of the ongoing care support and in some cases even health-related services for persons with disabilities (Gibson & Houser, 2007), as family continues to be the main source of ongoing care in the majority of advanced countries (Fine, 2012).

Although, there is no uniform description of unpaid care in the academic literature, the majority of definitions refer to unpaid care as informal care and therefore to the unpaid caregiver as an informal caregiver, which is defined as any “relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (FCA, 2014). This study is going to focus on informal caregivers as opposed to paid caregivers, due to the challenges faced by a caregiver who has a personal relationship with the person in need of ongoing care.

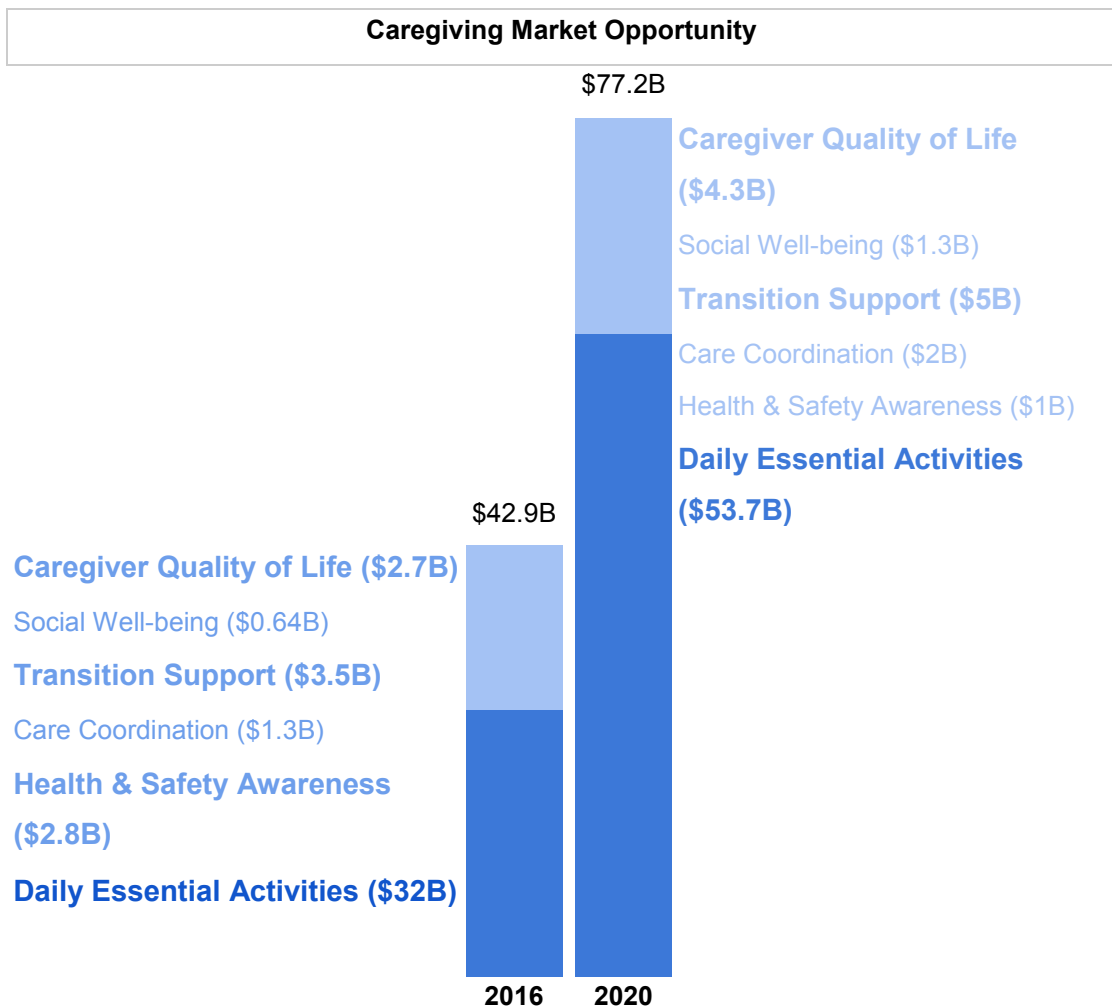
Informal caregivers were estimated to be 22 million in 2003, between 30 million and 38 million in 2006 (Gibson & Houser, 2007), 40 million in 2014 and expected to be 45 million in 2020 (American Association of Retired Persons, 2016). However, there are 177 millions of Americans which are expected to require care by 2020, compared with the estimated number of unpaid caregivers it is an insufficiency (Gibson & Houser, 2007). It is important to note that these estimates are at a narrow point in time, taking into account caregivers who performed their duties at the time of the survey or in the last month (Gibson & Houser, 2007). Therefore, the number of “informal” caregivers in a year could be underestimated, for example the AARP report of 2004 approximated a total of 44 million caregivers in 2003 (Gibson & Houser, 2007).

Additionally, more than 50% of caregivers say they provide all or most of the unpaid care, making them the primary caregiver (National Alliance for Caregiving & AARP, 2009), defined as the main source of care (Barbosa, Figueiredo, Sousa, & Demain, 2011). Secondary caregivers are defined as the individual or individuals who enter(s) the care cycle to offer support for the primary caregiver, but without taking on principal responsibilities for the care recipient (Barbosa et al., 2011).

### **3.1.2 Economic Value of Caregiving**

The contribution of “informal” caregivers to the U.S. economy was estimated to be at around \$350 billion in 2006, \$375 billion in 2007 and \$450 billion in 2009 (Gibson & Houser, 2007). The latest assessment on the economic value of “informal” caregiving is of \$470 billion in 2013 (Reinhard et al., 2015). Further, the value of “informal” caregivers is expected to continue to be the main foundation of long-term care services in the U.S. (Coughlin, 2010). Therefore, companies are recognizing the business opportunities a caregiving market opens, with an estimated market value of \$72.2 billion in 2020 only and a 13% growth rate from 2016 to 2020 (American Association of Retired Persons, 2016). **Chart 1**, below, shows the market opportunities for key areas in which informal caregiving have the most out-of-pocket spending.

**Chart 1. Caregiving Market Opportunity**



*Note.* Adapted from Caregiving Innovation Frontiers 2016. Copyright 2015 by AARP. Reprinted with permission.

Due to the value of unpaid caregivers’ services, the costs of implementing solutions to support them are small (Reinhard et al., 2015). For economic reasons alone, the caregiving sector establishes its importance and makes the case for the need of innovative solutions to offer relief to this sector.

### 3.2 Perspectives of the Informal Caregiver

The effects of demographic changes and chronic conditions, which translate into the substantial trend for older people to require on-going care, are significant for the governments and their health care systems. However, the consequences of the inadequate health care system for people that need on going have important

implications for caregivers. In order to understand the appropriate solutions for caregivers, it is important to first examine their challenges and different perspectives.

### 3.2.1 Caregiving Situation

Informal caregiving is a time-intensive role and typically a demanding role on a physical and emotional level (National Alliance for Caregiving, 2009). In order to understand how caregivers are affected by their role and their personal situation, a review of what their activity entails will be performed. Caregiving activities are characterized by the National Alliance of Caregiving (2009) in two categories: Activity of Daily Living (ADL) and Instrumental Activities of Daily Living (IADLs). **Tables 1** and **2** summarize caregiving tasks which fall into the two groups and their prevalence.

Table 1. Hours of help with Activities of Daily Living

| Help with Activities of Daily Living (ADLs)     |                 | Hours Caregiving per Week |             |
|---|-----------------|---------------------------|-------------|
|   |                 | 0-20 (n=826)              | 21+ (n=416) |
| Any ADL   | 59%             | 51%                       | 75%         |
| Getting in and out of beds and chairs           | 43%             | 36%                       | 59%         |
| Getting dressed                                 | 32%             | 22%                       | 51%         |
| Getting to and from the toilet                  | 27%             | 21%                       | 40%         |
| Bathing or showering                            | 26%             | 17%                       | 45%         |
| Feeding   | 23%             | 18%                       | 36%         |
| Dealing with incontinence or diapers            | 16%             | 9%                        | 31%         |
| <b>Most difficult individual ADLs</b>           |                 |                           |             |
| Dealing with incontinence or diapers            | 40% (difficult) |                           |             |
| Getting to and from the toilet                  | 33%             |                           |             |
| Bathing or showering                            | 31%             |                           |             |
| Base: Caregivers of Recipient Age 18+ (n=1,248) |                 |                           |             |

*Note.* Adapted from Caregiving in the U.S. 2015 – Focused Look at Caregivers of Adults Age 50+. Copyright 2015 by NAC and AARP. Reprinted with permission.

Table 2. Hours of Help with Instrumental Activities of Daily Living

| Help with Instrumental Activities of Daily Living (IADLs) |     | Hours Caregiving per Week |             |
|---|-----|---------------------------|-------------|
|   |     | 0-20 (n=826)              | 21+ (n=416) |
| Any IADL  | 99% | 99%                       | 100%        |
| Transportation  | 78% | 72%                       | 89%         |
| Grocery or other shopping                                 | 76% | 69%                       | 89%         |
| Housework   | 72% | 65%                       | 89%         |
| Preparing meals   | 61% | 49%                       | 86%         |
| Managing finances   | 54% | 47%                       | 67%         |
| Giving medications, pills, or injections                  | 46% | 34%                       | 71%         |
| Arranging outside services                                | 31% | 26%                       | 41%         |
| <b>Help with other Key Activities</b>                     |     |                           |             |
| Monitoring health of care recipient                       | 66% | 60%                       | 80%         |
| Communicating with health care professionals              | 63% | 56%                       | 80%         |
| Advocating with providers, services, agencies             | 50% | 45%                       | 61%         |
| Base: Caregivers of Recipient Age 18+ (n=1,248)           |     |                           |             |

*Note.* Adapted from Caregiving in the U.S. 2015 – Focused Look at Caregivers of Adults Age 50+. Copyright 2015 by NAC and AARP. Reprinted with permission.

Furthermore, the profile of informal caregivers has been documented by the National Alliance of Caregiving (2009) and the usual caregiver is a woman older than 49 years old on average with only 40% of them being male caregivers. Furthermore, 34% of caregivers provide care for two or more individuals. The majority of caregivers (86%) provide care for a relative and 36% of caregivers for a parent. In terms of care duration, caregivers have been providing care on average for 4.6 years, with one third for five years or more (National Alliance for Caregiving, 2009).

