End-users in recovery from substance use disorders as designers of Personas and digital games with therapeutic potential

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Abstract

Thirty-five million people worldwide are affected by Substance Use Disorders (SUDs). Digital games can exert therapeutic effect in this domain and the development of these games by the end users themselves tends to potentiate the adherence and effectiveness of the games. Personas is a consolidated technique to support design solutions. There are studies in the literature that examine the creation of personas with the participation of health professionals. However, patients are generally just information providers and a more active participation is a desirable outcome to improve the design of digital systems for the healthcare domain. This paper investigates the co-creation of personas and digital games with therapeutic potential by patients recovering SUDs. Twenty-one patients, one healthcare professional and four computer science professionals took part in the workshops. In total, were created seven personas and four digital games with therapeutic potential. By conducting a qualitative analysis, we were able to determine eleven lessons learned from the process.

Keywords: *Technology applied to health, Approach to design, End-user development, Substance abuse rehabilitation, Alcohol and drugs*

1 Introduction

Substance Use Disorders (SUDs) are characterized by the inability of an individual to reduce the use of a substance (e.g., alcohol or illicit drugs) and affect 35 million people worldwide (Heyer et al., 2020; Olafsson et al., 2020). The purpose of developing computational solutions for end-users is empowering them to create and modify their own digital artifacts to suit their needs (Barricelli et al., 2018; Lieberman et al., 2006). In the area of health, end-users are patients, health professionals and other interested stakeholders who are enabled to make use of the solution, as well as the data collected. The active participation of end-users in the construction digital solutions with therapeutic potential is important, because of the domain knowledge acquired and features such as the pathology itself. Moreover, the involvement of end-users, especially patients, in these practices may also bring therapeutic benefits (Souza, 2018; Garcia et al., 2019).

Personas can be regarded as realistic and concrete representations of the potential users of a system. They may include a wide range of different characteristics, such as physical and psychological features, professional background, personality, family traits and daily routine (Cooper, 1999). The use of Personas in the design and development of computational solutions for healthcare has been extensively discussed in the literature. Although some studies involve end-users in the creation of personas, they usually assign healthcare professionals or patients the role of information providers and not co-creators or co-developers of the systems (Rodrigues et al., 2015; Woods et al., 2017; Rodrigues et al., 2018; Huh et al., 2016; Holden et al., 2017; Souza et al., 2019). A more active participation is a desirable outcome to improve the design of digital systems for the healthcare domain.

Rodrigues et al. (2015) have outlined a method, aiming to add specific information to personas within the scope of therapeutic applications, which supports the active participation of health professionals. These authors (Rodrigues et al., 2018) describe an instance of this process with the active participation of health professionals in the construction of personas. In studies which described the participation of patients in the creation of personas (*e.g.* (Holden et al., 2017; Woods et al., 2017; Huh et al., 2016)), the patients only assisted the creation as information providers (*e.g.* by taking part in interviews and focus groups). Thus, there is a lack of studies in the literature that investigate the active involvement of patients as the creators of personas.

The purpose of this paper is to discuss the creation and use of Personas for the construction of digital games with therapeutic potential. The process of creating the Personas, as well as the construction of the games, was carried out by end users in recovery from Substance Use Disorders (SUDs).

The process of creating personas was carried out in a Psychosocial Support Center - Alcohol and Drugs (CAPS-AD). The personas creation activity was part of a project in which patients were invited and taught how to develop digital games with therapeutic potential. The project was approved by the ethics committee in 2018 and a cycle of activities took place at the CAPS-AD in the same year. This paper presents the results of a second cycle, which took place in 2019 at the same institution, but with different participants.

Therapeutic digital games have, among other benefits, the potential to increase patients' motivation and commitment to therapy (Funabashi et al., 2018). However, developing games that encourage positive, healthy behaviors is a challenge. The design of therapeutic digital games is in a critical context, which involves ethical and social responsibility (Ferrari et al., 2020). Bonacin et al. (2019) also point out challenges in development by end users. The authors point as ex-

amples how to promote democracy and equality during the design process and how to promote the effective participation of end users (Bonacin et al., 2019).

Understanding the domain in which the game relates is fundamental, as is promoting ways to support participation and communication between different stakeholders. Therefore, for this project, the SemTh approach was adopted, which assists in the participation of different stakeholders during all stages of the development of therapeutic digital games (Souza et al., 2019).

An instance of the Personas Enrichment Method (Rodrigues et al., 2014, 2015) is one of the initial activities of the approach (Souza et al., 2019). In this project, the personas were created by the CAPS-AD patients themselves, with the support of health professionals and computer professionals.

Twenty-one patients and one health professional of CAPS-AD, as well as four computer science professionals took part in the personas creation activity. The activities to instantiate the Personas Enrichment Process took place in at the CAPS-AD Center in September 2019. Seven personas were created and these were used for the creation of therapeutic digital games by patients.

The process of creating the personas, the personas that were created, a brief description of the games and the lessons learned are also presented in Souza et al. (2021). This paper is an extended and revised version of the paper by Souza et al. (2021), including a breakdown of the game implementation process by end users.

Activities to implement the games took place in November 2019. Lepi was used for implementation, a game editor software created by Garcia et al. (2019) that supports the development of digital games by end users (Garcia et al., 2019).

The contribution made by this paper stems from the personas themselves, how they were used in the creation of therapeutic digital games by end users and from the lessons learned in a real research setting.

Personas are capable of being reused to assist in the creation of other computer systems for people recovering from SUDs. The process of creating games by end users in recovery from SUDs has the potential to support other research in that domain. It is hoped that the lessons learned can encourage other researchers to adopt further co-design and co-development approaches in that field.

The remainder of this paper is structured as follows. Section 2 establishes the theoretical framework and conducts an analysis of related works in the literature. Section 3 describes the process of creating personas. Section 4 describes the therapeutic digital games created. Section 5 describes the lessons learned during the process. Section 6 summarizes the conclusions and makes suggestions for future work.

2 Background

This section establishes the theoretical framework adopted in this paper, based on Alan Cooper's (Cooper, 1999) Personas methodology and the Personas Enrichment Method (Rodrigues et al., 2014, 2015). A summary of studies related to this paper is also provided.

2.1 The Theoretical Framework

Personas is a technique created by Alan Cooper (Cooper, 1999). It is widely used in the field of computer solutions design. When stakeholders employ the technique, the resulting Personas tend to assist the creation of a product that better suits the needs and requirements of the end-users (Rodrigues et al., 2014).

According to Cooper (1999) (and corroborated by Pruitt and Adlin (2006)), Personas are concrete and realistic representations of potential users of a system. A persona can add features such as name, physical, biological, psychological, visual representations, demographic data, among other information that is necessary for the desired design process (Cooper, 1999; Pruitt and Adlin, 2006).

