Dissertação de Mestrado em Informática Médica

Development of a Smartphone application for Rheumatoid Arthritis self-management

Ana Rita Pereira Azevedo
2014
“Have the courage to follow your heart and intuition. They somehow already know what you truly want to become. Everything else is secondary.”

Steve Jobs
Dissertação de Mestrado em Informática Médica

Development of a Smartphone application for Rheumatoid Arthritis self-management

Supervisor: João Almeida Lopes Fonseca, MD., Ph.D.
Category: Auxiliary Professor
Affiliation: Faculty of Medicine, University of Porto

Co-supervisor: Àurea Rosa Nunes Pereira Lima, PharmD., M.Sc., Ph.D.
Category: Teacher Assistant
Affiliation: Department of Pharmaceutical Sciences, Higher Institute of Health Sciences – North, CESPU

Ana Rita Pereira Azevedo
2014
To my beloved family,
who among so many other things,
always support me.
Preliminary Note

I hereby declare that the work presented in this dissertation is my own work and that, to the best of my knowledge and belief, it contains original material, i.e. material that was not previously published or written by another person, or material accepted for any other degree or diploma of this university or any other institution of higher learning.

Porto, 6th August 2014

Ana Rita Pereira Azevedo

This dissertation has the collaboration of Faculty of Medicine of University of Porto (Faculdade de Medicina da Universidade do Porto), Rheumatology Service of the São João Hospital Center (Serviço de Reumatologia do Centro Hospitalar de São João), Molecular Oncology Group of the Portuguese Institute of Oncology – Porto (Grupo de Oncologia Molecular do Instituto Português de Oncologia – Porto) and Higher Institute of Health Sciences – North (Instituto Superior de Ciências da Saúde – Norte).
Acknowledgments

I would like to express my gratitude and heartfelt thanks to my supervisors João Fonseca (MD., Ph.D.) and Áurea Lima (PharmD., M.Sc., Ph.D.) for their guidance, motivation, rapid feedback and kindness throughout my dissertation. I could not do much without your guidance and support.

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I am thankful to people who participated in this study for their responses and cooperation. Your response to my questionnaire was important to the success of this dissertation.

I also take this opportunity to thanks my friends and colleagues for their support and feedback throughout my dissertation. Also I would like to thanks to Ricardo Correia (Ph.D.) for his rapid explanation about the phases this work should include and kindness to introduce me to my supervisor, which has a great knowledge about Smartphone applications development in health. I thank you all.

I would also like to express my gratitude to my lovely parents who have been tireless in encouraging and supporting me throughout my studies. Your wisdom and love has been motivation for my success.
Abstract

Introduction: Rheumatoid Arthritis (RA) is a chronic disease where self-management interventions are essential components of care to reduce RA burden. Smartphones have the potential to support in self-management tasks partly due to their ubiquity, portability, connectivity and capabilities.

Objectives: The main objective of this work was to develop a Smartphone application for supporting in RA self-management of Portuguese RA patients.

This work was divided in the following studies:

Study 1: A literature review was conducted to analyze the actual state of the art of Smartphone applications for RA self-management and revealed that research on development of such applications is sparse and there is none for Portuguese patients.

Study 2: A descriptive cross-sectional study was conducted with 100 patients with RA. A questionnaire was developed for the analysis of the usefulness of a RA self-management application, patients’ willingness to use and pay for it and the features the application should have. Descriptive statistical analyses and one sample t tests were performed. This study included more females (91.0%) and the mean age of the population was 57.3 ± 11.9 years. Patients reported having fear of disease lack of control (p=0.038), difficulty in dealing with feelings of sadness (p=0.005) and a bad global health (p<0.001). They presented multiple drug regimens (number of RA medications of 5.0 (2.0-15.0)) and a non-compliance rate of 40.0% mainly due to forgetfulness (67.5%). Ninety-four patients (94.0%) believed that they could have a more active role in self-management. Most patients (86%) reported it would be useful to develop a RA self-management application. Eighty-three percent of patients were willing to use a RA self-management application and 82% were willing to pay for it. The most cited features for self-management were information about disease and treatment and monitoring of disease and quality of life over time.

Study 3: The development of the Smartphone application – “Diário da AR” - included the steps of definition of functional requirements using the questionnaire’s results and literature review, and non-functional requirements, creation of use-cases diagrams, event list and, identification of system stakeholders and interface design. The “Diário da AR” should allow long-term recording and monitoring disease activity, provide step-by-step advises for living better with RA, alerts for taking medication or other tasks, register adverse drug reactions and enable viewing past actions and sharing.

Conclusion: This study suggests the usefulness and patients’ willingness to use and pay for a RA self-management application and provides insight on patients’ needs. Overall, the application has potential to be an innovative medium to endow patients to develop self-management skills.