### 3.2.2 Chronic Illnesses and their Implications

The individuals affected by chronic illnesses worldwide is expected to rise as longevity is increasing (WHO, 2016). The current statistics by the World Health Organization (2015) show that NCDs deaths are at 35 million with the number of individuals afflicted increasing every year. As a result, the number of individuals requiring ongoing care is growing as well, with an estimate of 85% growth over the next years, in older adults affected by a chronic illness (Sautter et al., 2014).

There is evidence that suggests that the demands of caregiving are linked to the care recipient's disease severity, conversely another perspective among academics is that caregiver characteristics could be more essential than care recipient characteristics – such as social support, family engagement, help with activities etc. (Sautter et al., 2014).

However, as reports began to investigate the different needs and experiences caregivers face, it is important to understand how different types of chronic illness translate to a caregiving level, and which factors would require consideration when proposing technological solutions.

The profile of the care recipient is summarized by the National Alliance for Caregiving (2015) as follows: the predominant care recipient is 75 years old or more, with 28% of care recipients being between 50 to 74 years old. Moreover, regarding care recipient's main condition as identified by the caregiver, **Table 3** provides information as reported by the AARP (2015).

Table 3. Types of Care Recipient Conditions

| Types of Care Recipient Conditions                      |     | Hours Caregiving per Week |             |
|---|-----|---------------------------|-------------|
|   |     | 0-20 (n=826)              | 21+ (n=416) |
| Any of these  | 95% | 94%                       | 96%         |
| Long-term physical condition                            | 59% | 57%                       | 64%         |
| Short-term physical condition                           | 35% | 36%                       | 33%         |
| Memory problem  | 26% | 25%                       | 28%         |
| Emotional/mental health problems                        | 21% | 21%                       | 21%         |
| Behavioral issue  | 7%  | 5%                        | 9%          |
| Developmental/intellectual disorder, mental retardation | 4%  | 3%                        | 6%          |

Base: Caregivers of Recipient Age 18+ (n=1,248)

*Note.* Adapted from Caregiving in the U.S. 2015 – Focused Look at Caregivers of Adults Age 50+. Copyright 2015 by NAC and AARP. Reprinted with permission.

Although, illnesses such as Alzheimer or developmental/intellectual disorders are not reported as the main condition there are approximately 22% of care recipients affected by at least one of these conditions (The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute (AARP), 2015).

Moreover, Alzheimer, dementia and other mental illnesses are complex caregiving experiences due to three key factors: extended care duration (< 5 years), difficult care coordination (medical tasks, monitoring health condition and care coordination with health professionals) and higher levels of emotional and physical stress (The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute (AARP), 2015). Consequently, more complex caregiving situations require a higher number of hours of care as the caregiver performs multiple medical or nursing tasks besides the daily living responsibilities leading to higher emotional and physical stress (NAC & AARP, 2015). Likewise, caregivers of Parkinson patients have to deal with higher numbers of care as the disease progresses (NAC & AARP, 2015). Additionally, caregivers often experience social isolation and poor social support due to the higher hours of caregiving (Morley et al., 2012).

Another chronic disease of interest, cancer, has significantly benefited from medical advances over the past decade increasing the care continuum (Ward et al., 2014). However, it is an illness that requires very much sensitivity, emotional and physical support having a unique health caring environment (Advanced Breast Cancer International Consensus Conference, 2016). When caring for a cancer patient, the following themes predominate in caregiving burden: lack of training, difficult care coordination among health professionals, treatment monitoring, difficulty of daily care (instrumental and personal) and lack of emotional support (Rha, Park, Song, Lee, & Lee, 2015).

The challenges of each type of disease from a caregiver's perspective vary, as each patient experiences different the illness and has diverse health requirements. Nevertheless, there is evidence suggesting some commonalities throughout the care continuum regarding caregiver's quality of life. Caregivers have a lower risk of burn-out and cope better if: there is in place a social support system or a social network



(Galvin et al., 2016), if there are available resource to educate and inform them about the illness and respective course of treatment (Willison & Hode, 2003) and if the role of caregiving can be shared with other relative or friend (The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute, 2015). An opposing viewpoint is that social support “was directly and moderately strongly related to their measure of well-being, depression”, with burden and well-being being different concepts; well-being defined as self-assessed satisfaction “in seven essential areas of a caregiver’s life: health, finances, housing, partner, recreation, religion, and transportation” (Chappell & Reid, 2002). Nevertheless, is an academic consensus that predictors of burden and well-being overlap (Chappell & Reid, 2002).

### **3.2.3 Impact on Physical and Emotional Health of the Informal Caregiver**

Providing ongoing care to an individual affected by a chronic illness has been often referred to as having a “caregiver career” due to the dynamic process which caregiving entails (Raina et al., 2005). As a result of that, there is an extensive body of literature that documents the negative effects of caregivers’ burden. Caregiving burden is essentially defined as the “caregiver’s perceived responsibilities and associated limitations on self and family” (Canning, Harris, & Keueher, 1996).

Further, the caregiving burden is differentiated on three dimensions, which are generally used to measure the level of burden. Savundranayagam, Montgomery, & Kosloski (2010) identified the three dimensions as follows: relationship burden (i.e., deteriorations in the relationship), objective burden (i.e., those resulting from IADLS), and subjective burden (i.e., psychosocial consequences).

As opposed to individuals who don’t provide care, caregivers show signs of depression, high level of stress and overall an inferior quality of life (Chang, Zhang, Jeyagurunathan, Lau, & Sagayadevan, 2016).

Improvements in health care technologies have increased the lifespan of the care recipient, thus increasing the period of caregiving. Due to the prolonged period of caregiving, caregivers are more likely to experience distress and physical strain (Sakakibara, Kabayama, & Ito, 2015). In the Caregiving in the U.S. (2015) report the duration of caregiving has an average of 3.7 years for older care recipients and 5.7

for younger care recipients, and it is correlated with a caregiver’s emotional and physical health.

A recent report on caregiver’s physical and emotional strain has found that 1 out of 5 caregivers has to deal with a high level of physical strain, while 1 out of 4 faces a moderate level of physical strain (NAC & AARP, 2015). However, when considering demanding caregiving situations, such as higher-hour caregivers – defined as caregivers who provide a minimum of 21 hours a week (National Alliance for Caregiving, 2009), the effect on physical strain is significantly higher.

Different levels of physical and emotional strain are associated with the difficulties of different types of illnesses. When caregivers were asked about the difficulty of health care tasks and care coordination for main illnesses – i.e. emotional illnesses in young care recipients and age illnesses in old care recipients, the perceived difficulty and burden is reported to be higher (NAC & AARP, 2015). **Table 4** shows the associated burden of main illnesses.

Table 4. Main Problem or Illness by Burden Category

| Main Problem or Illness by Burden Category            | Low burden | Medium burden | High burden |
|---|------------|---------------|-------------|
|   | (n=670)    | (n=416)       | (n=487)     |
| <b>Greater Prevalence in Higher Burden Situations</b> |            |               |             |
| Alzheimer's, dementia, forgetfulness                  | 8%         | 12%           | 13%         |
| Broken bones  | 1%         | 3%            | 4%          |
| Cancer  | 5%         | 6%            | 10%         |
| <b>Greater Prevalence in Lower Burden Situations</b>  |            |               |             |
| Arthritis   | 5%         | 2%            | 2%          |
| Mental/emotional illness, depression                  | 9%         | 6%            | 5%          |
| Old age   | 16%        | 10%           | 6%          |
| Base: Caregivers of Recipient Age 18+ (n=1,248)       |            |               |             |

*Note.* Adapted from Caregiving in the U.S. 2009. Copyright 2015 by NAC and AARP. Reprinted with permission.

Some conditions are linked to a higher burden level for the caregiver, such as Alzheimer, broken bones and cancer, and other conditions: arthritis,

mental/emotional illness and old age are frequently connected to a lower burden level. An explanation for that could be that some illnesses require more supervision or a different level of skills (e.g. dementia) as the health of the care recipient can decline rapidly or the care recipient can develop other health issues due to the main illness (e.g. depression). Schulz & Sherwood (2008) found that patients with dementia for example, are not likely to express appreciation for the care received, a factor linked to negative effects on caregiver's physical health.

Moreover, according to Jarvis et. Al (2006), the caregiver stress was predicted by the concerns of caregiving and the perceived reactions to caregiving, rather than the tasks of caregiving. For example, the caregiver worries about the burden of taking care in a safely manner for the patient when he or she has not received any training or support in coping with their distress (Reinhard et al., 2015).

Furthermore, the normal tasks of providing care, such as driving their care recipient to a medical appointment, are not reported as an issue, but the challenge of disrupting their normal responsibilities – e.g. work schedule, proves to be the stress factor (Chang et al., 2016). As there is a lack of support systems that could help with such situations, the caregiver burden increases, leading to higher levels of emotional and physical strain (Chang et al., 2016).

Furthermore, the lack of social support systems for caregivers has been investigated by academics in relation to caregiver's health. The caregiver role can impair relationships and caregiving burden was linked to deteriorating social support, which can turn into negative consequences for caregiver's mental health (Crespo, Rita, Santos, & Cristina, 2015). While positive social support correlates with lower burden levels. (Schulz & Sherwood, 2008).

Several studies have documented the family engagement level or social support in the caregiving process as the more important mediators in the caregiver's burden and emotional stress (Khalaila & Cohen, 2016). Nonetheless, it is important to distinct between the quality of social support and a large network of support, as the perceived quality of social support can have a higher positive effect on burden levels (Kahn & Antonucci, 1980).

Moreover, there is evidence of positive aspects of caregiving, with informal caregivers noting that the experience gives them a purpose and the opportunity to develop new skills, as well as improving their relationships with the ones around them (Schulz & Sherwood, 2008).

### 3.3 Innovation in Caregiving Support

The number of individuals suffering from chronic diseases has increased 4% on the course of 5 years from 2001 to 2006 and the number is expected to continue to rise with more than 1% yearly through 2030 as the population ages (Anderson, 2010).

Consequently, health care expenditure increased significantly and there are not enough resources to provide ongoing care for the projected number of individuals that will require it (Anderson, 2010). Currently, the health care system is not prepared to address the numerous needs of patients with chronic illnesses, and it is reported that coordinating care for these patients is challenging and support systems are yet to be easily available (Anderson, 2010).