Personas have a defined life-cycle, consisting of family planning, conception and pregnancy, birth, maturation, adulthood and retirement, death and/or reuse (Cooper, 1999; Pruitt and Adlin, 2006). Family planning involves a) assembling a team to meet and create the personas, b) determining the problem that can be overcome by the solution that will be built and c) devising an action plan. The conception and gestation includes an analysis of the data for the creation of the persona skeleton, which is born and validated, reaches maturity and can then be used in its adult life. After the persona has been used, it can retire, cease to be used, or be reused in another project (Cooper, 1999; Pruitt and Adlin, 2006).

According to Rodrigues et al. (2014), the Personas technique is, to some extent, suitable for the area of health. However, in such a complex scenario, there is a need for more granular Personas (for instance, more information is needed to better suit the domain). This level of detail can be achieved by involving stakeholders in the creation of personas (Rodrigues et al., 2014, 2015). Williams et al. (2014) also point out that in the health domain, it is essential to involve a wide range of specialists, with the aim of basing design on the realities of health care provision.

A process that enables stakeholders to take part in the creation of personas was formalized by Rodrigues et al. (2014, 2015). This process was called the Personas Enrichment Process. It consists of four stages (see Figure 1): 1) identification of the stakeholders; 2) characterization of the users; 3) creation of the personas; and 4) presentation and validation of the personas.
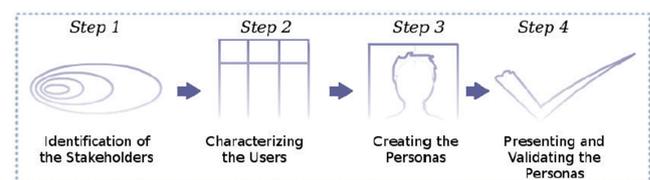

Figure 1. Personas Enrichment Process (Rodrigues et al., 2015).

The first stage of the process entails identifying the stakeholders and is illustrated by the Stakeholder Analysis Chart in Kolkman (1993), instantiated in Figure 3 and Figure 4 shows in the Section 3. In this stage, the artifact is used to identify stakeholders in the field of therapeutic applications. Its application can be carried out in a participatory way by designers, developers, professionals from other areas and any other stakeholders that are interested in the solution, such as

the family and the patients who are the intended audience of the solution (Rodrigues et al., 2014, 2015).

By following the chart, designers can benefit from obtaining a broader view of the stakeholders related to the solution. This view highlights the fact that stakeholders either exert an influence on the solution to be built or are themselves affected by it. The artifact represents the stakeholders in different layers, and gives them different responsibilities. At the center of the chart is the Therapeutic Application, followed by the Contribution layer, in which the actors (users) and those responsible for building the application must appear. The next layer is the Source, in which it must be informed the stakeholders responsible for providing information that can lead to the construction of the application. The next layer is intended for the Market, where the potential partners and competitors must be informed. The last layer, which is farthest from the application, is called the Community, which should include spectators, legislators and government agencies, among other stakeholders. The closer the layer is to the center, the more the application will influence (or be influenced by) the stakeholders of that layer (Rodrigues et al., 2014, 2015).

In a second stage of the Personas Enrichment Process, there is an instantiation of the artifact to characterize the users. The stakeholders previously identified as most interested in the application are regarded as potential users of the solution to be built. In the therapeutic domain, these users may be patients, health professionals, family members, or other people. It is necessary to create a chart (which is divided in four parts) to characterize each of the identified users (Rodrigues et al., 2014, 2015).

During the practice, a fictitious image of the patient should be provided together with a description of the ideal treatment and the influence of the stakeholders on the patient. It is also necessary to describe the clinical condition of the fictitious patient and to discuss possible problems that a therapeutic application may encounter when being used to assist this patient in the treatment (Rodrigues et al., 2014, 2015).

The data collected from these first two stages should be supplemented with data from the literature describing the profile of patients with the same pathology. The purpose of this is to obtain richer details (Rodrigues et al., 2014, 2015).

In comparison with the original Personas life-cycle devised by Cooper (1999), family planning is completed after the stages one and two of the Personas Enrichment Process. The third stage of the process covers the conception, pregnancy, birth and maturation of the Personas (Rodrigues et al., 2014).

In the third stage of the process, an analysis is carried out of the collected data, the characterization of the user profiles and the construction of the skeletons of the personas. A persona must be created for each characterization chart, and instantiated in the previous stage. If the team deems it necessary, more personas can be created to represent the summarized information (Rodrigues et al., 2014, 2015).

The personas are then presented to the healthcare professionals for validation. The professionals must assess whether the personas created really represent the focus group and then fill out the Personas' evaluation sheet. The photos attached to the profiles, together with the descriptions in the clinical pro-

files, the family background and the life history must also be evaluated, to ensure they are in accordance with the patients in the focus group (Rodrigues et al., 2014, 2015).

In the validation stage, the personas can be further refined, if necessary. When they reach their adulthood, the personas can then be used for design decisions while creating the solution. Once the construction of the solution has been completed, the reflection of the personas in the created solution can be evaluated and they can be used to build other solutions within the domain (Rodrigues et al., 2014, 2015).

The SemTh approach (Souza et al., 2019) assists in the design of therapeutic digital games and recommends using the Personas Enrichment Process as one of its initial activities. SemTh is a semi-participatory approach for the design of therapeutic digital games. The flow of the SemTh approach (see Figure 2) consists of four stages: 1) Clarification of the Design Problem; 2) Interaction Modeling; 3) Materializing Design; and 4) Evaluation. In each of the stages, the SemTh approach: a) suggests activities that can assist design, b) facilitates communication between different stakeholders and c) encourages active participation by end-users (Souza et al., 2019).
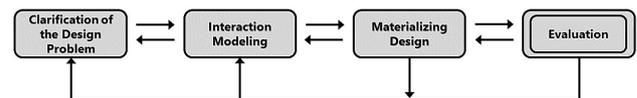

Figure 2. Flowchart showing the stages of the SemTh approach (Souza et al., 2019).

This paper covers the first and third stages of the SemTh approach. Describing the instance of the Personas Enrichment Process defined by (Rodrigues et al., 2014, 2015), which consists of one of the activities of the Clarification of the Design Problem stage. And describing the implementation of therapeutic digital games, activity of the Materializing Design stage of SemTh.

2.2   Related Work

The Personas technique is used to support building systems in different situations. In this paper, research was carried out to find out how end-users took part in assisting the creation of personas in the area of health. It relied on the Google Scholar search engine and the search string "Personas by end-users to health" was also included. The period covered was 2015–2020. The identified results were classified in order of priority, and the titles with the best classification were analyzed. Five studies that examined the creation of personas within the field addressed were selected.

