Enhanced Dialog between Formal and Informal Caregivers: Following a User-centered Design for Personas' Development

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Abstract

Background

The unprecedented increase in ageing population in recent decades has led to a shift in the epidemiological profile of societies, resulting in an increased prevalence of chronic diseases, cognitive impairments, and sensory loss in older adults and their elevated reliance on both formal and informal caregiving. Caregivers hold a vital role in older adults' healthcare, yet their health and well-being needs are often undermined. This paper ventures the exploration of both formal and informal caregivers' profiles through the development of personas.

Methods

Formal caregivers (N = 71) and informal caregivers (N = 54) were recruited in the study participating both in quantitative surveys and ad-hoc interviews including the measures Job Stress Scale, Zarit Burden Interview, Short Form Health Survey (SF-36) and Persona Perception Scale.

Results

Upon the analysis of the Persona Perception Scale and Job Stress Scale, the findings revealed high reliability scores, designating that the formal caregiver persona "Daphne" could adequately represent the actual target group. The results also showed that the informal caregiver persona "Elle" was an accurate reflection of the corresponding target group, after analyzing the findings retrieved from quality of life measurements and caregivers' burden.

Conclusions

User personas can enhance a deeper understanding of the target group and apprehend user preferences and experiences. To this end, personas can potentially provide empathetic and expansive benefits and be exploited as artifacts in attempting to successfully liaise with policy-makers and care providers in aligning key strategies and policies that will conclusively improve the quality of life of both care recipients and caregivers.

1. Background

The significant rise in population establishes a shift in the epidemiological profile, leading to an increased incidence of older adults' chronic illnesses, cognitive impairments and sensory decline, and escalating, consequently, their dependence on others for the provision of daily care [1]. In this sense, the task of caring, represented by the role of the caregiver, embodies acts and services that are addressed to help older adults efficiently involved in practical tasks of daily living and provide for their self-care [2].

Caregivers are distinguished as either informal or formal. Informal caregiving primarily refers to family carers, namely family members, close members of patient's personal surroundings, or non-clinical social workers, whereas formal caregiving mainly to healthcare professionals, specifically nurses, clinical staff, and physicians [3]. Informal caregivers constitute the cornerstone of the patients' holistic care system, as they both provide assistance with older adults' daily activities and direct care to navigate within complex healthcare and social services systems [4]. Formal caregivers acquire qualification and professional training that facilitate the provision of paid services in relation to community-dwelling older adults' long-term care [5].

Caregivers play a crucial role in older adults' healthcare [6], yet as a result of the various demands they face, their personal well-being can be undermined. Physical, psychological, and financial adversities as well as excessive caregiving demands [7] constitute the burden of caregiving that may imply significant effects on caregivers' mental wellbeing, immunity and longevity [8]. Individuals who experience caregiver burden may suffer from poor physical and emotional health [9], depression or anxiety [10] and feelings of emotional exhaustion. This can significantly reduce both caregivers' quality of life [10] and the quality and adequacy of the provided care [11]. Specifically, providing health and care services to patients suffering from neurodegenerative and chronic diseases, as well as disabilities to independent living and self-care is a demanding procedure that entails an adequacy of hard and soft skills with regards to the formal delivery of nursing tasks by professional health and care practitioners [12]. The very nature of this situation calls for a supportive home environment, where the patient's family undertakes the important role of the caregiver to ensure the sustainability of caregiving. Family, therefore, steps into the picture by struggling to perform like a trained formal caregiver, from a personal concern and close relation to the patient and in an informal manner. This can turn out to be very stressful, on account of their lack of training skills that this responsibility entails, combined with the cumbersome burden, anxiety and fatigue that accompany caregiving [13]. Affecting both informal caregivers' psychological state and their caregiving performance may result in the further deterioration of the patient's health [14]. Understanding caregivers' needs, diverse experiences and unique concerns along with the convoluted interactions among informal and formal caregivers with patients is of great significance [15]. In order to address these complex caregivers' needs, support and acquisition of essential knowledge and skills are required, which can be achieved through the exploitation of technology [16]. Innovative Assistive Technology (IAT) is considered an important multifaceted tool that can potentially support independence and quality of older people's life as well as imply experiences and challenges for informal and formal caregivers [17]. According to previous research, Assistive Technology (AT) has been linked with increased caregivers' sense of security and caregiving task efficiency as well as decreased burden and hours of caregiving [18]. In this context, the User-centered Design (UCD) approach is crucial for the development and implementation of digital and computer-based devices [19]. Personas or "user personas" are widely exploited within the UCD approach and constitute a detailed fictional representation of individuals, which can be used to adequately communicate key requirements, interests, needs and motivations of a specific target group [20]. Recently, groups operating under the W3C Patent Policy of the World Wide Web Consortium (W3C) Web Accessibility Initiative (WAI), produced a document presenting such personas

