The Definition and Use of Personas in the Design of Technologies for Informal Caregivers

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Abstract. This paper refers to the significance of defining and using personas for the design and development of technological solutions for informal care. It not only argues for the importance of carefully defining personas, but also discusses the influence that personas exert in the design decisions made throughout the process. We illustrate these two aspects with empirical results gathered in the project TOPIC – The Online Platform for Informal Caregivers – in which a series of online technological solutions are being designed and developed to integrate a *CarePortfolio* to provide caregivers with emotional, informational and tangible support, as they go on to handle their care responsibilities.

Keywords: Personas · User-centered design · Informal care · Ethnographic study

1 Introduction

The past number of years has witnessed an increase in the demand for care work, which in the European Union is primarily provided by informal caregivers [1]. Such work is often associated with high psychological pressure, which subjects caregivers to a great deal of emotional stress, usually evolving to some sort of emotional burden [2, 3]. Furthermore, informal caregivers can sometimes be exposed to severe physical loads stemming from the care procedures they perform, which can potentially lead to the development of a physical burden as well [4]. Such physical and psychological burdens can increase the risk for both psychical and physical morbidity and mortality among caregivers [5]. Therefore, it can be argued that informal caregivers are our society's "hidden patients", who deserve especial attention and need support [6, 7].

One possibility of support refers to providing technological solutions to help informal caregivers to deal with their care work and be in contact with people in similar situations, with whom they could share their burden [8]. This is the main goal of TOPIC, ¹ a European project funded by the AAL Joint Program, aiming at designing

¹ For more information, visit the project website at: http://topic-aal.eu.

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and implementing technological solutions to support informal caregivers to reduce the impacts of the potential burden stemming from the care work that they carry out.

In order to design systems that support informal caregivers' daily lives and potentially reduce their burdens, it is crucial to understand their needs, problems, and expectations. Hence, the project has been using a user-centered design approach and applying qualitative ethnographic methods [9]. One of the main tools being used in the project to keep the users' needs in focus is personas [10, 11], which have been created based on the empirical data collected for the project. This paper reports on the approach that we used to define our personas and discusses how the defined personas have impacted on our design decisions.

The paper is organized as follows: Sect. 2 introduces the notion of personas and discusses literature on the relevance of using it in user-centered design efforts; Sect. 3 provides an overview on the personas devised for TOPIC; Sect. 4 discusses how the empirical data collected for the project informed the elaboration of the project personas and introduces the impacts that our personas had in our design decisions; finally, we conclude with a further reflection on how personas have shaped our design.

2 Related Research

Personas are a useful methodological tool in defining and assessing system requirements for challenging user groups, like older persons, with regard to their diversity [11, 12]: they are crucial to find accurate representations of the target group and are a valuable approach in capturing the conceptual model of the users, so that usable and useful technologies can be designed and developed to meet their needs, capabilities and expectations [10]. For instance, the Center for Usability Research and Engineering (CURE) in Vienna have demonstrated how important it is to use personas to identify and describe certain type of users – like older persons – for a better estimation of the European population [13].

Furthermore personas are valuable in providing a shared basis for communication between all relevant groups of stakeholders and make design decisions more transparent [14]. However, personas are not a self-sufficient tool: although Bredies [15] defends that the relevance of a persona approach to design is more relevant than using interviews for eliciting requirements, authors like Pruitt & Grudin [14] argue that personas should complement and not replace other quantitative and qualitative methods; according to them, personas can amplify the effectiveness of the other methods used for the requirements elicitation. Combined with scenarios in which personas' context and main activities are described a thorough picture can be provided to help understand the circumstances under which a certain group of people (as potential users of systems in development) live and what their habits and expectations are, especially in relation to technology support for everyday life.

Personas can be defined according to Moser et al. [12] by three different approaches: purely qualitative, purely quantitative and mixed qualitative and quantitative. Although these three approaches exist, there is no framework to inform the decision about which approach should be used. In an attempt to close this gap, Moser et al. propose the use of decision diagrams to support choosing the appropriate approach for the creation of personas [12].