For economic and ethical reasons, it has become imperative for the industry to fund and implement solutions for caregivers and the care recipient. Due to the proliferation of wireless technology and its easy implementation, the health care industry has increasingly been driving innovation initiatives in the field with the hope that these technologies will decrease costs (management of CDs is estimated to account for 80% of growth in healthcare costs) (Whitney, Mlis, & Gleason, 2016). Moreover, these technologies have increased performance being able to deliver services in real-time and in remote areas (Whitney et al., 2016). Mobile health or mhealth is defined as “the use of mobile information and communication technologies to leverage health outcomes” (The Global mHealth Initiative, 2015).

Additionally, technology and mobile use is prevalent among caregivers, **Table 5** provides information about usage of electronic resource among caregivers.

Table 5. Use of Technology in Caregiving

| Use of Technology in Caregiving                |     |
|--|-----|
| Any technology 45%                             | 45% |
| An electronic organizer or calendar 24%        | 24% |
| An emergency response system, such as Lifeline | 12% |

|  |     |
|--|-----|
| Any device that electronically sends information to a doctor or care manager to help manage his/her health care, like a device that transmits blood sugar or blood pressure readings | 11% |
| An electronic sensor that can detect safety problems in the home and take steps to help, like when someone falls, wanders away, or leaves the stove on                               | 9%  |
| A website or computer software to keep track of his/her personal records   | 7%  |
| A text reader for individuals with low vision  | 3%  |
| Any other technology   | 3%  |
| Base: Caregivers of Recipient Age 18+ (n=1,480)  |     |

*Note.* Adapted from Caregiving in the U.S. 2009. Copyright 2015 by NAC and AARP. Reprinted with permission.

In order to understand the benefits of technology in the informal caregiving industry we need to look at what caregivers perceive as helpful.

UnitedHealthcare and The National Alliance of Caregiving (2011) reported that the most helpful technologies for informal caregivers are: “to deliver, monitor, track or coordinate their loved one’s medical care.” The reported benefits of using technology by UnitedHealthcare and The National Alliance of Caregiving (2011) are primarily to reduce hours spent caregiving, secondly to manage caregiving tasks more easily, thirdly to decrease the feeling of being unsuccessful and finally to decrease perceived stress. Additionally, The National Alliance for Caregiving (AARP Institute, 2015) highlights a series of needs which caregivers could use a technology relief from: planning and coordinating care, finding reliable information on their loved one’s condition and options, support with end of life decisions, digital inclusion for seniors and respite services or products.

Technology products or services dedicated to informal caregivers could potentially improve their quality of life and of their care recipient, making it easier for them to do more with less effort (Mehta & Nafus, 2016). However, to create and implement good technology solutions is still challenging, as there are a few existent solutions in the market and entrepreneurs or product developers lack user data for analysis (Mehta & Nafus, 2016). Nonetheless, The Atlas of Caregiving Pilot (2016) found that studying family caregiving with one measurement – i.e. electronically collected data might provide information that lacks depth as informal caregiving is a complex environment. To identify

helpful solutions a combination of analyses might be required: “technology can form one piece of the puzzle, while human analysis, particularly by the individual involved, can form the complementary piece used to make sense of the data collected” (Mehta & Nafus, 2016).

Moreover, *The Atlas of Caregiving Pilot* (2016) highlights some of the main challenges, product developers and entrepreneurs might face. For product developers, the study suggests that the traditional market research techniques are likely to be insufficient when identifying helpful product features, and combining analysis of big data with human analysis might be essential.

A further challenge is represented by the overall burden of caregiving, caregivers lacking availability to try new things and make the time to learn how to use them. Therefore, product designers and entrepreneurs need to consider coaching as a product feature and constantly educate caregivers on the usefulness of a product. Furthermore, easy to use products that don't add on the overall caregiving burden are crucial (Mehta & Nafus, 2016).

Deploying and developing these types of tools is critical for capturing data, even if they might fail in the market at first, they can provide new possibilities for products in the future as there is limited knowledge on what caregiving entails (Mehta & Nafus, 2016).

## 4. Case Study – The Weal Life

In this section a company overview will be provided alongside a detailed analysis of its main product. In addition a roadmap will be drafted in order to assess how different healthcare environments can be serviced.

### 4.1 Company Overview

Providing care for a loved one, be a spouse, a family member, or friend with a chronic or immobilizing health illness is becoming increasingly common nowadays as population ages and home care resources are more available (Reinhard et al., 2015). Without informal caregiving, the U.S. health & long-term services and supports (LTSS) systems would suffer enormously under the pressure of economic costs (Reinhard et al., 2015). In addition, informal caregiving is a burden on the caregiver's own needs and life, with 66% of caregiver missing on work responsibilities, 47% have financial struggles and 70% have experienced depression or emotional stress (NAC & AARP, 2015)

The Weal Life is a mhealth start-up based in San Francisco, USA which will launch its product - the mhealth application called The Weal Life in January 2017 aiming to address the overwhelming needs of the informal caregiving market.

#### **The Weal Life team**

The Weal Life team is composed of 5 individuals - as **Table 6** on the next page shows, based in San Francisco, United States of America. At this stage, the development phase, the company doesn't require other resources. However, it is expected to grow its operational structure after the product launch, when additional needs will need to be addressed (e.g. app maintenance, user support, marketing activities etc.).

Table 6. The Weal Life Team Structure

| <b>Team</b>     | <b>Role</b>   |
|-----------------|---|
| Keely Stevenson | CEO   |
| Josephine Lai   | Consultant: healthcare & policy sector                                |
| Jacob Waddles   | Consultant: technology development, product management                |
| Maria Sendra    | Consultant: law, emerging technology, private equity & global markets |
| Kyle Tsai-Simek | Product Design  |

*Note.* personal communication, October 26, 2016

### **The Weal Life Product**

The Weal Life seeks to address the needs of the informal caregiving market by leveraging mobile technology to offer support in coordinating care (from task execution to crowd sourced purchases for the care recipient) while providing a social support platform to connect caregivers. More specifically, The Weal Life is a mobile project management application which includes an actionable gift registry of on-demand services and products and a resource library.

The management tool helps unpaid caregivers in managing various tasks (transportation, shopping, nutrition or meal preparation, visits, information etc.) while involving other members to contribute to the care of loved ones (personal communication, October 30, 2016).

Therefore, the proposed mhealth solution of The Weal Life has 4 functions as follows:

1. A Management Tool
2. A Chat Function
3. A Gift Registry Tool
4. A Curated Library

The Weal Life aligns each function of the app to the following objectives:

1. to be the “go-to” app for caregivers to stay organized
2. to offer support emotionally by making the experience more joyful
3. to offer support with the financial strain by sharing purchases and costs
4. to make it easier for the caregiver and teammates to learn and find resources on the caregiving process



*Source: personal communication, October 26, 2016*

Another important characteristic of The Weal Life is the user profile, which requires the creation of a caregiving team; the user introduces other individuals who are involved or can be involved in care responsibilities such as: a life partner, a neighbor, a close friend etc. (personal communication, October 26, 2016)

### **The Weal Life Mission**

The Weal Life's summarizes its main goal as: "to stay true to our Joy Factor commitment and opportunities for "Caring Lightly"." (personal communication, October 26, 2016).

In the term of its mission The Weal Life describes it as "*We use technology to make it easier to care for one another, especially during a health crisis, aging or chronic illness. We value personal relationships by making the experience of caring for others less overwhelming, more collaborative and more meaningful & joyful.*" (personal communication, October 26, 2016).

### **The Weal Life Business Model**

The revenue model is based on affiliate marketing, in which each transaction facilitated for affiliate partners (e.g. Amazon, EBay etc.) from The Gift Registry tool earns a percentage for The Weal Life (personal communication, November 2, 2016).

The Weal Life revenue model centers on the premise that the needs of each caregiver situation will be identified and the affiliate links provided will answer to those needs, for caregivers to purchase "the solution" when necessary (personal communication, November 2, 2016).

This strategy is aligned with a good execution of an affiliate marketing program, as Hoffman (2016) argues that "content is created to inform, and then they monetize within it where possible." However, a potential downside of this model could be the substantial sales volume that Weal Life needs to facilitate in order to create a steady revenue stream.

Furthermore, the second source of revenue for The Weal Life is through future sponsorships that can provide appropriate brand association.

## 4.2 The Impact of The Weal Life on the Caregiver’s Quality of Life

There is an extensive body of research on informal caregiving, mostly on the following areas: caregiver characteristics, outcomes of the caregiving role (e.g. on caregiver’s emotional, physical, financial health) and caregiver’s resources, necessities and coping strategies.

However, to our understanding there are some research gaps to be filled on caregiver’s coping strategies- as to which type of approach is more effective in dealing with caregiving burden, and more recently which services or interventions are available and more suitable to offer support for the caregiver (Barbosa et al., 2011). Therefore, an analysis to identify sources that guide or inform on a caregiver’s journey and to understand to the best of our ability which are more effective seems suitable to fill the mentioned gap and help us to propose The Weal Life roadmap for guiding principles to improve a caregiver’s well-being.

### 4.2.1 Analysis of Sources that Guide a Caregiving Journey

We will research some of the evidence available to guide/inform the informal caregiving journey since it is suitable to anticipate guiding principles for our The Weal Life roadmap.

Firstly, the AARP report (American Association of Retired Persons, 2016) identified six areas of opportunities for caregiving innovation, as detailed in **Table 7**, describing caregiver and care recipient necessities, interests, and behaviors. From these six areas, three areas (highlighted in bold) are consistent with the objectives of The Weal Life and can be used as a main resource to guide our framework.

Table 7. Areas of Opportunity in the Caregiving Industry

| <b>Areas of Opportunity in the Caregiving Industry</b> | <b>Examples</b>                |
|--|--------------------------------|
| Daily Essential Activities                             | Meals, home and personal care, |

|                                      |   |
|--------------------------------------|---|
|                                      | home repair, delivery, transportation services  |
| <b>Health &amp; Safety Awareness</b> | Health vital alerts, diet and nutrition, medication management, personal safety monitoring, telehealth                                  |
| <b>Care Coordination</b>             | Care planning, care professional engagement, records and benefits management, recovery support  |
| <b>Caregiver Quality of Life</b>     | Respite and backup care, social support, health and wellness, financial/job security  |
| Social Well-Being                    | Digital inclusion, life enrichment and empowerment, community networking, life companions   |
| Transition Support                   | Home retrofit services, long-term care insurance planning, long-term care provider referral, legal assistance, hospice/funeral planning |

*Note.* Adapted from Caregiving Innovation Frontiers 2016. Copyright 2015 by AARP. Reprinted with permission.