[21]. Personas facilitate better focus on primary users' behavioural patterns and needs, as they provide a basic prototype of users for the interaction of the target group [22]. They can set the basis, when designing and developing the prototype along with the testing, where users can discuss the potential interaction of the persona with the digital solution suggested [23].

Whilst caregiving adversities have been widely addressed, most studies focus on exploring informal caregivers' reality [24], while much less is known about the burden and difficulties of formal caregivers. Conducting an exploratory study to provide a comprehensive understanding of both informal and formal caregivers' needs is crucial to achieve integrated care through the development of user personas that could be exploited as artifacts to successfully liaise with local agencies, policy-makers and care providers, in an effort to ultimately improve quality of life for both care recipients and caregivers. This paper ventures the investigation and identification of attitudes, behaviors and well-being of both healthcare workforce along with intimates and family members through the development of suitable personas. Following a UCD approach, specific objectives under the aim of this study are to address formal and informal caregivers' needs in terms of training and skills development and tackle predicaments including insecurity, exhaustion or burn-out syndrome and psychological deterioration, when providing care to care recipients.

2. Methods

2.1. Rationale for the personas' development

The research presented in the current paper was conducted within the context of H2020 SHAPES project (Smart & Healthy Ageing through People Engaging in Supportive Systems) [25]. SHAPES intends to design and create an open Ecosystem enabling the large-scale deployment of a broad range of interoperable solutions to improve health, wellbeing and independence of older individuals, while enhancing the long-term sustainability of healthcare systems in Europe. Following evidence-based results from the SHAPES project and applying an innovation helix approach, the Medical Physics Laboratory of Aristotle University of Thessaloniki, Greece and the 5th Regional Health Authority of Thessaly & Sterea in Larissa, Greece joined forces, aiming at exploring and identifying both formal and informal caregivers' real-life experiences and illustrating a detailed representation of their reality.

2.2. Participants

The target population of this study consisted of *formal caregivers* ($N = 71$), including healthcare professionals, nurses and direct care workers, who take care of residents in specialty care units in hospitals and geriatric care facilities. The majority of formal caregivers were females (78.9%), with an average age of 39.75 (SD $\pm$ 7.004) years, 64.8% were married, 28.2% single and 7% divorced, while their average job experience was 134.25 (SD $\pm$ 66.949) months. In addition, *informal family caregivers* ($N = 54$) were recruited in the study, of which fifty ($N = 50$) participated in a quantitative survey and four ($N = 4$) in ad-hoc interviews. The majority of informal caregivers were females (76%), with an average age of 57.3 years (SD $\pm$ 13.8), 88% were married, 42% had completed secondary education, while 36% were retired

with a stable income. Moreover, approximately half of the participants were adult children (48%), providing an average daily care of 12 hours ($SD \pm 8.4$) with average caregiving duration of 29.1 months ($SD \pm 19$). Lastly, the 52% of the participants had no professional support.

2.3. Measures

Job Stress Scale

Overall job stress was assessed using the Job Stress Scale developed by Parker and DeCotiis [26]. The scale includes 13 items and incorporates two subscales; a) Time Stress and b) Job Anxiety. Responses are measured using a 5-point Likert scale with a numerical score ranging from (1) Strongly Disagree to (5) Strongly Agree. Higher scores indicate higher levels of job stress, while lower scores indicate respondents reporting less stress. This scale is regularly used to assess overall job stress and acquires adequate psychometric properties [27].