Notwithstanding the existence three approaches for defining personas, we argue that it is not clear what each of these approaches entails and what is the process to be followed for their definition. Therefore, we set out to clarify the process for defining personas through the mixed qualitative and quantitative approach, which according to our finding is the best approach for elaborating and choosing personas that can be indeed representative of the target group.

3 Methodology

In TOPIC, we base our research work on a user-centered design approach supported by ethnographically informed studies. We started our project with a pre-study to understand the daily lives of our informal caregivers and to identify their problems, needs and burdens. The pre-study was conducted with 10 informal caregivers – 1 male and 9 female. They were facing different care situations: 5 were caring for their spouse, 3 for their parent and 2 for their child. 2 out of the 10 users were not living in the same household as their care receiver. The age of the informal caregiver participating in the pre-study ranged from 55 to 80 years – the average was 64 years. 2 out of the 10 informal caregivers were still working – the rest retired or unemployed.

The pre-study began with a *first contact interview* at the homes of the informal caregivers: We talked about their situation, their care receiver and themselves. Furthermore we gave them a short overview about the project and what they have to expect. Then we started with the *participatory observations*: For this part of the pre-study we defined 3 to 4 appointments with the informal caregivers where we visited them again in their homes and observed their daily life – at each appointment for approximately half a day. Before and after each appointment we conducted *informal interviews* through which we engaged in deep conversations with our participants about their situation, the status of the care receiver and also about news that happened since the last appointment. Always when possible, we also tried to involve the care receiver in the conversations.

At the beginning of the participatory observation phase we also distributed a *cultural probes* kit for collecting additional data about the care situation and the caregivers' everyday lives. The kits contained a diary (for caregivers to write down daily activities, feelings and thoughts), an *actimoClock* (for them to register the different kinds of work and activities during a day), polaroid camera (to capture situations of the daily life), smiley stickers (to underline emotions in the diary and/or *actimoClock*), a social map (to visualize the frequency and amount of social contacts) and picture cards (to describe feelings and thoughts related to pictures showing different care situations). Furthermore we included two questionnaires: A care questionnaire to gather (socio-demographic) information about the care receiver, the care situation and also the informal caregiver itself, and the Zarit Burden questionnaire to stage the level of burden from that the informal caregiver is suffering at the moment.

Once finished the participatory observation phase, we carried out an *in-depth interview* with the care receivers to clarify what we saw during the participatory observations and what we read from the filled items of the cultural probes. Based on all data resulted from the pre-study, we tried to identify and define personas from different

perspectives to be used for the TOPIC project. We basically focused on *person-related* characteristics, but also included all necessary aspects of care- and context-related characteristics to understand and better identify the personas we need. We elaborate on our approach to define our project personas in the following sections.

4 Personas Definition and Its Impacts upon Design Decisions

In preparation for the definition of our project personas, we created an overview table with the different characteristics of our participants (Table 1), so to visualize the variety of profiles we had. Knowing that personas must be representative of the users of the system being designed and the activities that they will perform on it, we focused on typical characteristics used for defining personas (e.g., age, gender, social environment, etc.) [16] and added some new ones that fitted to the context of informal care (e.g., care situation, care receiver, relationship with care receiver, etc.), as suggested by CURE [13].

After careful consideration of the profiles of the participants in our sample, we started working on the characteristic of our project personas. As a result, we elaborated two personas, namely Anna and Otto, whose characteristics are listed in Table 2. Besides Otto and Anna, we also created a non-persona called Carola (Table 3). Carola represents people that are not potential users of our future TOPIC platform. Defining a non-persona has been proven to be a good design practice, since it reminds the designers of the types of people whom they are not designing for [14]. The personas and non-personas work together in opening and restricting the design possibilities, so to achieve an appropriate list of requirements accurately addressing the user needs. Drawing on the results of our pre-study data analysis, we were confident that by addressing the *person-related*, *care-related* and *context-related* aspects, we would create precise representations of the different types, or archetypes, of people for whom we are designing in the TOPIC project.