In the first area of opportunity relevant to our framework, Health & Safety Awareness, are included: “Reminder apps, monitored pill boxes or pharmacy apps to manage medication timing and dosages, adherence, refill records and diet and nutrition apps or messaging tools.” (American Association of Retired Persons, 2016). Analyzing the existent competitors in the mentioned area and their respective solutions the following guidelines, Table 8, have been highlighted, considering also secondary research resources on caregiving guidelines:

Table 8. Analysis on Competitors and Suggested Guidelines: Health & Safety Awareness (source: author’s own based on several sources)

| <b>Guidelines</b>                              |   |
|--|---|
| <b>Health &amp; Safety Awareness Resources</b> | <b>Medication management Guidelines</b>               |
| Reminder Rosie                                 | - provide details or context about the purpose of the |

|  |  |
|--|--|
| <i>A smart device to record and program audio medication and appointment reminders in their own voice.</i> | reminder<br>- use of generic alarms can be frightening for sensitive patients (the use of a familiar voice can be an alternative)  |
| Droplet<br><i>Smart reminder</i>   | - team engagement (setup reminders with multiple people, configure reminder to the right team member)  |
| Mango Health<br><i>Managing medications and health habits</i>  | - include a reward system to incentivize healthy habits<br>- include information on drug interactions  |
|  | <b>Diet and nutrition Guidelines</b>   |
| Nutrition Tips for Caregivers Report   | - easy meal planning: providing information for what types of foods to prepare (diet requirements)<br>- meal ingredients checklist<br>- log water intake & hydration reminder<br>- monitoring for changes in amount and types of food eaten, or shifts in schedule (e.g. a reward system to log information and actionable alerts) |

*Note.* Retrieved from <http://www.reminder-rosie.com/>. Copyright 2013 by Reminder Rosie. Retrieved from <http://www.dropletlife.com/>. Copyright 2015 by Droplet Life. Retrieved from <https://www.mangohealth.com/>. Copyright 2016 by Mango Health. Adapted from Nutrition Tips for Caregivers 2013. Copyright 2013 By God’s Love We Deliver. Reprinted with permission.

In the second area of opportunity, Care Coordination, are included: “Planning, creating, reminding, coordinating, updating care tasks, reviewing, scheduling, communicating with doctors and hospital” (American Association of Retired Persons, 2016). Considering the existent solutions in the market the resulting guidelines, shown in Table 9, are considered:

Table 9. Analysis on Competitors and Suggested Guidelines: Care Coordination (source: author’s own based on several sources)

| <b>Guidelines</b>               |  |
|---------------------------------|--|
| <b>Care Coordination</b>        | <b>Care Planning Guidelines</b>  |
| Caresolver<br>A care management | - include customized (on care recipient profile) task-based care plans of clinical & non-clinical aspects of delivering care e.g “if a |

|  |   |
|--|---|
| platform for family caregivers   | senior has diabetes, send her to a podiatrist to check for foot ulcers" or "remove area throw rugs so seniors don't trip and fall"                          |
| Brain Aid<br>Mobile tool for independence and autonomy   | - recalculate scheduled tasks and routines when changes happen (e.g. push back groceries shopping to 4 o'clock)   |
| Care Monster<br>Care Coordination app  | - rotate caregiving responsibilities<br>- easy scheduling for visit plans   |
| Lotsa Helping Hands<br>A coordinated caregiving community with family and friends                            | - allow users to send encouragement messages and send updates<br>- allow other team members to volunteer for tasks  |
| Care connection<br>Website   | - include caregiving tips and hacks for ADLs  |
| <b>Transportation Guidelines</b>   |   |
| UberASSIST<br>Ridesharing service for special needs<br>Lift Hero<br>Transportation service for special needs | - integrate a booking tool to help with transportation tasks from services which are suitable for people with disabilities and educated about special needs |

*Note.* Retrieved from <https://angel.co/caresolver>. Copyright 2013 by Caresolver. Retrieved from <https://www.brainaid.com/>. Copyright 2010 by Brain Aid. Retrieved from <http://www.care.ly/>. Copyright 2016 by Carely. Retrieved from <http://lotsahelpinghands.com/>. Copyright 2015 by Lotsa Helping Hands, Inc. Retrieved from <https://careconnection.aarp.org/>. Copyright 2016 by AARP. Retrieved from <http://ubermovement.com/uberassist/>. Copyright 2016 by Uber Technologies. Retrieved from <https://www.lifthero.com/>. Copyright 2012 by Lift Hero.

Thirdly, Caregiver Quality of Life, focuses on: “Caregiver support groups, social networks, knowledge-sharing platforms, Wellness programs, DIY tools, Personal budgeting/financial planning, work-life balance programs”. Analyzing the existent solutions in the Caregiver Quality of Life market the following guiding principles have been considered:

Table 10. Analysis and Suggested Guidelines: Caregiver Quality of Life (source: author’s own analysis)

| <b>Guidelines</b>                |   |
|----------------------------------|---|
| <b>Caregiver Quality of Life</b> | <b>Social Support</b>   |
| Team Engagement                  | - create or include an option to join a support group with similar caregivers, who can provide insights and can offer encouragement   |
|                                  | - calculate or track how much time is dedicate to caregiving in order to assess how much time is needed from other individuals to assist  |
|                                  | - asses who else from caregiver's close friends or family can be involved in the support group (invite friends, family member, neighbors to the app and add members to the team etc.) |
|                                  | <b>Health and Wellness</b>  |
| Reliving stress                  | - build caregiver's knowledge and team's awareness by providing informing articles on care recipient illness and techniques to manage the disease                                     |
| Prevent                          | - caregiver checklist for burden levels: Zarit Burden Interview   |
| Building Resilience              | - alert to include time for self-care (block time in the calendar tool)   |
|                                  | - include meditation material or games to help relax  |
|                                  | <b>Financial Security</b>   |
| Planning                         | - inform on future products needed for each illness   |
|                                  | - offer tool for fundraising events inside the team to help with the purchase of certain products   |
|                                  | - offer price comparison among different providers (e.g. Amazon Home, Ebay etc.)  |

Moreover, other guidelines were considered as shown below in **Table 11**, from the Atlas of Caregiving Pilot Study Report (2016) which advances implications for product designers and entrepreneurs based on their study pilot findings on caregivers.

Table 11. Implications for Product Developers and Entrepreneurs

| Implications for Product Developers and Entrepreneurs |   |  |   |
|---|---|--|---|
|   | The Problem   | The Solution   | Considerations  |
| Caregiver's lack of time                              | "Caregivers need confidence that someone will be right there with them to make things easy, and assurance that a product will not make life even more complicated than it already is." (FCA, 2016)  | need help to research, assess, buy, and learn about valuable caregiving products, resources and services | product developers need to consider educating and supporting the users as a critical part of the product.   |
| Trackers & Data Insights                              | "Many participants found it interesting to learn just how much they did, and to discover things they were unaware of."<br>"In some instances, participants can take the opportunity to rethink some aspects of their situation."<br>(FCA, 2016) | create a log tool and allow data visualization to users  | product developers need to consider easy to use design and to consider inconsistent usage, with the user stopping to use the tool and returning to it at a later time |

*Note.* Adapted from Atlas of Caregiving Pilot Study Report 2016. Copyright 2016 by Family Caregiver Alliance. Reprinted with permission.

It is important to mention that all solutions which included paid caregiving services were not taken into account for the purpose of our study which refers to informal caregiving.

#### 4.2.2 Triangulating the Sources for The Weal Life Holistic Guidelines

Furthermore, after understanding key factors that could be considered for The Weal Life mobile application, an illustration of how these guidelines fit into each function of the mobile application will be performed. The mapping of these guidelines will then be applied to two caregiving stories, in order to better understand how The Weal Life app can have an impact on caregiving responsibilities.

Firstly, the management tool function of The Weal Life app offers a management & scheduling tool which aims to develop in future versions of the app into a smart task management tool – using predictive modeling (analyzing anonymous data across all users and the user’s personal pattern) to plan tasks for days ahead, to suggest tasks, to recommend optimal scheduling times (task urgency, weekdays vs. weekends etc.), track goals. The recommended features are shown in the figure below.

**Figure 1. The Weal Life management & scheduling tool: Guidelines** (source: author’s own analysis from Table 8-11 and personal communication, November 9, 2016)