Zarit Burden Interview

The Zarit Burden Interview (ZBI-22) consists of 22 items with five ordered frequency-related response categories ranging from (0) Never to (4) Nearly always. A total score is calculated between 0 and 88, where higher scores indicate greater levels of caregiving burden [28]. The items address the perceived impact of care provision on caregivers' physical and emotional health, social activities and financial status.

Short Form Health Survey (SF-36)

The SF-36 was developed by Ware et al [29] and contains 36 items, which can be categorized into eight clusters including physical function (PF), role physical (RP), bodily pain (BP), vitality (VT), role emotional (RE), mental health (MH), social function (SF), and general health (GH). The scores of each cluster are added, and these scores are transformed into eight different scales scoring from 0-100 and higher scores indicate greater health status.

Persona Perception Scale

The Persona Perception Scale was developed by Salminen et al [30], in order to test and validate the accuracy and credibility of personas' development. The scale includes 28 items clustered into eight different dimensions: consistency, completeness, willingness, credibility, clarity, similarity, likability and empathy. Each item is evaluated using a seven-point Likert scale, ranging from (1) Strongly Disagree to (7) Strongly Agree and, according to previous studies, it has been recognized as a reliable survey instrument [24].

2.4. Procedure

The method followed for the personas creation process was in accordance with the traditional persona research, development and validation process [31] combining both quantitative analysis of questionnaire

data collected from Greek populations with qualitative methods during the period of 2018 and 2021. However, the exact methodology applied was adjusted by taking into consideration the distinct attributes and needs of the two target groups respectively (Fig. 1).

The first step for the formal caregiver personas' development was a preliminary exploration of the literature review along with the consortium expertise. Essential data emerged that led to the creation of a draft persona through a deeper understanding of users' reality and identification of important underlying users' requirements and expectations. Intending to develop a persona to be of the highest correspondence with the target group, a focus group with formal caregivers was, subsequently, conducted. In particular, healthcare professionals participated in a workshop aiming to provide essential feedback on their needs, concerns and experiences and share their insights on the draft persona. Data and information collected were then used in order to make adjustments to the revised persona. Consequently, a questionnaire including the Job Stress Evaluation and the Persona Perception Scale was distributed to formal caregivers online via Google Forms. The results analysis of this survey allowed for the identification of relevant patterns of formal caregivers' reality and rendered possible the validation of the final version of the formal caregiver persona, namely "Daphne" (Annex 1).

The conceptualization of the informal caregiver persona was initially based on the existing literature review in order to assess the local socio - demographic characteristics, psychological burden and quality of life of informal caregivers for dementia patients [32]. In particular, a questionnaire was developed, comprising three distinct parts: a) Socio-demographic and personal data, the experience of the caregiver, b) the Zarit Burden Interview and c) the Short Form Health Survey (SF-36). The questionnaire was distributed to a focus group of 50 adult informal caregivers of dementia patients in the Local Primary Health Care Unit (TOMY) in the Ampelokipoi district, in Larissa, Greece. Result analysis of the questionnaires led to further qualitative analysis, including ad-hoc and face-to-face interviews performed by a healthcare professional recruiting 4 informal caregivers. Transcribing and analyzing the interviews produced new findings that led to the refinement of the draft persona and the development of the informal caregiver persona "Elle" (Annex 2).

2.5. Statistical Analyses

The statistical analysis was conducted through SPSS (IBM SPSS Statistics 23). For formal caregiver Cronbach's alpha coefficients for internal consistency and Pearson's rho correlation coefficients were calculated, in order to assess the reliability of Job Stress Scale and Persona Perception Scale. Normality analysis of the independent variables based on Kolmogorov-Smirnov and Shapiro-Wilk tests was conducted for the case of the informal caregiver. Consequently, Kruskal Wallis Test, Pearson and Spearman Correlations were used to identify the impact of the measured individual parameters including demographics and daily caregiving duration on informal caregivers' burden and quality of life.