In the following section, we will discuss how our findings from the pre-study have informed the definition of the characteristics and therefore for the personas and non-persona. In doing so, we aim to illustrate the relevance of empirical data for the definition of personas.

4.1 Person-Related Characteristics

Person-related characteristics mainly refer to demographic information concerning the profiles of the types of users targeted by the system – for TOPIC, the informal caregivers. The three characteristics that we decided to represent were *age*, *gender* and *mobility*. These allow inferring quite a few things in terms of functional and non-functional requirements for the representatives of the target group. For instance, it is known that the older the people are, the bigger the possibility for them to suffer from some types of sensory impairment that comes with the age [17], e.g., visual impairments, which have a stronger impact on the activities of daily living than hearing impairments [18]. This means that the interfaces should be prepared to require less effort to read, which can be done with the use of larger fonts, the presentation of less

characteristics
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			Table 1. Sun	nmary of the	e pre-study p	Table 1. Summary of the pre-study participants characteristics	acteristics			
	Reisende ^a	Netzwerk ^a	Kreativ ^a	Yoga ^a	Wandern ^a	Sorgsam ^a	Pünktlich ^a	Adrett ^a	Liebe ^a	Ehrenamt ^a
Age	92	58	56	59	72	29	80	59	09	55
Gender	Female	Female	Female	Female	Female	Male	Female	Female	Female	Female
Care situation > 2 yrs.	> 2 yrs.	> 2 yrs.	> 2 yrs.	> 2 yrs.	> 2 yrs.	2 yrs.	> 2 yrs.	> 2 yrs.	> 2 yrs.	> 2 yrs.
Care receiver Partly mobil	Partly mobile	Partly	Fully	Partly	Partly	Partly mobile	Partly	Partly	Non-mobile	Partly mobile
	husband	mobile	mobile	mobile		wife		mobile	daughter	daughter
		mother	mother	mother	husband		husband	husband		
Mobility	Full mobile	Full mobile	Full mobile	Full	Full	Full mobile	Full	Full mobile	Full mobile	Full mobile
				mobile	mobile		mobile			
Social	Children,	Friends	Daughter,	Friends	Friends	Friends, but	Sons,	Colleagues,	Husband,	No contact to
environment	nieces,		nephew,			no contact	few friends	sons,	2. Child,	family, no
	neighbors,		friends			to sons		friends	friends,	friends
	friends								colleagues	
Isolated	No	No	No	No	No	No	Yes	No	No	Yes
Living	Live together	Live	Live	Live	Live	Live	Live	Live	Live	Live together
situation		separated (58 km)	together	together	together	separated (4 km)	together	together	together	
Relation with CR	Lovely but stressed	Tensed	Annoying	Lovely	Lovely	Attentive	Lovely	Distanced	Lovely	Lovely
Financial	No	No	Yes	Yes	No	No	No	No	Yes	Yes
achemaency										
Technical skills	Average	Average	Average	Average	Average	High	Low	High	Average	High
Internet access	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes

^aPseudonyms are used to assure confidentiality to the participants and imprint one of the strong characteristics of the person in question.

		1
	Anna	Otto
Age	60 years old	70 years old
Gender	Female	Male
Living situation	Live separated	Live together
Care situation	Starting (inexperienced with care procedures, takes care of some chores at the care receiver's house, share the care responsibility with her daughters)	3 years (experienced with care procedures, takes care of all chores at the house, does not share the care responsibilities)
Care receiver	Partially mobile mother	Non-mobile wife
Mobility	Very good	Not very good anymore
Social environment	Husband, children	No contact to children
Isolated	No	Yes
Relation with CR	Non-aggressive	Aggressive
Financial dependency	Exists (Anna depends on her mother)	Does not exist.
Technical skills	High	Low
Internet access	Yes	Yes