Holden et al. (2017) attempted to create biopsychosocial personas for elderly patients with heart failure. The authors based their investigation on a quantitative analysis of data abstracted from the medical records of 32 elderly people suffering from this condition who had, recently been admitted to a hospital. The end-users (the patients) took part in the research as information providers. In addition to the data obtained from medical records, data from patients were collected through interviews and questionnaires. The study discusses the creation of personas, but it does not describe whether they were used to implement any system.

Personas created in the domain of Online Health Communities (OHC) are examined by Huh et al. (2016). In seeking to support the OHCs, the authors created four personas that illustrate the requirements and needs of the users. They supplemented this information by conducting interviews with 16 users and OHC administrators, and applying an online questionnaire, which received 184 responses. As in the case of Holden et al. (2017), Huh et al. (2016) are only concerned with the creation of personas, and they do not describe how they were used.

An mHealth application (Woods et al., 2017) was carried out with the aim of assisting patients suffering from heart failure. The term mHealth is used to refer to health practices that are supported by mobile devices, such as smartphones and tablets. The project was carried out through a co-design and with the participation of seven patients, four family members and multidisciplinary professionals. The Personas technique was applied to form the profiles of the potential users of the system. The end-users took part in building the personas, though they have had an informational role. Ethnographic interviews conducted with eleven self-selected patients and family members provided an in-depth understanding of how their daily lives had been affected by heart failure. The interviews lasted about an hour and were conducted on the campus of a hospital. An "Empathy Map" was completed after each interview to obtain both subjective and objective qualitative data. Similar themes were merged, which resulted in the formation of four profiles. Fictitious sociodemographic information was added to make the personas realistic and relatable, while maintaining the anonymity of the interviewed participants.

A workshop was held with the design and development team to introduce the personas. Posters were designed that included the personas, with the aim of representing the needs, ideas, patterns of behavior and anxieties of possible end-users of the mHealth application. An "Idea Matrix" was designed which included several post-its on a large whiteboard divided into a grid of four columns (representing each persona) and three lines (representing each design criterion). The design team members were asked to find solutions for each design criterion based on the needs of each persona (Woods et al., 2017).

Rodrigues et al. (2018) and Rodrigues et al. (2015) examined the active participation of end-users (health professionals) in the construction of the personas. Rodrigues et al. (2018) created personas as a part of a system to provide assistance in the treatment of children with cancer. Rodrigues et al. (2015) used the creation of personas as a means of finding solutions to help patients with chemical dependency and depression.

The goal of Rodrigues et al. (2018) was to devise a digital game to assist in the treatment and well-being of children with cancer in a hospital. A team formed of computer and health professionals used the Personas Enrichment Process (Rodrigues et al., 2014) to create three personas within the domain. After the necessary data had been collected, the personas were enriched with data from the literature on childhood cancer to assist in the development of prototypes for a digital game.

Subsequently the project was resumed in the course of a research project on the design of therapeutic digital games (Souza et al., 2019). The aim of this research by Souza et al. (2019) was to formalize an approach within this category of digital games. When evaluating the approach adopted here, the project for devising games for children with cancer by Rodrigues et al. (2018) was resumed and the personas that had been previously created were used. The three personas were validated by the new team and three others were created. The team for this project also comprised computer and health professionals, some of whom also took part in the creation of the first personas. On the basis of the existing personas, a platform was built that added a web system and a mobile game to assist children with cancer and their families (Souza et al., 2019).

In the area of mental health, we took note of the study by Rodrigues et al. (2015) in which the authors attempted to build a computational solution to assist young patients in a hospital with illicit drug dependence and suffering from depression. The work examines the application of the Personas Enrichment Process (Rodrigues et al., 2014, 2015). The process was instantiated with the participation of health professional end-users, but there was no patient participation. In total, six personas were created that aggregate information about the patients' clinical profiles and their relationships with stakeholders and technology. Two game prototypes were developed on the basis of these personas, one related to drug dependency and the other related to depression.

Table 1 provides a summary of the related works. On the basis of these studies, a gap can be detected in the literature with regard to creating personas with the active support of patients, who are the key beneficiaries of digital therapeutic solutions.

Table 1. Summary of related works. Source: The authors.

Study / Domain in health	End-user participation	Were the personas used?
(Holden et al., 2017) / Cardiac insufficiency (heart failure)	End-users (patients) as providers of information, through interviews and a questionnaire.	No.
(Huh et al., 2016) / Online health communities (OHC)	End-users as providers of information, through interviews and questionnaire.	No.
(Woods et al., 2017) / Cardiac insufficiency (heart failure)	End-users (patients) as providers of information, through interviews.	Yes.
(Rodrigues et al., 2018) / Support for the treatment of children with cancer.	Health professionals actively participating.	Yes, later.
(Rodrigues et al., 2015) / Mental health (chemical addiction and depression)	Health professionals actively participating.	Yes.
This paper / Substance abuse rehabilitation	Health professionals and patients actively participating.	Yes.

In the final section of 1, data are included from this paper to establish how it relates to the other studies. In that section, it can be seen that this paper emphasizes the active partic-

ipation of health professionals and patients, which was not found to be the case in the other studies.

3 The Personas Creation Process

The personas creation process outlined in this paper was conducted as a part of a larger project aimed at enabling end-users in an alcohol and drugs abusive rehabilitation center to devise therapeutic digital games. The study took place in a CAPS-AD. This section examines the research setting, and the persona creation process while also conducting an analysis of the generated artifacts.

3.1 The Research Setting

Psychosocial Care Centers (CAPS), with their different modalities, are institutions designed to provide open health-care and support services for the local community. Their teams are made up of multidisciplinary professionals who work in an interdisciplinary way and give priority to patients with mental disorders. CAPS-AD is a CAPS that specializes in disorders caused by alcohol and drugs (da Saúde, 2017).

In this paper, professionals from a CAPS-AD (in partnership with computer professionals) embarked on a project to design therapeutic digital games at the center. The project sought to provide CAPS-AD with the means to allow patients to create digital games with therapeutic potential. The SemTh (Souza et al., 2019) approach was employed to encourage the active participation of multidisciplinary teams to design these games. The project was carried out in ten meetings held between August and November 2019, every 15 days at CAPS-AD.

When the meetings at CAPS-AD were planned, it was decided that SemTh would start to be applied in the second meeting. The number of meetings was defined according to the availability of the CAPS-AD. The activities were explained and exemplified at each meeting. Computer professionals were present helping the patients and the psychologist. The four computer professionals involved had already worked on user studies and had experience with the proposed activities. The computing professionals had the role of explaining, exemplifying and supporting the filling in of the artifacts.