3. Results

3.1. Formal caregiver

Reliability Analysis of the Scales

Cronbach's Alpha coefficient was used to validate the internal consistency of the Job Stress Scale and the Persona Perception Scale. Table 1. shows that the scales are reliable, as the values of Cronbach's Alpha based on Standardized Items are above 0.7.

Table 1
Job Stress Scale and Persona Perception Scale reliability statistics

	Variable	Cronbach's Alpha	Number of Items
Job Stress Scale	Job Anxiety	.86	5
	Time Stress	.92	8
Persona Perception Scale	Consistency	.91	4
	Completeness	.92	4
	Willingness to Use	.87	3
	Credibility	.90	3
	Clarity	.94	3
	Similarity	.86	4
	Likability	.94	4

Correlation Analysis

Pearson's correlations were computed, in order to investigate if there was a linear relationship between subscales of Persona Perception Scale and various variables (Table 2). More specifically, the analysis revealed a significant positive correlation between willingness to use score and the education level ($r = .272$, $n = 71$, $p = .022$), as well as a significant negative correlation between empathy score and the job experience ($r = -.260$, $n = 71$, $p = .028$). Furthermore, a significant positive correlation was also revealed between the similarity score and job anxiety ($r = .432$, $n = 71$, $p = .00$), as well as the time stress score ($r = .582$, $n = 71$, $p = .00$) respectively. The results showed a significant correlation between the time stress score and likability score ($r = .330$, $n = 71$, $p = .05$) and empathy score ($r = .294$, $n = 71$, $p = .013$) respectively. Lastly, a significant negative correlation was found between participants' persona perception as a real person character and persona's consistency ($r = -.432$, $n = 71$, $p = .00$), completeness ($r = -.414$, $n = 71$, $p = .00$), credibility ($r = -.475$, $n = 71$, $p = .00$), clarity ($r = -.466$, $n = 71$, $p = .00$), similarity ($r = -.270$, $n = 71$, $p = .023$), likability ($r = -.251$, $n = 71$, $p = .035$) and empathy ($r = -.314$, $n = 71$, $p = .08$).

Table 2
Paralleling general demographics of participants and formal caregiver persona

	Participants	Formal caregiver persona
Age	39.75 years (SD $\pm$ 7.004)	45 years
Gender	78.9% Female	Female
Occupation/Profession	40% Nurses	Nurse
Marital Status	Married/Domestic Partnership 64.8%	Divorced
Job experience	134.25 months ($\pm$ 66.949)	72 months (6 years)
Digital Literacy	Level 1 - Basic User 39.4% Level 2 - Independent User 36.6%	Level 2 – Independent User
Use of Technology	Never 52.1%	Unmet need of exploiting new technology
Exercise Frequency	Once a week 40.8%	Unmet need of exercise 2–3 times a week
Job Stress	29,29 (13–65)	Highly stressed

3.2. Informal caregiver

The mean value of the studied key factors on the informal caregivers was 22.4 (SD $\pm$ 6.6) for personal tension (Zarit-1), 13 (SD $\pm$ 5) for role tension (Zarit-2), 10 (SD $\pm$ 4) for deprivation of the relationships (Zarit-3) and 3 (SD $\pm$ 4) for caregiving administration (Zarit-4). The above values resulted in an average score of the Zarit burden Interview scale (Total Zarit) was 48 (SD $\pm$ 13.7), indicating moderate to severe psychological burden. Additionally, the mean score of SF-36 was 42.6 (SD $\pm$ 14), demonstrating moderate level of quality of life. Correlation analysis has been performed after performing normality tests on the independent values. Consequently, Pearson analysis revealed a significant positive correlation between the age and the calculated scales Zarit-1 ($r = .328$, $p = .020$) and SF-36 ($r = .551$, $p < .001$) of the informal caregivers. Additionally, the same analysis showed that the number of months caring for patients is an important factor for the quality of life (SF-36) of the informal caregiver ($r = .329$, $p = .020$). Spearman correlation analysis revealed that the time spent helping the patient per day strongly relates with Zarit-1 ($r = .437$, $p = .002$), Zarit-3 ($r = .469$, $p = .001$), Zarit-5 ($r = .355$, $p = .011$) and SF-36 scores ($r = .555$, $p < .001$). Moreover, the performed Kruskal Wallis Test showed that the relationship with patients significantly affects Zarit-2 ($p = .039$), Total Zarit ($p = .041$) and SF-36 ($p = .018$) calculated scores while the informal caregiver's education level ($p = .006$) and job status ($p = .004$) correlates significantly with the computed SF-36 score. Interestingly, it was found that the reception of professional support did not affect the burden level nor the quality of life of the informal caregivers.