Table 2. Overview of the characteristics of personas Anna and Otto

Table 3. Overview of the characteristics of the non-persona Carola

	Carole (non-persona)
Age	50 years old
Gender	Female
Care situation	2 years (visits the CR twice a week, manages the paperwork)
Care receiver	Partly-mobile father, live in a retirement home
Mobility	Not very good anymore
Social environment	Existing, has own family and work
Isolated	No
Living situation	Does not live with the father in the same house
Relation with CR	Lovely and non-aggressive
Financial dependency	Exists
Technical skills	Average (she uses computer at work)
Internet access	Yes for her children

information in each interface and careful positioning of the interface elements [19]. Also, taking account of people's ages, it is perfectly possible to assess the types of technologies they grew up with, which can be a source of inspiration for the design

of interaction mechanisms with which the users are familiar. In the following, we discuss how the attributes assigned to our personas and non-persona connects with the pre-study data analysis.

Age. The age in our sample was in average 64 years. This is similar to the general situation in Vienna, where the average is 63 years, and the age ranged 55 to 72 years for persons taking care for people older than 60 years [4]. Therefore, we decided to assign Anna and Otto an age within this age range. Anna was given 60 years and Otto 70 years. The gap of 10 years was chosen deliberately because we judge that 10 years of age would impact considerably on the skills and health situation of people, especially when it comes to older adults. It is widely accepted that 10 years entail considerable changes in the types of technology available. Therefore, considering that Anna and Otto are separated by a 10-year time frame means that they have been born in times where the technological apparatus available to them was considerably different. In terms of design implications, this would mean that the solutions should be flexible enough to be used by people with different technological backgrounds. Concerning Carola, our non-persona, she was aged 50 because this lies under the TOPIC participant inclusion criteria of 55 + years of age.

Gender. The general situation in Vienna shows that more than two-thirds of all informal caregivers are female [4]. Compared to our sample, male caregivers were underrepresented - for the pre-study, only 1 male informal caregiver has accepted to partake in the data collection activities of the project. Nonetheless, we have decided that it would be important to have both genders represented in our personas. Past and current research has demonstrated that gender plays a very important role in informal care: there are many differences in caregiving related to gender. For instance, there is evidence of a generalized culture assuming that women should take over the role of caregiving: they are often likely to shoulder the bulk of caregiving responsibilities compared with their male counterparts [20]. This does not come without a cost. Since female caregivers usually do not seek support with the care responsibilities in which they should engage, they have a higher prevalence of chronic health disorders, stress, anxiety, depression, and social isolation. Also female caregivers are more restricted in their mobility and life activities and have a worse self-care compared to male caregivers [21]. This information is important for designing different types of supports for caregivers with different gender.

Mobility. The mobility of both the informal caregivers and the care receivers is a very important issue for the design of technological solutions for informal care. Knowing whether (i) the caregivers can freely move and engage in short distance mobility, (ii) the care receiver can accompany them or (iii) stay alone at home for short periods of time when the caregivers need to be absent leads to different types of requirement to be fulfilled. Although we observed homogeneity in our sample, we decided to have one of our personas, Anna, as fully mobile, the other, Otto, as partially mobile due to limited physical ability. This actually reflects the results from some other studies pointing out to possible degeneration of physical movements with the passage of the years – also showing an obvious worsening from the age group 50-69 years to the age group older than 70 years [22]. We found out relevant to represent such a variety in order to prepare our system accordingly.

4.2 Care-Related Characteristics

In addition to demographic information, personas must voice the users' goals and aspirations. Designers should be reminded of what the users want to achieve through the system and understand what types of activities are meaningful for them [16]. Providing TOPIC is thought for informal caregivers, it is important to make it clear the types of care situations with which the users of the system are involved. The care-related characteristics focus on this. It mainly describes the care context in which persona is situated and, consequently, it provides information about the care receivers and their health condition. In the following, we present the rationale behind choosing the specific care related characteristics for our personas.