The first meeting would be used to explain the project to the participants (patients and health professionals), as well as the Informed Consent forms and give the patients training on the basic functions of the computer. At the first meeting, computer professionals introduced the project to the participants, showed the patients the basic functions of the computer. The patients also played games created by computer professionals. For some patients this was their first contact with the computer.

Data to identify patient profiles were collected. 21 patients (19 men and 2 women) aged between 27 and 55 years participated in the personas creation activities. Of these, 6 patients completed high school, 2 had not completed high school and 13 patients had not completed elementary school. Of the 21 patients, 9 reported that they have never used a computer. Only 4 patients had attended the CAPS-AD for over a year.

Motor skills, cognitive and general characteristics of patients who attend the institution are evaluated by the health professionals of the institution and considered confidential information.

A brainstorming session was held in the second meeting when the SemTh approach was first adopted. The purpose of this was to find out the patients' ideas and expectations about the project and what they wanted to create. The activity planned for this meeting was carried out by dividing the patients into two groups of five patients each, and the main ideas raised were documented. The separation of the working groups was carried out by the psychologist. She has knowledge of the interpersonal characteristics of patients and, not knowing in detail the activities that would be performed, she had the autonomy to separate patients into work groups, not generating bias with regard to the application of activities by them.

The third and fourth meetings were aimed at instantiating the Personas Enrichment Process, which is outlined in this paper. The details of the activities carried out, as well as the description of the patients of each group and the results of the personas created, are set out in Subsection 3.2.

3.2 Describing the creation of the Personas

As shown in Subsection 3.1, the creation of the personas took place in the third and fourth meetings at CAPS-AD. CAPS-AD is an open door service, in which everyone who arrives is free to take part in all the activities held on any given day. The activities of the Personas Enrichment Process are sequential and the turnover of the participants was a challenge. In an attempt to overcome this, at each new meeting the researchers reviewed the objectives of the activities and what had been done in the previous meetings.

The third meeting at CAPS-AD was attended by three computer professionals, the psychologist at CAPS-AD and thirteen patients who wanted to participate in the project. The professionals explained the project as a whole again and defined what personas are, as well as the enrichment method that would be applied at that meeting. The psychologist divided the patients into two new groups, hereafter called Group 1 and Group 2. When selecting them for the groups, she took account of the real circumstances of the patients' lives and their backgrounds. One of the key factors noted by the psychologist in making the division was with regard to patients who were (or had been) in homeless. Group 1 consisted of patients who had never been on the street and Group 2 was allocated to those who were or had already been in that situation. Each group met in a different room to carry out the activities and was accompanied by a computer professional.

When the students were engaged in the planned activity, the Stakeholders' Chart, the User Characterization Chart and skeleton structure sheets were used for the personas. The artifacts used were printed on A4 paper. There were also post-its and printed images representing people, together with public domain images, which can be freely accessed on the Internet.

Regarding the Personas Enrichment Process (Rodrigues et al., 2014, 2015), the first stage was to fill out the Stakeholder Chart. Groups 1 and 2 completed the task, accompanied by the professionals (see Figure 3 and Figure 4).

Figure 3. Stakeholders' Chart - instantiated by Group 1. Source: The authors.

Figure 4. Stakeholders' Chart - instantiated by Group 2. Source: The authors.

At the beginning of the planned activities, the patients had difficulty in understanding what should be done. The professionals helped them by giving examples of people and institutions that might be interested in the game that would be developed. After the professionals had given some examples, the patients were able to complete the Stakeholder Chart.

The members of Group 1 defined patients, family, and health professionals as the main stakeholders, and referred to them as Contributors (in Portuguese, *Contribuição*). In the case of the members of Group 2, the principal stakeholders were the CAPS-AD staff, the staff of the temporary house (shelter), friends and schools. In the Sources of Information (in Portuguese, *Fonte*), Group 1 included professionals, friends, patients, family members and literature as sources of information for the solution that they would create. Group 2 chose the participants and professionals of the CAPS-AD as the only sources. In the Market layer (in Portuguese, *Mercado*), Group 1 cited other CAPS, clinics, therapeutic communities, schools and religious institutions as possible beneficiaries of the solution. Group 2 cited other CAPS-AD and the Family Health Unit as beneficiaries. Finally, in the Community layer (in Portuguese, *Comunidade*), Group 1 cited hostels for the homeless, the Health Secretariat, community centers, foster homes for minors, the Brazilian Bar Association, the Association of Parents and Friends of Exceptional Children and the Government, as stakeholders for the solution. Group 2 included CAPS, the Pop Center, the Afro-Center, the Street Population Forum, the Sports Center, the Basic Health Unit, the Department of Transport, the Department of Health and the Department of Housing.

The computer professionals noted the absence of the 'family' stakeholders in the Group 2 chart and questioned the psychologist. She stated that patients who have been homeless have less family support, which is the reason why Group 2 did not even consider the family as an interested party, since they believed the family they had was the CAPS-AD staff.

After completing the stakeholder chart, the groups started to fill in the Persona Characterization Chart. A little confusion arose with the term 'personas'. As the project was carried out in Brazil, in Portuguese 'personas' sounds very similar to '*personagens*' (which in English means characters). Sometimes the patients had to be reminded that the personas being created were potential players for the games and not the actual characters of the game. At the end of the third meeting, the groups ended the instantiation of the stakeholder chart, filled out the characterization charts and started creating the persona skeleton.

The fourth meeting was attended by three computer professionals, the CAPS-AD psychologist and fifteen patients. The purpose of this fourth meeting was to finalize the creation of personas and validate them. This activity was in a sequence that followed the activity of the previous meeting. Of the fifteen patients present, only seven were at the previous meeting.

The psychologist once again divided the patients into two groups, and this time the inclusion of new participants in a particular group depended on their real-life circumstances and affinities. In this fourth meeting, the groups finished filling out the boxes for the characterization of personas and created the skeletons of the personas. Figure 5 shows the characterization chart of one of the created personas, the Andrew.

Figure 5. Characterization Chart of the Persona Andrew. Source: The authors.

Andrew's profile described him as nervous, anxious and impatient; he also had suicidal tendencies. He was unemployed and had lost contact with his family. The ideal treatment for him was medication, occupational therapy, attendance of lectures and enabling him to bond with a family. Other possible solutions were to show him that he could

have other forms of pleasure, and also to encourage the practice of sports and encourage socialization. The characteristics pointed out in the chart are reflected in the persona created and, later, in the game that was developed.