Analysis of interviews with informal caregivers

Face-to-face interviews with four informal caregivers revealed essential information with regard to informal caregivers' quality of life and psychological condition. This qualitative data was indissolubly associated with caregivers' relationship with the patient, duration and management of caregiving as well as patients' disease severity. Consequently, the informal caregiver persona was further refined reflecting the data retrieved from the qualitative analysis and concluded to Elle. Therefore, the mean age of the informal caregiver persona was increased to 73 years while the level of digital literacy was assessed to be low. Table 3 associates our analysis findings with the designed informal caregiver persona.

Table 3
Paralleling general demographics of participants and informal caregiver persona

	Participants	Informal caregiver persona
Age	57.34 years (SD $\pm$ 13.8)	73 years*
Gender	76% Female	Female
Occupation/Profession	36% Retired	Retired
Marital Status	88% Married	Married
Education	42% High School	High School and of Low Digital Literacy*
Patient's disease	100% Dementia	Assist person with Dementia
Months helping patient	29.1 months (average)	3 years approximately*
Professional support	52% No	No
Total Zarit	48 (average)	Moderate to severe psychological burden*
SF-36	42.6 (average)	Moderate level of quality of life*
*After interviews refinement		

4. Discussion

The present study ventured the investigation and identification of both formal and informal caregivers' profiles through the process of personas' development. As most studies so far have focused on exploring informal caregivers' reality and daily living [33], this study attempted to fill a gap by attempting to conceptualize both formal and informal caregivers' needs and outline their profiles. Our findings bring a different perspective following a UCD approach to tackle adversities with regards to formal and informal caregivers' burn-out syndrome and psychological burden.

Upon the analysis of the Persona Perception Scale, findings revealed high reliability scores, indicating that the formal caregiver persona could adequately represent the actual user target group. In particular, participants with higher educational levels were more willing to exploit the formal caregiver persona. This

is in line with the findings from literature [23], demonstrating that user personas were developed, in order to gain a deeper understanding of the user target group and apprehend user expectations, experiences and anticipated behaviors beyond demographics, and, therefore, build empathy patterns among end-users. User personas offer the potential to “humanize” and replace quantitative data with people-based data reflections that individuals inherently empathize with [34]. More specifically, articulate personas form useful, rounded and realistic representations of the underlying target group that exist in real life and provide empathetic and expansive benefits [35].

In addition, participants with higher job anxiety appeared to reflect greater resemblance with the persona and those with greater scores of time stress revealed higher scores of empathy and similarity with the persona. In accordance with these results, the formal caregiver persona “Daphne” was presented as a highly stressed individual, due to the extreme workload, long shifts and other factors related to job stress and burnout syndrome. Our findings suggest that participants strongly related with the persona outline, indicating that the persona resembled participants’ stressful reality deriving from their everyday job related experiences and circumstances. Therefore, in the present study, participants highly empathized with “Daphne”, emulating the key behavioural patterns, experiences, habits, concerns, interests and needs, which derive from their reality and everyday living.

In continuation to the aforementioned findings, the informal caregiver persona’s profile was also outlined, aiming to address informal caregivers’ moderate quality of life and moderate to severe psychological burden. Results analysis showed that parameters including caregivers’ age, relationship with patients, education, job status, duration of assisting and supporting patients strongly influence the lifestyle of the informal caregiver. Furthermore, the psychological burden and quality of life of informal caregivers were higher in females, while general health status was better in males. These findings are in accordance with the results from a meta-analysis conducted in the United Kingdom [36], which involved British, German, and Polish caregivers of Alzheimer’s disease patients with an average age of 50–60 years, through the exploitation of the same research evaluation measures, revealed that informal caregivers’ poor sleep quality, high rates of depression along with heart and metabolic diseases. Additionally, our results indicate that there is no significant difference in the degree of burden and quality of life between informal caregivers, who sought support from a healthcare professional and those who did not. Lastly, most of the informal caregivers acknowledged that their family income was decreased, since the onset of the patient’s chronic disease occurred and highlighted that the monthly cost of providing medications and treatments was a high expenditure. These findings are in accordance with another study [37] and confirmed by the informal caregiver persona “Elle”.