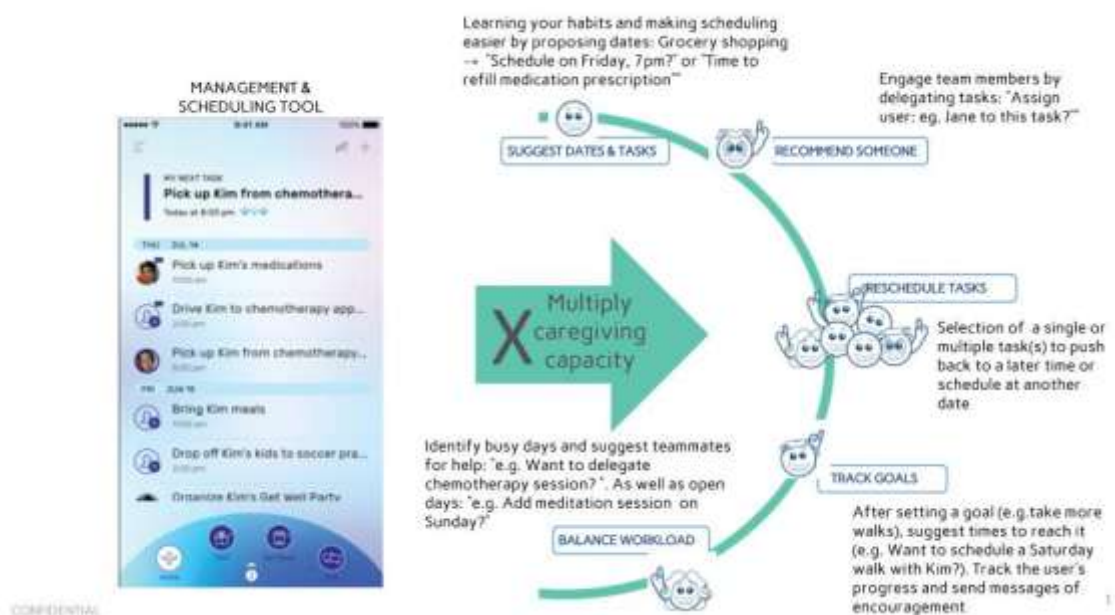


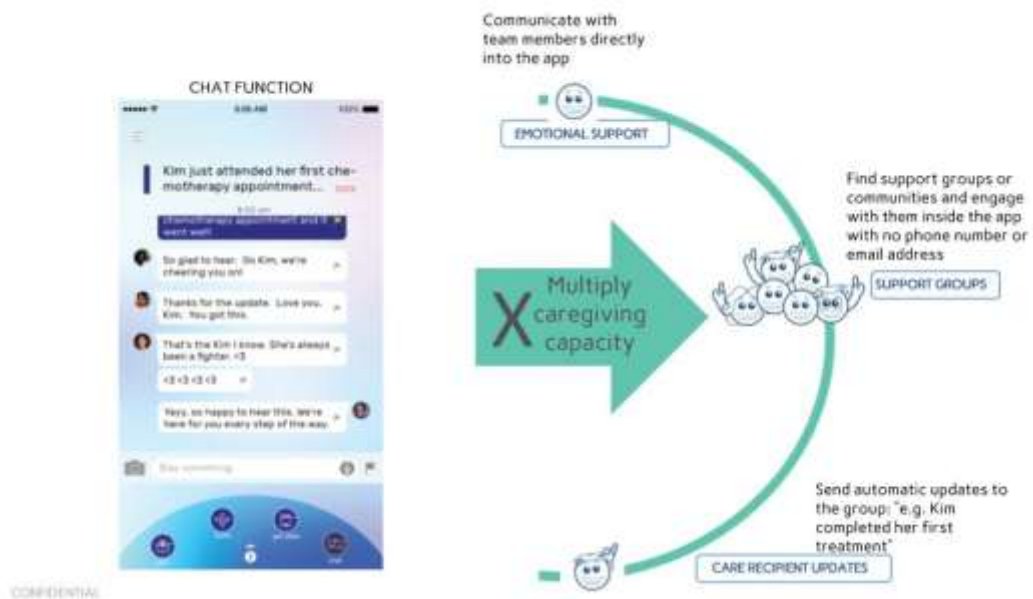
Image source: print screen from The Weal Life beta mobile application

1. Suggest dates & tasks
2. Recommend help
3. Reschedule tasks
4. Track goals
5. Balance workload

Secondly, The Chat function aims to connect the team members with each other, without the usage of a phone number or email address, communication being done privately inside the app. Moreover, the chat tool allows sending quick updates regarding the care recipient’s recovery journey with the help of universal messages, e.g. “Sending best wishes”, “First chemotherapy completed.” etc.



**Figure 2. The Weal Life chat tool: Guidelines** (source: author's own analysis from Table 8-11 and personal communication, November 16, 2016)

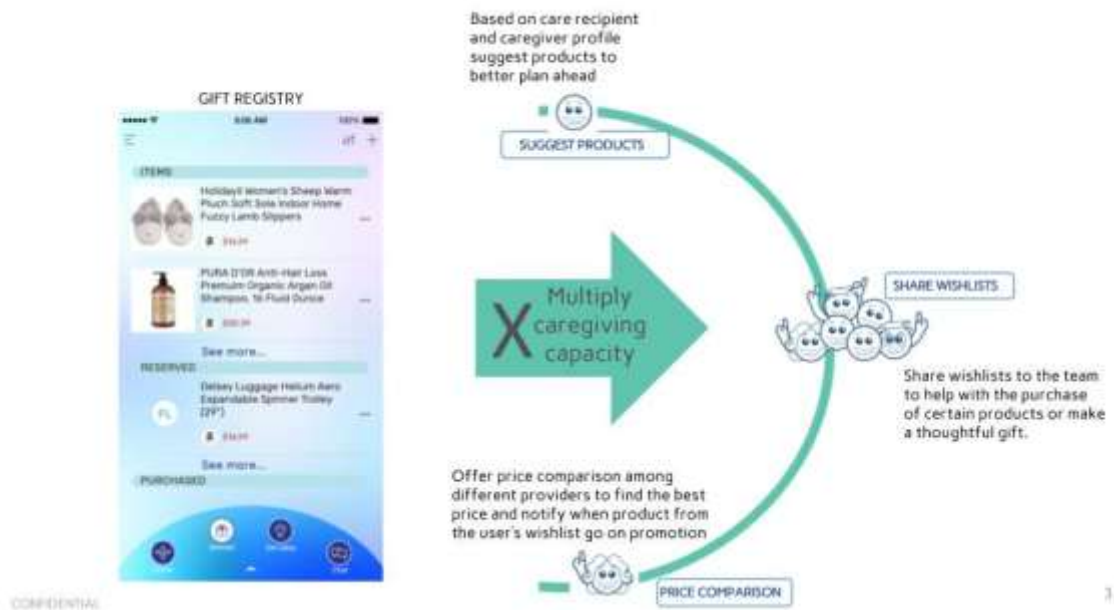


*Image source:* print screen from The Weal Life beta mobile application

1. Emotional support
2. Support groups
3. Care recipient updates

Thirdly, the Gift Registry function, Figure 3 on the next page, aims to help with the financial strain experienced by caregivers, offering a tool to share costs by creating wish lists which team members can view and choose to gift a product in order to offer their help with the caregiving process.

**Figure 3. The Weal Life gift registry: Guidelines** (source: author’s own analysis from Table 8-11 and personal communication, November 23, 2016)



*Image source:* print screen from The Weal Life beta mobile application

Finally, The Curated Library’s purpose is to help caregivers easily find resources and valuable information, in order for them to cope better with the feeling of distress, respectively when feeling unprepared or uncertain about what an illness entails. Furthermore, the library wants to act as “joyful factor” for caregivers, including articles about personal care and ideas of activities to do for and with your ill loved one.

**Figure 4. The Weal Life curated library: Guidelines** (source: author's own analysis from Table 8-11 and personal communication, November 30, 2016)

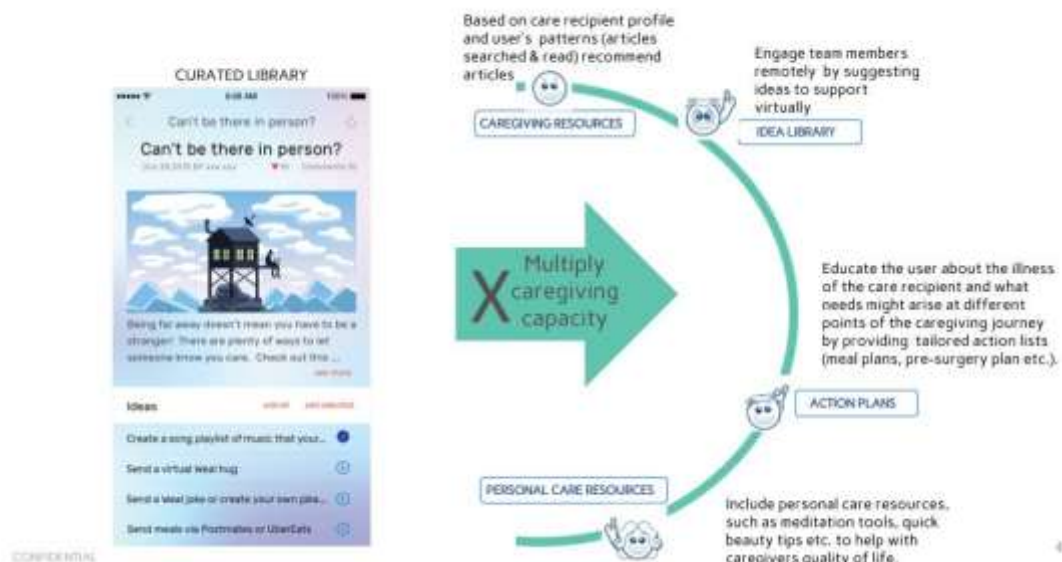


Image source: print screen from The Weal Life beta mobile application

1. Caregiving resources
2. Idea Library
3. Action Plans
4. Personal care resources

### 4.2.3 Mapping out The Weal Life framework for two caregiving stories

In this section The Weal Life framework will be applied to two specific caregiving journeys, breast cancer treatment and Parkinson respectively, in order to exemplify the main needs that The Weal Life can address.

#### 4.2.3.1 Odette and Marco

#### **Odette and Marco case: Adapted from The Atlas of Caregiving Pilot Report (2016)**

Odette is a 70-year-old woman who cares for her 70-year-old husband, Marco, who suffers from Parkinson, Lewy Body Dementia and Type 1 Diabetes. Although Odette is the primary caregiver for her husband, her caregiving philosophy

is that she should seek support for everyday caregiving responsibilities with paid or unpaid aid as often as possible.

She has responsibility for 24/7 care for her husband, as Marco struggles with mobility, strength and minor cognitive problems caused by his main illness, Parkinson. Moreover, due to his secondary disease, Type 1 Diabetes he requires special meal preparation. As a result of that, Odette has responsibility for the meal preparation, ADLs activities (bathing, dressing etc.), financial management, and accompanying Marco to various doctor appointments, including scheduling weekly massage therapy sessions.

Both, Odette and Marco, retired from their careers, in government and as a clergyman respectively. In order to cope with their financial strain, Odette and Marco share their home with paying tenants.

Support for caregiving responsibilities is provided by two home care aids, one provides daily support and weekly correspondingly, and one of the tenants, a friend of Marco's, helps Odette twice per week to look after her husband in the afternoon.

Odette and Marco also share their home with their son and son-in-law, while their daughter lives less than 20 minutes away. Their children offer support occasionally and weekly, respectively.

In addition, to their care network, The Atlas of Caregiving Pilot (2016) informs on Odette's time spent on caregiving activities over a 36 hour period, as detailed in **Exhibit 5**. Odette's 36-hour Log shows that she is most engaged in coordinating health care professionals (90 minutes), scheduling visits to health care professionals including transportation (45 minutes and 90 minutes) and managing medical activities for her husband at home (42 minutes).