Groups 1 and 2 created a total of five personas which were evaluated by the psychologist. As a result of the evaluation, it was observed that three of the personas did not have the characteristics of an alcoholic and drug addict; one of them was characterized as a CAPS-AD professional. Not in all personas there was explicit information about substance abuse, but they had some pathology from substance abuse (e.g. aggressiveness, depression, suicidal thoughts). Therefore, none were discarded from the study.

The professionals then became aware of the need to create more personas to follow the project, with data from the literature related (Capistrano et al., 2013; Fernandes et al., 2018; Angeli, 2015) to people recovering from SUDs. As a result, two new personas were created by the computer professionals and validated by the psychologist. The psychologist agreed in her report that the photos associated with the profiles, the descriptions of the life history and the family background, and the descriptions of the clinical pictures corresponded with the patients in the focus group.

The persona creation activities resulted in five personas (Andrew, Carlos, José Largatixa [*sic*][1], Lauany and Marcos) that were created by the patients who took part in the project, with the support of professionals, and two personas (Gabi and Pablo) created by computer professionals based on their experiences and data from the literature. Figure 6 shows the descriptions and representative images of the created 7 personas. The personas were originally created in Portuguese and translated for this paper.

4 Implementation of Digital Games with Therapeutic Potential

To implement the games, the patients were divided into three groups. Each group could choose the personas whom they wished to design their games for. The group 1 chose the personas Andrew, Gabi and Carlos. The group 2 chose Pablo, Gabi and José Largatixa. And the group 3 chose Carlos and Marcos.

The games had to be developed to support the treatment of patients with the profiles of the chosen personas. The goal of the patients in the creation activities was to design games that could help the chosen personas.

Four meetings were held at the CAPS-AD for the games creation. Altogether 21 patients contributed to the activities of the games development meetings. Four therapeutic digital games were created.

The groups started the process of creating game, by listing the requirements of the game, the settings, characters and its history. The personas were very important in this process. When patients were confused about how to perform an activity, the professionals reminded them that the goal was to create a game to help personas.

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[1] "Lagartixa" means gecko/lizard in Portuguese. The name for the persona has been misspelled as "Largatixa".

Andrew
Andrew likes sports, but he injured his knee and was traumatized. He is 28 years old and started having family problems since childhood. His parents are separated, causing a lot of pain in Andrew, who was raised by his grandparents. He fell in love with a girl who only made his life worse, only took it to the bottom. He plays the guitar and likes to talk to people. Andrew is humble, intelligent and likes to help others. He is participatory and has many friends. He is looking for help to improve his internal pain.

Carlos
Carlos is a very stressed person, has no family support and feels very alone. Carlos is 30 years old, he is convinced and proud. He always tries to solve everything himself, but he can't do it. Because of Carlos' way, people started to move away from him. He started doing volunteer work with children and the elderly to try to improve. He liked the volunteer work with children so much and he started study pedagogy in college. With the college he got a paid internship, which slightly improved his financial condition. His dream is to finish the college to work on projects with children.

José Largatixa
José Largatixa is 40 years old and suffers from alcoholism due to family alcohol history. He came from a sexist family who claimed that an adult man had to drink. If the other men in the family drank, he had to drink too. In addition to alcohol, José has also been a smoker since he was 10 - 11 years old. When he goes to "darkness" (train track) he is physically worn out (clothes, cleaning, looks, weight loss).

Lauany
Lauany is sentimental, she is a recent graduate in psychology and she is 23 years old. Even with her problems, she dedicates herself to work at CAPS-AD. She is doing yoga to relieve her stress. She was betrayed by her fiancé, went into depression and she is away from the service for treatment with a psychologist. In addition, she recently lost her mother. She has been meditating, doing yoga, ballroom dancing, going to the psychologist. She likes to read and write poems. With all this, she is improving her quality of life.
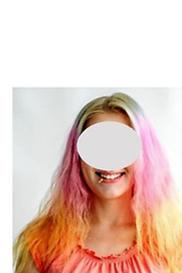
Gabi
Gabi is 20 years old and has been using substances since she was 15, when her parents separated. She says she started using it as an escape from her parents' constant fights. Gabi left school, left home, and went to live with her "friends" in an alley in the city. She went through situations that she didn't even know existed, used all kinds of substances, suffered abuse. At the age of 17 she was removed from the streets (from "hell" as she says) by the tutelary council and went to a shelter. When her parents finally met her again and she moved in with her mother. Gabi suffers from depression and had her self-esteem destroyed by the times she lived on the street. She has tried to stop substance use, but sometimes relapses. She cannot forgive her parents, saying that they are to blame for everything. Although she lives with her mother for 3 years, their relationship is not good. Gabi is undergoing psychological treatment in order to overcome her traumas and abandon substance use.

Pablo
Pablo is 25 years old, he is divorced and has a 3 years old daughter. In his life divided between moments of instability and mental and emotional stability, he managed to finish high school and, in his good times, he managed to work and live well with his daughter. Pablo is an alcoholic, having been introduced to alcohol by his father at the age of 5. He developed a mood disorder due to alcohol use. Today, after breaking up and barely being able to see his daughter, he started undergoing treatment to try to stop drinking and to control his mood. Pablo has had severe withdrawal crises and his shaking is already constant and hinders him when making certain movements, such as writing, cooking and using the computer.

Figure 6. Descriptions of the created personas. Source: The authors.

Table 2 shows a summary of the games created and the personas used in each game. The therapeutic features of the games, their scenarios, storytelling and scoring criteria are also briefly referred to in the table.

The Lepi tool was used to implement the games created. Lepi is a desktop tool for game development by and for ev-

Table 2. Summary of the games created and the personas used. Source: The authors.

Games / Personas Used	Therapeutic Content of the Game	Scenarios	Storytelling and Score
Game 1 / Andrew, Carlos, Gabi	Practicing sports and collective activities. Encouraging non-use of alcohol. Living with family, friends and using CAPS-AD.	CAPS-AD, soccer field, pool, party, square.	Playing sports: Deciding to play a sport – the character wins points and the family appears to cheer him. If the character decides not to play a sport, he/she loses points Party: If the character decides to drink alcohol, he loses points.
Game 2 / Gabi, José Largatixa, Pablo	Encouragement to seek help at CAPS-AD. Encouraging non-use of alcohol and other substances. Family support. Given an incentive to study.	CAPS-AD, square, grandparents' house.	Grandparents encourage their grandson to go to CAPS-AD for help. If the grandson goes to CAPS-AD he recovers, goes back to school and wins points. If the grandson does not go to CAPS-AD he goes to the square, where he meets colleagues who offer him alcohol and drugs. If he accepts them he loses points.
Game 3 / Carlos, Marcos	Encouraging social interaction. Practice of sport and music. Encouraging non-abuse of substances.	Court, square, music school.	The character is invited to play basketball; if he agrees, he gets points and manages to help a friend by encouraging him to start music lessons. If the character decides not to play and stays in the square, he is invited to use drugs. If he takes them he loses points.
Game 4 / Carlos, Marcos	Encouraging social interaction and to practice sport. Encouraging non-abuse of substances.	Court, square, street alley.	The drug user character can decide either to stay on drugs and thus lose points, or try to recover. To try to get over the problem, he can seek to practice sports.

eryone. In other words, Lepi is designed to provide the means to allow anyone to create digital games that others can play (Garcia, 2019). Figures 7a, 7b and 7c shows the creation of game scenes in Lepi, patients building the game and patients playing the created games.