Potential limitations of the study relate to the recruitment and retention of informal older adults’ caregivers in research studies, which is often a complex and challenging process that requires careful and adequate planning of necessary steps for recruitment and consideration of the essential resources. Additionally, further limitations refer to the low levels of digital literacy detected among older adults living in Greek regional locations and the lack of anterior familiarization with the venture of personas’ design and development. Furthermore, to comply with pandemic-related containment measures during COVID-19

pandemic, data collection methods were adapted to these unique circumstances. Therefore, a focus group with formal caregivers was conducted online and a limited sample size was detected with regards to the informal caregivers' participation in the conduction of interviews.

Future directions may focus on multicomponent technology-based interventions that offer a combination of different approaches such as psychoeducation, supportive approaches, and skills training in a cost-effective way. These interventions could act as an enhancement of efficiently alleviating caregivers' psychological burden and burn-out syndrome among healthcare professionals [38]. This venture could be promoted by programs carried out in collaboration with local health units, local authorities and patient associations, which aim to help caregivers understand the disease, its symptoms and its progression and to acquire knowledge, skills and abilities that will not only help patients but will also lead to the improvement of their own well-being [39]. It is important to advocate integrated care, which incorporates the collaborative interaction of healthcare system stakeholders with informal caregivers, aiming to achieve person-centered medical and behavioral care among older adults with different needs [17]. Such activities will ease the way forward for a digitally enabled, integrated, and person-centred healthcare, elements of which are currently studied within a Europe-wide joint action, called JADECARE [40]. Consequently, the promising benefits stemming from the exploitation of AT, promoting integrated care that focus on the sufficient communication among formal and informal caregivers and coherent transfer of essential information for the management of the patients' disease.

Conclusions

The act of caregiving might generate a number of negative financial, social, psychological and health life consequences for the caregiver, which highly increase caregivers' burden and, therefore, affect both caregivers' and care recipients' quality of life. It is important to identify the unique needs and concerns of formal and informal caregivers, in order to adequately outline their profile and meet their behavioural patterns, expectations and experiences. The efficient and adequate development of integrated assistive technologies and their implementation in the act of caregiving could act as an enhancer for improving caregivers' overall quality of life. Essential insights on healthcare providers' and informal caregivers' health and well-being are outlined in the two developed user personas that can be exploited as artifacts to promote effective and sufficient public health policies, key strategies and practices and successfully liaise with local agencies, policy-makers and care providers, in an effort to ultimately improve quality of life for both care recipients and caregivers.

Abbreviations

IAT

Innovative Assistive Technology

AT

Assistive Technology

UCD

Declarations

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Ethics approval and consent to participate

The research was conducted based on the ethics guidelines produced in the SHAPES project. Additionally, this study has received the ethical approval from the scientific committee of the 5th Regional Health Authority of Thessaly and Sterea, Greece. The interviewees have been informed for the purposes of the research and consented to participate in the study. The questionnaires have been anonymously answered.

Availability of data and material

Data is available in part within the corresponding SHAPES deliverables and in the master thesis as given in the references.

Ethics approval and consent to participate

The protocol was approved by the Bioethics Committee of the School of Medicine of the Aristotle University of Thessaloniki. All participants were informed about the purpose and context of the study as well as the free withdrawal from the study at any time for any reason. Each participant provided informed consent and was also reassured of confidentiality and anonymity.

Competing Interests

The authors have no competing interests or other interests that might be perceived to influence the results and discussion reported in this study.

Consent for publication

Not Applicable.

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Figures

Figure 1

Visualization of the process that was used to derive the formal and informal caregiver personas

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