Care Situation. Most of the caregivers in our sample are caring for an ailing relative for more than two years. However, the needs of informal caregivers who are starting caring for somebody and the ones of those caring for someone for a longer period of time are considerably different. For instance, many participants told us about the difficulties they faced at the beginning with all the bureaucracy regarding social welfare benefits, for which they are eligible, the lack of information about the procedure to apply for it. On the other hand, participants also mentioned that once you get the gist of it, you do not need this type of information. Instead, for caregivers who have been caring for somebody for a longer period of time, the need for support with the emotional burden they experience is definitely more important than information about the procedures to apply for financial benefits or the care procedures. Not only that, according to the participants, more experienced caregiver could in fact provide the aforementioned types of information to caregivers starting with the care work. From our observations, it was clear that some of our participants, like Mrs. Liebe, were very experienced with the care procedures that they had to perform. Hence, we decided to make one of our personas – Anna – as a beginner caregiver and the other – Otto – as a more experienced one. Regarding Carola, we decided to assign her a care situation that is not the focus of our project, i.e., one in which the caregiver is not really engaged in the care work. In Carola's case, the father lives in a retirement home and she visits him just twice a week in order to check upon him and sort out any paper work that is necessary for his permanency and for the treatments that he must receive.

Care Receiver. Information about the family relationship of the caregiver and the care receiver as well as about the mobility capabilities of the care receiver is very important to better define the care context with which the caregiver deals with. Most of our participants were taking care for their spouses, their parents or their children. Following these observations, we decided to have one of our personas – Anna – caring for her mother, whilst the other – Otto – is caring for his wife. To have these different family relationships reflected in the personas is important, because it exposes some differences in the pattern of caregiving depending on who are you caring for [23]. In addition to that, we described Anna's mother as partly mobile whilst Otto's wife is non-mobile. By partially mobile we mean that the person can walk short distances, even though with difficulties. Non-mobile means that the person cannot walk and can have some other types of motor impairment – e.g., parts of the body can be paralyzed. This differentiation is rather relevant in terms of system requirements and allows for the description of different scenarios.

Living Situation. This attribute provides information telling whether caregivers and care receivers live in the same household. We found it important to account for it, as our data suggested that it is directly connected with feeling of security. From the data analysis it became noticeable that informal caregivers who do not live together with the care receivers experience certain emotional burden stemming from the uncertainty about how the care receivers are doing when they are not around. Although situations in which informal caregivers and care receivers live together in the same household is commoner in our sample, Robison et al. [24] show that almost three quarters of all care situations correspond to caregivers and care receivers living in different households. Providing these distinct residential situations (i) may contribute to increased social isolation, decreased preventive care, greater activity restriction and less relationship strain in shared households [21, 24] and (ii) can lead to different technical requirements, we decided to represent this diversity in our personas.

Relation with Care Receiver. Empirical evidence collected through fieldwork suggested us that the quality of the relation between the caregiver and the care receiver can be a source of emotional and psychological burdens. Although, we observed that in one half of our sample the relationship between the informal caregivers and their ailing relatives was good, the relationship in the other half of the sample showed that sometimes the caregivers have to deal with difficult situations. Since one of our aims is to provide informal caregivers emotional support so that the impacts of any burden stemming from the care work can be relieved, it is important to have this issue represented in one of our personas, so to provide the necessary tools for this. However, we should also account for good relationships, as these leads us to different user needs.