Moreover, Odette's needs include emotional support and to relieve the pressure of feeling always "on call for problems" (Mehta & Nafus, 2016). Potentially relevant information for The Weal Life contribution to Odette's caregiving environment could also be represented by the fact that Odette could improve Marco's care by engaging him in small daily activities: "Odette was surprised to note how often she had helped Marco to use the bathroom. She wondered whether the frequency of his trips was a symptom of boredom, and if he might take fewer bathroom breaks if he had more engaging activities."

Odette’s main identified needs are: coordinating care for Marco, scheduling tasks and visits, decreasing her own emotional/physical stress, finding trusted medical and non-medical information for Marco. Therefore, Odette’s caregiving responsibilities may benefit from three of The Weal Life’s main functions: The Management & Scheduling Tool, Chat Tool and The Curated Library.

Firstly, The Management & Scheduling Tool, **Exhibit 1**, could provide support in handling multiple tasks and visits which Odette has to organize. Secondly, The Chat function, **Exhibit 2**, could help with emotional support and lead to reflection on which members of Odette and Marco’s care team could be available for reach when unexpected changes happen with Marco. For example, the team feature of The Weal Life can offer a clear representation of each person involved and their availability e.g. syncing calendars or providing idea of who to help even from distance i.e. recommending the daughter to schedule doctor appointments, i.e. **Exhibit 1**, second feature. Odette can also benefit from sending notifications in real time regarding Marco’s progress and plan for assistance directly inside the app.

Finally, The Curated Library feature, **Exhibit 4**, can directly support with activities ideas –i.e. Idea Library, tailored to Marco’s illness. A detailed example of how The Curated Library can support is shown in **Table 12**.

Table 12. Exemplification of Get Ideas Features for Marco & His Team (source: author’s own based on several sources)

| <b>Ideas Library Examples</b> | <b>Parkinson Care Recipient</b>   | <b>Sources</b>  |
|-------------------------------|---|---|
|                               | "Help your loved one practice their brain power. Try the Lumosity app. Find out more here." | Games for people who have Parkinson's Disease. Retrieved from <a href="http://www.agingcare.com">www.agingcare.com</a> . Copyright 2016 by AgingCare  |
|                               | "Take your loved one for a spin. Buy here dancing lessons DVDs or find a                    | Family Activity Ideas for People with Parkinson's Disease. Retrieved from <a href="https://www.michaeljfox.org">https://www.michaeljfox.org</a> . Copyright 2000 by The Michael J. Fox Foundation |

|   |   |
|---|---|
| class near you."  |   |
| "Gift your loved one a Tangle. Don't know what a Tangle is? Find out more." | Games for people who have Parkinson's Disease. Retrieved from <a href="http://www.agingcare.com">www.agingcare.com</a> . Copyright 2016 by AgingCare  |
| "Create a music playlist for your loved one."                               | Music helps mood and movement in Parkinson's patients. Retrieved from <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4553388/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4553388/</a> . Copyright 2015 by Raglio. |

However, an important limitation has to be considered: Odette’s resistance to adopt technology. Odette might struggle to use technology (not easy to use or time consuming) or perceive it as an extra task which adds to her burden.

Additionally, Odette might not realize the need for such a tool, before actually experiencing it. In this case, a solution could be represented by an educational feature that could come with the product, in order to exemplify how to use it and provide technological support when needed.

Moreover, to address the barrier of adoption, a mobile based solution such as The Weal Life could benefit from endorsements of healthcare professionals, which could present the product to caregivers and inform on its benefits.

#### *4.2.3.2 Emma and Kim*

##### **Emma and Kim case. Adapted from The Weal Life, internal documents (2016)**

Emma is a 39-year-old woman who is providing care for her sister, Kim, diagnosed with cancer. Emma is the primary caregiver for Kim, with Kim’s husband offering his support and facilitating some of the caregiving duties as well.

The care network of Kim’s includes her parents: Daichi and Rosalind and three friends who offer basic support, as detailed in **Exhibit 6**. All Kim’s primary caregivers, including Kim have demanding careers, which take a lot of time off and as a result increases the difficulty of managing caregiving tasks.

In addition, Emma reports that she has an unpredictable schedule, which includes traveling and taking care of her two kids. Emma is looking forward to help

her sister get through her cancer treatment to the best of her ability with her caregiving philosophy being: “to bring people together for fantastic results.” (personal communication, December 7, 2016). Therefore, Emma makes use of a large support network of family and local friends. However, she is careful not to impose too much on any person.

Emma’s main needs as described by her include: to organize and manage tasks easily and learn about Kim’s healthcare needs. Another important characteristic of Emma’s preferences is that she enjoys using technology to ease her day-to-day responsibilities.

Therefore, Emma’s caregiving responsibilities may mainly benefit from two of The Weal Life’s main functions: The Management & Scheduling Tool and The Curated Library.

Firstly, The Management & Scheduling Tool, **Exhibit 1**, directly addresses Emma’s need to organize her day to day life with respect to Kim’s condition. Secondly, The Curated Library, **Exhibit 4**, can offer tailored resources which Emma can explore to better understand the disease and its complexities. A lot of information is available from many stakeholders at the news of a chronic illness: healthcare professionals; internet etc. making it difficult for care recipients and caregivers to understand all of the information and to relevant information as well.

The Weal Life can help curate action plans; recommend tools and resources that may be helpful to plan for the future, and reach individual or team goals in respect to the healthcare environment, i.e. Kim’s cancer. **Table 13** shows an exemplification of possible resources tailored to Kim and Emma’s cancer treatment journey.

Table 13. Exemplification of Curated Library features for Kim & Her Team (source: author’s own based on several sources)

|                                 | <b>Cancer Care Recipient</b> |                                  | <b>Sources</b>  |
|---------------------------------|------------------------------|----------------------------------|---|
| <b>Curated Library Examples</b> | Side effects                 | "What to eat to improve anemia?" | Relieving Side Effects of Breast Cancer Treatment. Retrieved from <a href="http://sharing.mayoclinic.org/">http://sharing.mayoclinic.org/</a> . Copyright 2016 by Sharing Mayo Clinic |
|                                 |                              | "How to manage lymphedema."      | Relieving Side Effects of Breast Cancer Treatment. Retrieved from   |

|  |              |  |   |
|--|--------------|--|---|
|  |              |  | <a href="http://sharing.mayoclinic.org/">http://sharing.mayoclinic.org/</a> . Copyright 2016 by Sharing Mayo Clinic   |
|  |              | "Signs your loved one is depressed"  | Relieving Side Effects of Breast Cancer Treatment. Retrieved from <a href="http://sharing.mayoclinic.org/">http://sharing.mayoclinic.org/</a> . Copyright 2016 by Sharing Mayo Clinic |
|  | Treatment    | "A gene expression profiling test might help planning cancer treatment. What is it?" | Relieving Side Effects of Breast Cancer Treatment. Retrieved from <a href="http://sharing.mayoclinic.org/">http://sharing.mayoclinic.org/</a> . Copyright 2016 by Sharing Mayo Clinic |
|  |              | "Confused about what to ask your doctor? Try these questions first."                 | Preparing for your appointment Retrieved from <a href="http://sharing.mayoclinic.org/">http://sharing.mayoclinic.org/</a> . Copyright 2016 by Sharing Mayo Clinic                     |
|  |              | "Understanding operations available for breast cancer treatment"                     | Breast Cancer Treatment. Retrieved from <a href="http://sharing.mayoclinic.org/">http://sharing.mayoclinic.org/</a> . Copyright 2016 by Sharing Mayo Clinic                           |
|  | Action Plans | Prepare a Treatment Bag checklist  | Prepare a Treatment Bag. Retrieved from <a href="https://www.livestrong.org">https://www.livestrong.org</a> . Copyright 2015 by Livestrong  |
|  |              | Prepare for Treatment with us (1 week plan)  | Prepare for Treatment. Retrieved from <a href="https://www.livestrong.org">https://www.livestrong.org</a> . Copyright 2015 by Livestrong  |
|  |              | Eat healthy (4 week plan)  | Author  |

In addition, the care team feature as mentioned in Odette and Marco case can help visualize which people from the care recipient circle can provide help, how fast or when. Furthermore, some of Kim’s supporters remarked: “He wants to help but not have too much of a presence.”, “She wants to stay on the peripheral of the situation; doesn't want to get too involved.” (personal communication, December 7, 2016).

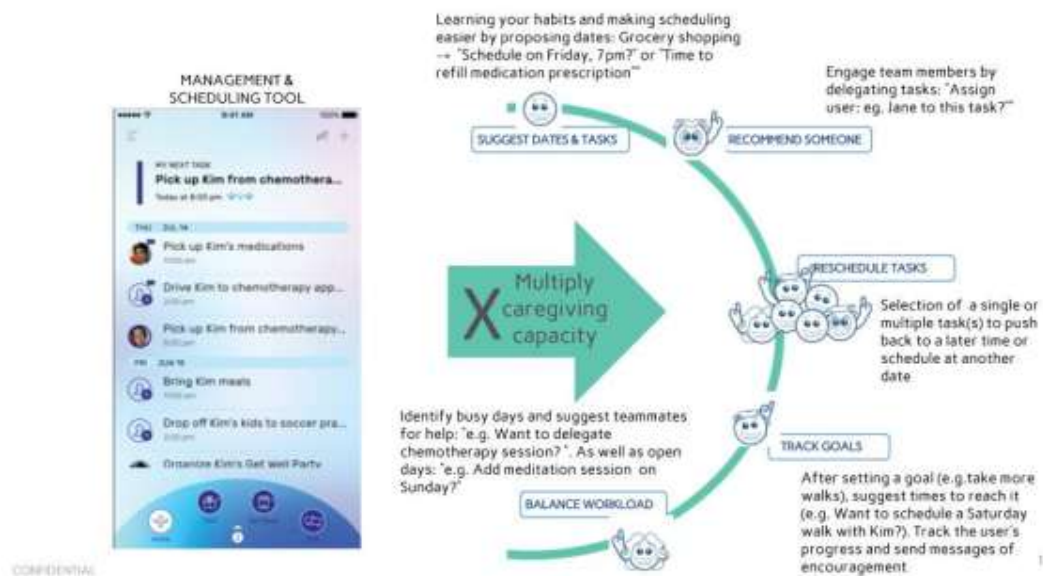
Therefore, The Gift Registry function, **Exhibit 3**, could represent an opportunity for Emma to activate Kim’s support network for help, without requiring too much effort from their part – i.e. gifting an item useful for Kim from distance can be a valuable aid, without requiring presence from the supporter. For example, an



organic skin care package bought from Kim's or Emma's Gift Registry wish list – as dry skin can be a side effect of chemotherapy (Pruthi, 2016).