(a) Construction of one of the scenes in the game created by Group 1.

(b) Patient constructing scenes from the Group 2 game.

(c) Patients playing one of the games created by Group 3.

Figure 7. Patients building and playing the created games. Source: The authors.

In all games the intention of the stories was for the players to think about better decisions and reflect on the consequences of their decisions. With this, we seek to encourage them to make more positive decisions in a real case. In the subsections 4.1, 4.2 and 4.3 present the games created by each of the groups.

After the creation of the games, there was a meeting in which the patients could play the games created by other colleagues. More details about this round of games are presented in subsection 4.4.

4.1 Details of the game created by Group 1

The game created by group 1 was based on the practice of sports. The group defined that the game's story would revolve around characters who attended CAPS-AD and were deciding which sport they were going to practice. The group also defined that the family should appear in the game. Figure 8 shows the first scene of the game and the scene in which the player must choose which sport to practice. The player also has the option of not playing any sport.
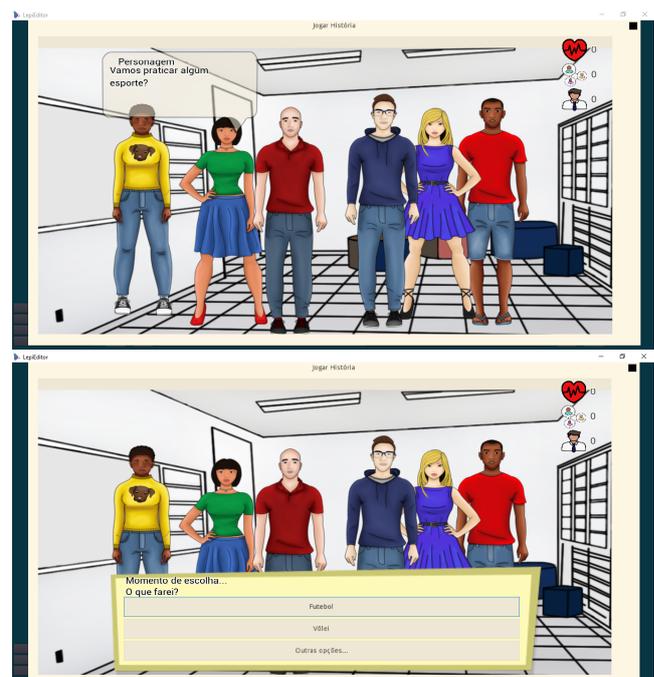
Figure 8. First scenes of the group 1 game. Source: Screenshot of the group 1 game.

The requirement to involve sports came from the characteristics of the Andrew persona. Andrew likes sports, has many friends and family problems, was raised by his grandparents after his parents split up.

With the practice of sports, the group also sought to encourage socialization, considering the characteristics of the Carlos persona. Carlos has difficulties in relating to people, he is very proud and convinced but he feels very alone.

Family and friends also appear in the game created by group 1. In the scenes in which the characters are playing sports, these people appear cheering them on (see Figure 9). In addition to the Andrew persona, Gabi also shows family-related characteristics. Gabi has family problems and blames

her parents who are separated for her problems, has low self-esteem, depression and has lived on the street.

Figure 9. Family and friends cheering for the characters. Source: Screenshot of the group 1 game.

The game's story ends according to the player's choices. The scene in Figure 9 has a positive outcome, meaning that the player made good choices and made good decisions throughout the game. The game has a negative outcome if the player chooses not to play sports.

Figure 10 shows a scene when the player chooses not to play a sport with his colleagues. In the scene the character appears in a square, feeling alone and soon after someone appears offering drugs for him.

Figure 10. Scene after the player chooses the option of not playing a sport with his teammates. Source: Screenshot of the group 1 game.

4.2 Details of the game created by Group 2

Group 2 chose the personas José Largatixa, Gabi and Pablo. The three chosen personas had family problems. José Lagartixa and Pablo had problems with alcoholism. Gabi had problems with false friends that led her to the drug path. The story in the game covered issues such as family, alcohol abuse and drugs abuse, traits that relate to the personas chosen by the group. Thus, the results of the game suggest that the patients used the personas, as intended, in the construction of the game.

The group defined, as requirements, that the game should include the family, education, therapeutic activities, encouraging behavior change and attendance at CAPS-AD. The story of the game created by group 2 begins with a conversation between a young man and his grandparents. The young man says that he is not well and that he is using alcohol and drugs as an escape mechanism for his problems. Figure 11 shows the screen where grandparents offer help asking if

their grandchild has already sought treatment and the screen where the player can choose an answer option.

Figure 11. Scenes of the group 2 game Source: Screenshot of the group 2 game.

Among the options presented in Figure 11, if the player makes the decision to go to CAPS-AD the story continues in the CAPS-AD scenario (see Figure 12). In the game's story, after the character goes to CAPS, he decreases substance use, goes through withdrawal crises, but continues with treatment. At the end of the story, the character manages to recover, which is the positive outcome of the game.

Figure 12. Character arriving at CAPS-AD. Source: Screenshot of the group 2 game.

If the player decides not to accept the help, the story goes to its negative outcome. In this case, the character meets friends (see Figure 13) who make him drink. However, the story of the game does not end like that, with this negative outcome. Even if the player does not choose to go to CAPS-AD at first, the story continues until the character remembers the grandparents' advice and decides to be treated.

4.3 Details of the games created by Group 3

Group 3 chose the personas Carlos and Marcos. Carlos' traits include feeling very alone, not having family support, and

Figure 13. Character in the square with friends offering alcoholic drink. Source: Screenshot of the group 2 game.

being proud. He does volunteer work and is trying to finish college. Marcos, on the other hand, stopped his studies after his parents divorced. With the bad company he was with, he entered the world of drugs. Considering the chosen personas, group 3 created 2 therapeutic digital games.

The requirements, specified by the group, for both games were to encourage making good friends, avoiding bad company, looking for a church or some form of spirituality. The group also defined that questions involving family and scenarios such as court, square, street, alley and graffiti should appear in the game.