Financial Dependency. Another characteristics that we judge relevant to represent are financial dependency, as we observed that it impacts most of the times upon the relationship between the caregiver and the care receiver. Financial dependencies in both ways were observed in our sample. For instance, Ms. Yoga is financially dependent on her mother, who seemed to play a dominant role in the relationship. On the other hand, Mrs. Liebe's and Ms. Ehrenamt's daughters depend financially on their mothers, who happen to be their caregivers. Except four cases, no financial dependency has been found between the caregivers and their care receivers. However it is worth pointing out that this does not guarantee the rise of some issues in the relationship between the caregivers and the care receivers. Mr. Sorgsam, for instance, told us about the extra work that required from him to keep his and his partner's expenses separated. He explained that they decided to keep their expenses totally separated. They have separate incomes and bank accounts, but Mr. Sorgsam is the one responsible to sort all the financial issues out. In terms of work, this requires half an hour everyday from him to log into the spreadsheets he uses to control their monthly expenses what he has spent and what she has spent during the day.

4.3 Context-Related Characteristics

This cluster includes characteristics describing the social context as well as technologies in use or under consideration. The social context of a future user of the TOPIC platform is a very important point in defining personas: both the social environment,

meaning how does the family circle and the circle of friends and acquaintances look like, and the isolation, indicating how intense the contact is to members of these circles, describes the social context. The social context of a persona implies how big the need of social contacts over digital media could be. Defining Internet access and technical skills for a persona on the TOPIC project is necessary to identify the users' technological skills and allow the designers to focus on these different needs in aspects like usability, user interaction and user experience.

Social Environment. In terms of social environment, we observed very different situations in our pre-study regarding this characteristic about family and friends. In general, it can be said that the social surrounding from informal caregivers starts shrinking as soon as they engage in handling a care situation. Because some informal caregivers of our sample have no regular or any contact at all to their family especially their children, friends are very important although often rare. But if the family is available, they are an important help. Our data also shows that (former) colleagues and neighbors are an important part of their social life. These issues have been addressed by having Anna with a loving family and lots of friends around her, and Otto without contacts with his friends and his children.

Isolation. Although in most cases, people have to accept the fact of being isolated due to external reasons, we also observed informal caregivers who choose to be in such situations. Despite the fact that just two participants from our sample seem to be socially isolated, we judged relevant to represent both manifestations of this characteristic in our personas: Anna and Otto shows different needs and requirements to the platform, due to their different isolation levels.

Technical Skills. More than half of our sample considers having average technical skills, whilst one third of them consider being highly skilled with technology. As observable in Table 1, only one user low skills about technology. In order not to forget to take into consideration the needs of these three groups we defined Anna as being experienced with technologies and Otto as the newbie with it. Although only one participant from our sample considered having low technical skills, past research shows that for the age group we target, it is very common to find people with low or no technical skills [25]. In terms of design implications, this means that the platform must show high usability levels, being simple to understand and use and accommodating also the needs of more skilled people with technologies.

Internet Access. Concerning Internet access, all, but one participant has it. Therefore both Anna and Otto have been defined as having access to it. This also goes towards the fact that the final product of the project will be an online platform. Carola, our non-persona, has no Internet access, highlighting the fact that we are designing for people who can go online.

5 Conclusion

Meaningful personas like Otto and Anna and the non-persona Carola are a very helpful tool for the design of systems, especially in terms of their functionality, interfaces and interaction mechanisms. Personas' age is connected to their technical skills and the level of technical skills itself influence the design of the user interfaces. One of the

biggest challenges in TOPIC is to define simple and usable user interfaces to support not only experienced users but also the newbies. However, we do not lose sight of configurability and personalization, so to accommodate more advanced users.

Furthermore, the different time periods of caring for someone reflects on the different needs and expectations from the platform: people who are new to a care situation seek for information from experienced users and the experienced informal caregivers want to help by providing tips and advices. Mobility is a very important aspect we have to support both from the caregivers' and care receivers' point of view. In order to support mobility of caregivers, we have to think of wearable technologies equipped with GPS for the care receiver in the future work.

To conclude, social support provided by a community of peers or care professionals, different ways of communicating by using messages, notes, video and audio transmissions, information about legal, medical or care-related procedures and measures are some examples that call for a care-related protected multi-level platform like TOPIC *CarePortfolio*.

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