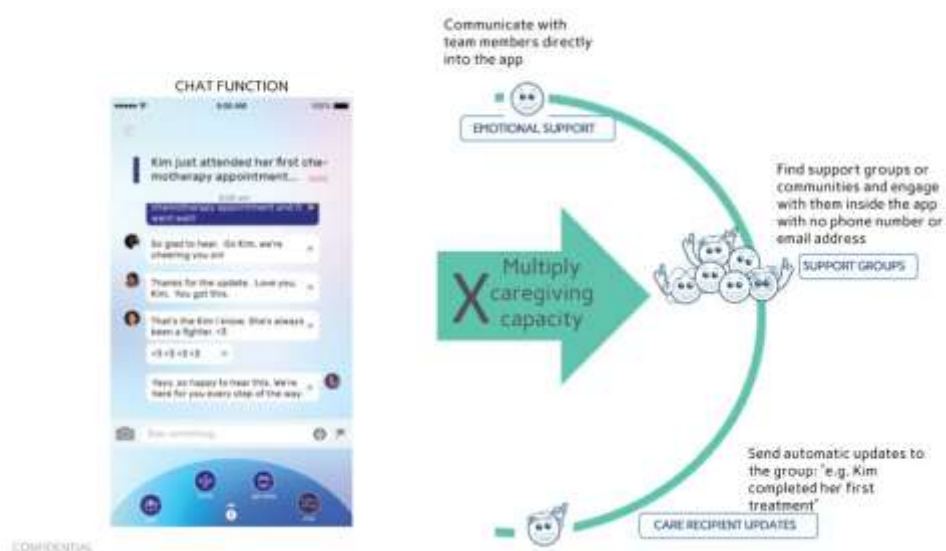
## Exhibits

Exhibit 1 – The Weal Life Management & Scheduling tool



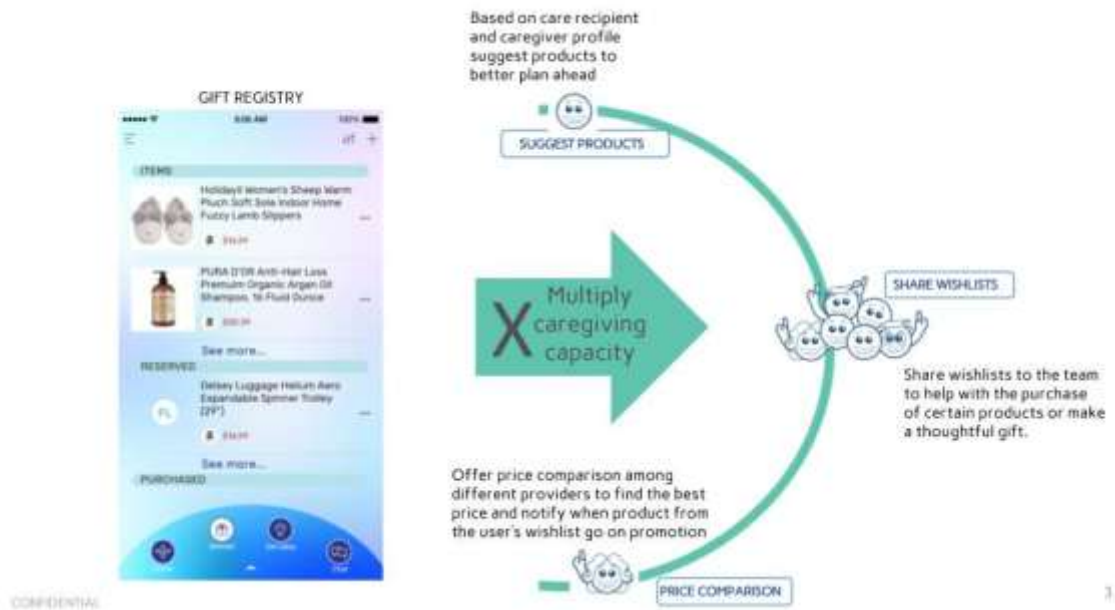
Source: author's own analysis from Table 8-11 and personal communication, November 9, 2016

Exhibit 2 – The Weal Life Chat Tool



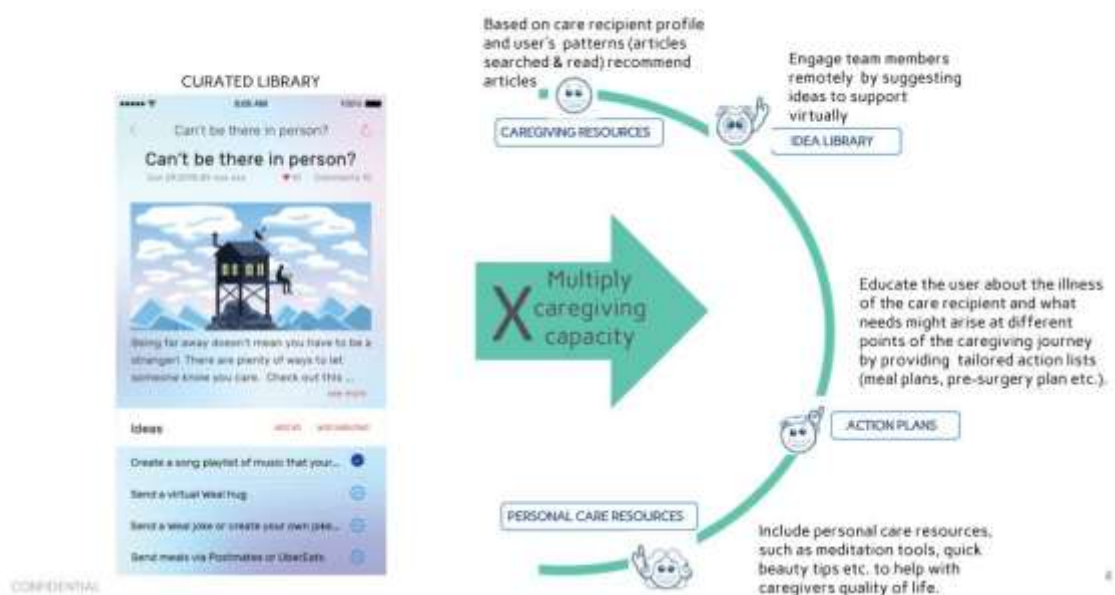
Source: author's own analysis from Table 8-11 and personal communication, November 16, 2016

### Exhibit 3 – The Weal Life Gift Registry



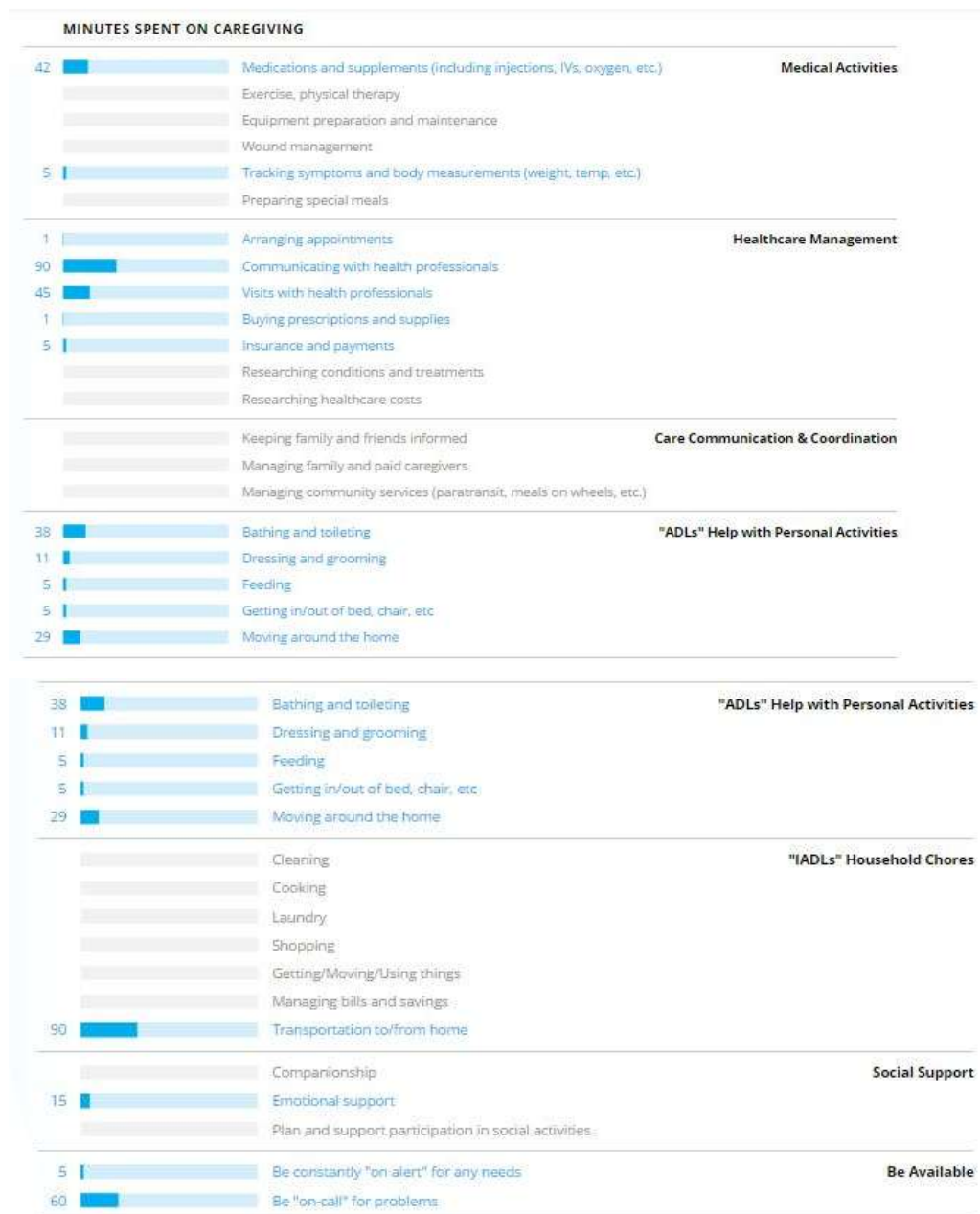
Source: author's own analysis from Table 8-11 and personal communication, November 23, 2016

### Exhibit 4 – The Weal Life Curated Library



Source: author's own analysis from Table 8-11 and personal communication, November 30, 2016

## Exhibit 5 – Odette’s Caregiving Activities (36-hour Log)



Source: Atlas of Caregiving Pilot Study Report 2016

## Exhibit 6 – Kim’s Support Network



Source: *The Weal Life* internal documentation 2015

## 5. Teaching Notes

### 5.1 Learning Objectives

This case study aims to help students learn about the caregiving industry, its challenges and areas of opportunity for innovation from an informal caregiver's perspective. Moreover, students attending innovation and entrepreneurship courses can become familiar with a mhealth solution for caregivers, The Weal Life, and learn relevant factors to be considered when building a technology solution for informal caregivers.