The first game was about social interaction as a way to combat substance abuse. This game added questions about sports and music.

Figure 14 shows the scene of one of the positive outcomes of the game, when the characters decide to take a music class. With music they made good friendships, which motivated them for good actions. This game contains more scenes and a story that presents more decision options for the player. The story goes through decisions to play a sport or not, use drugs or not, take music lessons or not, among others.

Figure 14. Scene from one of the positive outcomes of game 1 of group 3. Source: Screenshot of the group 3 game.

One of the negative outcomes of the game is shown in Figure 15. In the scene, the player's decisions lead the characters to an alley where they are using drugs. They are approached by police officers and taken to the police station.

The second game created by group 3 starts with one character offering drugs to another. The player has the option to choose to use it or not. If the player chooses not to use drugs, the game goes to scenes where the character is playing sports with his friends (see Figure 16).

If the player's first decision is to accept the drug, in the next scene the character appears asking God for help in
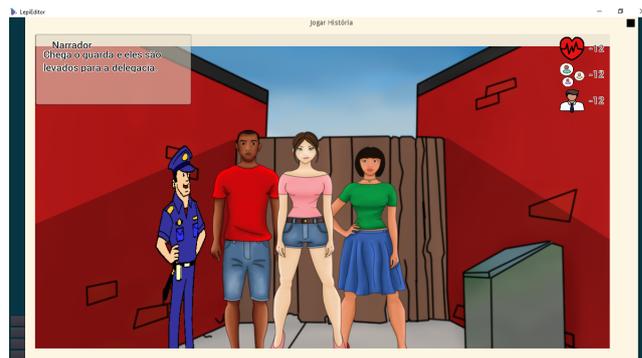
Figure 15. Scene from one of the negative outcomes of game 1 of group 3. Source: Screenshot of the group 3 game.

Figure 16. Scene of the character doing sport. Source: Screenshot of the group 3 game.

thought. At that moment the player has more options to choose (see Figure 17), continue in the drug world, go to the Church or look for a graffiti workshop.

Figure 17. One of the scenes with decision options. Source: Screenshot of the group 3 game.

4.4 Playing the games created by peers

After the creation of the games by the work groups, a meeting was held so that the patients could play the games created by peers. The purpose of the meeting was to provide interaction between patients and evaluate patients' emotional response after playing the games. All participants could play the games they created and the games created by their peers.

Figure 18 shows two pictures of patients playing the games. It was observed that they felt proud to show the games they made to their peers. Only one patient, still resistant to computer use, did not want to play the games.

After the patients played the games, we applied the Self-Assessment Manikin (SAM) (Bradley and Lang, 1994) to an-

Figure 18. Patients playing the games created by peers. Source: The authors.

alyze their emotional responses. SAM is a non-verbal assessment technique that directly measures happy, excited, and controlled associated with a person's affective reaction to a stimulus.

Thirteen patients wanted to respond to the SAM. Figure 19 shows the graph generated from the responses. Regarding happy, 12 indicated they had a high level of happy and 1 left the SAM line related to happy blank. In relation to excited, 9 responded being highly excited, 1 responded being medium to high excited and 3 responded being low excited. As for controlled, 1 indicated feeling low controlled, 1 indicated being neutral, 2 indicated feeling medium to high controlled, 8 indicated feeling high controlled and 1 left the SAM line related to controlled blank.
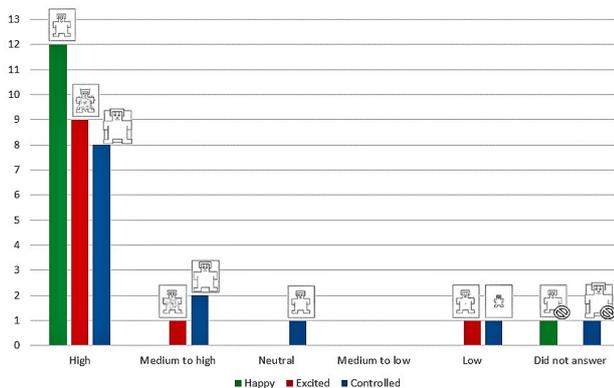

Figure 19. Graph of SAM application results. Source: The authors.

After analyzing the SAM responses, the results suggest that when playing the games, patients in general had a good emotional response. Most of them reported having a high rate of happy, excited and controlled.

It was also possible to verify, through observation, that they were happy and proud to show the games to their peers. And the patients also left suggestions for improvement for the games. For example, they suggested putting in every game a last screen with the character recovered by following the 'good path' proposed in the games.

5 Lessons Learned

After conducting an analysis of the entire persona creation process carried out in this project, we were able to determine eleven lessons that had been learned. The persona creation activities carried out by end-users and patients of CAPS-AD, were examined to find out these lessons. Account was also taken of how the personas created, were reflected in the therapeutic digital games that were developed. These lessons are the result of analyzing the generated artifacts and observing the work of the computer professionals (researchers) and the health professional who accompanied the activities.

The lessons learned were grouped into 3 categories, namely: Lessons on care when dealing with vulnerable people in this area; Lessons on patients as creators of personas; Lessons about the work team and their roles. Each of the 11 lessons is described below.

5.1 Care when dealing with vulnerable populations in this area:

(1) The cognitive and physical condition of the patients may be compromised. Patients who attend CAPS-AD tend to have cognitive and sometimes physical deficits, caused by their addiction to substance abuse throughout their lives. The psychologist who accompanied the activities highlighted this fact. In her view, people who usually go through CAPS-AD without experiencing any cognitive and/or physical deficits, are able to enter the labor market and society again. As a result, they do not identify with CAPS-AD activities and do not attend its meetings. Some of the patients also had a low level of literacy and difficulty with written activities. They were assisted by the professionals and colleagues during the activities that depended on reading and/or writing. Thus, it is necessary to take note of the activities being carried out and adapt them to the conditions of the patients.

(2) It is important to listen to patients and care about them. The time allocated to activities should include a period for welcoming patients, understanding their own motivations and assessing their willingness to speak and participate. Several patients want to speak, tell their own stories, and be part of the group. Thus, it is essential to listen to them in this situation. The CAPS-AD psychologist who followed the activities reported that many researchers go to CAPS-AD with the aim of just studying the patients, but this research was designed to give them something useful - the games created. It is necessary to care about the patients and not just be concerned with the results of the research.