The proposed learning objectives of this case are:

- To give students awareness about the importance of the caregiving industry: economic value, social impact etc.
- To make students understand the main health outcomes of an informal caregiver: burden, physical/emotional health etc.
- To explore implications of caregiver's needs for entrepreneurs and how certain approaches of technology development can answer those needs.
- To understand The Weal Life's primary mission and motivation.
- To highlight an example of a solution deployed in this area, The Weal Life, including the connection between the wants and needs of two unpaid caregivers and The Weal Life's applicability to these stories.
- To advance brainstorming about opportunities for joining the caregiving marketplace.

### 5.2 Suggested Teaching Methods

In order to use the case study as a teaching method, four teaching questions were developed to support a brainstorming session and a discussion on the Caregiving Industry and the mhealth start-up, The Weal Life. The following Teaching Questions (TQs) are recommended, but not exclusive:

**TQ1.** What are the main areas of opportunity for caregiving innovation that you can identify, according to AARP (2016)?

**TQ2.** What are the main challenges and implications for entrepreneurs or product developers of the Caregiving Market?

**TQ3.** How can a mobile management solution improve a caregiver's psychosocial well-being to manage day-to-day treatment and better cope with the emotional and physical stress? Consider the case of The Weal Life. Draw future lessons.

**TQ4.** Which are the key factors that a mobile caregiving support tool can consider in order to provide an individualized approach, tailored to meet individual healthcare environments?

Students should firstly understand the case study all through their own reading and reflection. They are expected to know the scope of the caregiving industry, main challenges and caregiver's perspective before exploring in the classroom the case study and TQs.

The professor could take an active learning approach by creating groups of 5-6 students to brainstorm on their perception of the caregiving industry and The Weal Life proposed solution. The professor would guide the brainstorming session with the help of the Teaching Questions and objectives so that at the end of the class each team could share its own insights on key features for a mobile technology solution such as The Weal Life in the informal caregiving industry.

### **5.3 Teaching Questions and Discussion**

The following answers aim to act as a guide for the Teaching Question discussion in order to explore this case study:

**TQ1.** What are the main areas of opportunity for caregiving innovation that you can identify, according to AARP (2016)?

In this teaching question, the answer can be found in the 3.1.2 sub-chapter of The Caregiving Sector. As the National Alliance for Caregiving (2016) reports the main areas of opportunity identified from "the needs, wants, and challenges of unpaid caregivers, from the caregivers' perspective", offering entrepreneurs or investors a clear guide on market segments of the caregiving industry. The AARP (2016) defines the six areas of opportunity for technology solutions as: Caregiver

Quality of Life, Social Well-Being, Transition Support, Care Coordination, Health and Safety Awareness and Daily Essential Activities.

Then, the students should brainstorm other types of areas that have not been considered, but could be relevant. For example, The Atlas of Caregiving Pilot (2016) advises on other type of consumer challenges, such as sleep deprivation (caregivers are especially affected due to a high level of burden), which could open the possibility for product sellers to directly target caregiving as an individual segment for their products.

**TQ2.** What are the main challenges and implications for entrepreneurs or product developers of the Caregiving Market?

The main challenges and implications can be drawn from the Perspectives of the Caregiver chapter as well as Innovation in Caregiving. Firstly, students need to understand the main challenges faced by a caregiving situation in order to understand the challenges in deploying technology solutions for them.

Then, students should be able to identify and discuss the following implications and challenges for product developers and entrepreneurs according to Mehta & Nafus (2016):

- Developing a tailored solution, may not be beneficial for the caregiver if it makes the caregiving process overall more demanding, even if improving a specific task.
- Developing and correcting rapidly features as the product is in use is crucial - caregiving situations are highly unpredictable situations
- Continuous usage might prove problematic; entrepreneurs and product developers should focus on developing constantly great solutions even if for temporary use, as caregivers experience frequent, often drastic changes over the course of a treatment.
- Caregivers might lack the availability to research, try, buy, learn, and repair potentially useful caregiving products- educating them might be fundamental in implementing a technology solution.

**TQ3.** How can a mobile management solution improve a caregiver's psychosocial well-being to manage day-to-day treatment and better cope with the emotional and physical stress? Consider the case of The Weal Life. Draw future lessons.

In this case, the professor should start by asserting that there has yet to be proven how a mobile management solution such as The Weal Life can improve a caregiver's psychosocial well-being. The health outcomes of the mhealth intervention tool can represent a future research for students interested in this topic.

The beta version of The Weal Life mobile application will be implemented in January 2017, following the launch, valuable user data will be collected which could be used to measure the health outcomes in a future study. But students should be able in the classroom to use the illustrated caregiving stories of Odette & Marco and Kim & Emma (see Table 12 and 13) from the case study to lead a debate on how a mobile based intervention can ease the burden of caregiving.

Below are highlighted some important guidelines to be considered when discussing the stories:

- Being by identifying who are the main players involved in each of the stories (primary caregiver, secondary etc.).
- Consider the implication of the care recipient's illness (students should already be familiar, after carefully reading the case, about chronic illnesses and their characteristics in relation to caregiving).
- Identify main needs of the primary caregiver and their preferences
- Discuss how each need could be answered by The Weal Life features (main challenges and implications).

**TQ4.** Which are the key factors that a mobile caregiving support tool can consider in order to provide an individualized approach, tailored to meet individual healthcare environments?

In this question the professor could start by focusing the discussion on the information provided in the 3.3 Innovation in Caregiving Support chapter, where the main needs of unpaid caregivers are detailed, as well as the expected benefits for usage of technology solutions. To understand caregiver's needs and wants is a



critical step towards proposing technology solutions and specifically to understand which key factors can be considered to create a useful product in this market (easy-to-use, a coaching feature etc.). However, according to Mehta & Nafus (2016) given the unique environment of an unpaid caregiver a qualitative analysis is not enough to identify which factors are relevant for them. Authors Mehta & Nafus (2016) suggest as starting point, a combination of research methods which should include in particular a simple yet effective: human analysis, where the entrepreneur or product developer tries to make sense of the data collected directly asking the user.

Afterwards, the professor can move on to the case study, where The Weal Life features are presented alongside an analysis of solutions already present in the market which can offer clues as to what are those product features which informal caregivers value. Moreover, students would already be familiar with the caregiving stories presented and should be able to draw parallels between the unique characteristics of each case and how each illness (the healthcare environment) entails different needs.

## 6. Conclusions and Future Recommendations

The case study highlights the prevalence of unpaid caregivers as the number of individuals affected by one or multiple chronic conditions increases, alongside the steadily increase of associated healthcare costs. There has been a significant evolution in terms of individuals caring for a loved one, emerging as an industry on its own, yet there have not been created many solutions to support them. Henceforth, a better understanding of what caregiving entails is needed, in order to develop practical solutions that can ease the burden of caregivers.

The Weal Life mission aligns with the informal caregivers' needs as it aims to develop a mobile technology solution to help manage and plan caregiving responsibilities more effectively and make the overall experience more joyful. The San Francisco based start-up has been developing their beta version through primary research on caregiving stories and secondary resources.

The main research question was to try to understand how a mobile based intervention can improve a caregiver's well-being, as well as which key factors The Weal Life can consider in order to tailor to each caregiver's unique healthcare environment.

The research revealed that in order to improve a caregiver's well-being is important to look in detail at their needs and create solutions which adapt rapidly. Even if complex and varied situations exist: different illness, different support networks etc. there are a set of challenges or pain points which every caregivers faces at a certain time in the care process, which opens the possibility of a comprehensive mhealth solution. Developing a useful tool for caregivers should help with the caregiving burden without imposing more cognitive or physical effort. In terms of the key factors to be considered, some actionable insights have been captured: care management feature, compiled trusted resources, social engagement feature and a financial aid feature, from the particular case of The Weal Life.

However, the research only begins to identify some important characteristics and expanded research efforts have to be deployed in order to develop powerful tools.

Therefore, some limitations of the case study have to be considered. Firstly, the approach to use a case study as a researching method, more specifically a case study on a single mhealth solution for caregivers, The Weal Life, can condition the conclusions reached to the company's context and data provided. In addition, the use of only two stories in analyzing different needs as subject to different chronic illnesses might as well limit the conclusions drawn. Having more than two stories could provide a more comprehensive look at the reality of different caregiving environments. Nevertheless, the use of more stories entailed the use of a more quantitative method of analysis, in order to subtract the necessary conclusions.

Moreover, a single case study might not be a representative sample for mhealth solutions for caregivers as a whole. However, given the novelty of mhealth solutions in this particular industry, the conclusions reached could prove to be a useful tool for future researchers to investigate further upon. Secondly, the case study was developed making use of information provided by The Weal Life, personal communication with The Weal Life and secondary data available from The Weal Life, as a result, the lack of quantitative data limits the findings.

Finally, the lack of studies in this area might lead to different ways of understanding the needs and challenges of a caregiver, which might in turn lead to different interpretations of technology solutions.

In terms of future recommendations, an important future research could be represented by the analysis of different chronic illnesses. A research of this type would provide valuable insights into how different caregiving environments entail different needs of informal caregivers. Furthermore, in order to build a stronger set of findings a quantitative analysis might be considered by future researchers interested in this topic.

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