(3) It is also important to know what vocabulary is appropriate to the domain. The language that is used by professionals and researchers must be carefully chosen within the context of the research. It is also necessary to pay attention to the behavior and attitudes of the participants. Professionals should also pay attention to how they behave themselves and how they communicate with patients. With re-

gard to this question, researchers must be relaxed, and speak calmly, slowly and confidently to avoid making patients agitated and apprehensive. The adopted language should avoid terms that might seem to belittle the self-esteem of the patients. In the activities carried out at CAPS-AD, some new terms often employed by computer professionals were learned, such as: i) substance abuse - i.e. the problem with the context is not use, but abuse; ii) substance users - the psychologist hardly ever referred to patients as alcohol and drug users, she referred to substance users; iii) disorganized - when patients are unable to avoid abuse, or are not working, or have problems at home. That is, when they are out of control, the psychologist referred to the expression "they are disorganized"; and iv) "in situation of street", in English homelessness - to refer to patients who are homeless.

(4) Practical examples should be given for each activity. The creation of personas is something new for patients and should be explained in a way that comes close to the language they understand. One possible way to explain how the activities and artifacts should be generated is through practical examples. It is thus deemed necessary to adopt a process of creating personas that are already instantiated, by showing examples of what they should do and what the expected results are.

(5) There is a large turnover of patients. When applying a sequential process in an open-door institution, such as CAPS-AD, it is necessary to learn how to deal with the question of "patient turnover". To get around this situation, it should be remembered, during each activity, that the objective of the project as a whole, is to show what has already been achieved and provide guidance on what can be expected from the following activities.

5.2   Patients as creators of personas:

(6) Patients are interested in technology. Most of the patients who took part in the project, were very interested in technology and in learning more about it. This is despite that fact that they previously had little knowledge of the use of technology. Before the computer could be used for carrying out activities, there was a need for previous training on its correct use. By using the computer, it was possible to determine how motivated the patients were and the learning made them feel more socially included.

(7) End-users (patients) are able to create personas. The studied patients managed to create personas that represent the domain for the rehabilitation of patients from substance abuse. With the support of the computer and health professionals, CAPS-AD patients were able to go through the Personas Enrichment Process (Rodrigues et al., 2014).

(8) Patients tend to create personas based on their real circumstances. In the analysis of the generated artifacts, it was possible to determine that the patients created the personas based on their own life experiences, and not only by summarizing data. It should be mentioned that this is indeed the goal of creating personas - to represent the users of a system in the most realistic way possible. Here are some examples:

1. In the activity of filling out the list of interested stake-

holders, one of the groups put the family as an interested party, while the other group did not want to do this since they maintained that the CAPS-AD staff was their family. According to the psychologist, this difference could be attributed to the life experience of the patients in both groups. The group that did not want to include the family had patients who were homeless;

2. While the group that had street patients portrayed their personas as still being in search of improvement or lacking optimism about their prospects of improvement, the other group created personas with optimistic situations, in which they had already recovered from their addictions;

3. The features of substance abuse were also more explicit in the group that had homeless patients;

4. Other questions that motivated this lesson learned were patients who wanted to name their children after the personas, or patients who stated that the persona created looked like a colleague from CAPS-AD, as well as patients who included stories of their lives or family members in the personas.

(9) The patients are able to identify with and feel affection for the personas created. When they were choosing the personas that they would use to create their games, the patients tended to select the personas created by themselves. The patients were divided into three groups to create the games. Each group could choose which personas they would use. The patients who took part in the creation of the personas wanted to use the personas they had created themselves rather than those created by other participants. Decisions made in games that have the potential to assist the treatment of personas (and based on their characteristics) appeared more often in games created by groups that had more members and who also took part in the creation of the personas. One of the personas created by the patients was not chosen – precisely the persona who was named after the daughter of one of the patients who helped to create it, but was not included in the game development activities.

5.3   The work team and their roles:

(10) The participation of health professionals is required. Health professionals have the theoretical and practical knowledge that is needed to deal with situations in the domain, which computer professionals are not trained to handle. It is health professionals who know the reality of the lives and history of the patients. They know the most appropriate language to use and are able to give patients guidance on how to carry out activities. With regard to the creation of personas and game development, the group which was most assisted by the psychologist added more real data related to the chosen domain. Thus, it is advisable that the number of health professionals should be chosen in accordance with the needs of the groups. Each group must contain at least one health professional and one computer professional.

(11) The participation of professionals in the field of computing is recommended. The activities carried out and the artifacts used to create the personas are far from

the real world of the patients and outside the domain of study of health professionals. In addition, several patients have little or no knowledge of technology, especially with computers, and it is necessary to train them on how to use the computer before carrying out the activities. Thus, computer professionals are needed to monitor the activities.

6 Conclusion and Suggestions for Future Work

This paper makes three key contributions, namely, the personas created by end-users, the games implemented by end-users based on personas, and the lessons learned from the process of creation. The process of creating personas and implementing of the games took place in the midst of a real environment for the rehabilitation of patients suffering from substance abuse, and involved the patients themselves actively participating in the creation process.

The persona creation activities were a part of a larger project, which aimed at designing therapeutic digital games for end users. The patients created the personas and later used the personas created to develop their own therapeutic digital games. Altogether 7 personas were created and 4 digital therapeutic games were built.

The personas created by the patients and outlined in this paper, have the potential to assist in the creation of other computer systems for similar domains to the one explored here. Moreover, as a result of the process carried out, the professionals identified 11 lessons that can serve as a guide for other researchers.

It should be emphasized that it was only possible to identify these lessons because the researchers (professionals in computing) had direct contact with the studied public. The activities were carried out in the patients' own environment (at CAPS-AD) and different results could be expected if the activities were carried out in a controlled environment (at the University, for example).

Among the lessons learned, the patients' ability to create personas stands out. Even though they had no knowledge of the techniques needed for creating personas and suffered from cognitive impairments, the patients managed to create personas after being given a brief explanation. In the case of other projects involving a similar audience, it should also be underlined that it is important to be familiar with the terms appropriate to the domain. There is also a need to know how to listen to patients and have at least one health professional and a computer professional for each group of patients.

The greatest limitation found from the researchers' standpoint was the high turnover of patients during the activities. As the Personas Enrichment Method requires sequential activities and owing to the format of the activities in CAPS-AD, it was not possible to structure the teams in a way that allowed all the members to take part in all the stages of the process on an ongoing basis.

A second limitation that has been identified is the lack of any evaluation of the therapeutic effects of the activities carried out. Only an observational analysis was conducted by the psychologist who accompanied the project, but there was no evaluation based on scientific methods.

In future works, it is recommended that a comparative analysis between personas created by patients and personas should be conducted by professionals. Another potentially valuable future study would be assessing the therapeutic potential of games created by patients with the personas. A third future work would be to apply the Personas Enrichment Process to other patients, either in the same domain or in domains concerned with assisting other pathologies.

Acknowledgements

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