Keywords: Rheumatoid Arthritis; Self-management; Smartphone application.
Resumo

**Introdução:** A artrite reumatóide (AR) é uma doença crónica na qual as intervenções de autogestão são componentes essenciais de saúde para reduzir o impacto desta doença. Os Smartphones têm potencial para auxiliar nas tarefas de autogestão, em parte devido à ubiquidade, portabilidade, conectividade e capacidades destes dispositivos.

**Objetivos:** O objetivo principal deste trabalho foi desenvolver uma aplicação para Smartphone para auxiliar na autogestão da AR pelos Portugueses com esta doença. Este trabalho foi dividido nos seguintes estudos:

**Estudo 1:** Uma revisão da literatura foi realizada para analisar o estado atual da arte de aplicações para Smartphone para a autogestão da AR e revelou que a investigação sobre o desenvolvimento destas aplicações é escassa e não existe nenhuma aplicação deste tipo para os Portugueses com AR.

**Estudo 2:** Um estudo transversal descritivo foi realizado com 100 doentes com AR. Foi elaborado um questionário para a análise da utilidade de uma aplicação Smartphone para a autogestão da AR, da predisposição dos doentes para usar e pagar por esta e as características que a aplicação deverá ter. Foram efetuadas análises estatísticas descritivas e testes t de uma amostra. Este estudo incluiu mais mulheres (91,0%) e a idade média da população foi de 57,3 ± 11,9 anos. Os doentes referiram terem medo da perda de controlo sobre a doença \( p=0,038 \), dificuldade em lidar com sentimentos de tristeza \( p=0,005 \), e avaliaram a sua saúde global como má \( p<0,001 \). A população apresentou regimes terapêuticos múltiplos (número de medicamentos para a AR de 5,0 (2,0-15,0)) e uma taxa de não adesão à terapêutica de 40,0%, principalmente devido ao esquecimento (67,5%). Noventa e quatro doentes (94,0%) acreditavam que poderiam ter um papel mais ativo na autogestão da sua doença. A maioria dos doentes (86%) achavam útil desenvolver uma aplicação de autogestão da AR. Oitenta e três por cento estavam dispostos a utilizar uma aplicação de autogestão da AR e 82% pagariam por esta. As características mais citadas para a autogestão foram a informação sobre a doença e tratamento e a monitorização da doença e da qualidade de vida ao longo do tempo.

**Estudo 3:** O desenvolvimento da aplicação Smartphone – “Diário da AR” - incluiu as etapas de definição de requisitos funcionais, usando os resultados do questionário e a revisão da literatura, e de requisitos não-funcionais, criação de diagramas casos-uso e lista de eventos, identificação dos stakeholders do sistema e design da interface. O “Diário da AR” deverá permitir monitorizar e guardar a atividade da doença a longo-termo, fornecer conselhos passo-a-passo para viver melhor com AR e alertas para tomar a medicação ou outras tarefas, registar reações adversas de medicamentos e permitir a visualização do histórico e partilhar.

**Conclusões:** Este estudo sugere a utilidade e a predisposição dos doentes com AR de
usar e pagar por uma aplicação *Smartphone* para auxiliar na autogestão da RA e fornece informação sobre as necessidades dos doentes. No geral, a aplicação tem potencial para ser um meio inovador para dotar os doentes a desenvolver capacidades de autogestão.

**Palavras-chave:** Artrite Reumatoide; Autogestão; Aplicação *Smartphone*.
Preamble

Using mobile phones for health-related purposes have been studied for some years now and new concepts such as mobile health have been introduced. Mobile health is believed to have a great potential in taking health-related applications to a higher level especially with the introduction of the Smartphones. The ubiquitous nature of Smartphones, the advantages of being personal, portable, connected, intuitive and computationally powerful, and the capability to support applications (“apps”), highlights the need to explore this technology as a way of assisting with the adoption and maintenance of self-management behaviors.

Self-management, a subset of self-care, is defined as a decision to be actively involved in managing a disease and develop practical skills to effectively self-manage. Self-management interventions are a key factor in Rheumatoid Arthritis due to the chronic and progressive character of this disease. Recent literature suggests that traditional self-management interventions can empower Rheumatoid Arthritis patients to become effective health-care consumers in addition to improving clinical outcomes. Although and despite all the advantages, at this moment, research relating to the development and evaluation of Smartphone applications for Rheumatoid Arthritis self-management is sparse. In addition, there are any applications in Portuguese from Portugal for this purpose. In this context, emerged the idea of develop a Smartphone application for supporting in Rheumatoid Arthritis self-management by Portuguese with this disease.

The structure of this dissertation is divided as follows:

Chapter 1. Introduction
This introductory chapter provides a brief description of Rheumatoid Arthritis, explains the role of self-management interventions in this disease, and exploits the applicability of Smartphone applications for Rheumatoid Arthritis self-management.

Chapter 2. Objectives
This chapter presents the main and secondary objectives of this work.

Chapter 3. Justification
This chapter describes all the facts and knowledge that supported/justified this investigation work arising from the literature review.

Chapter 4. Study 1: Literature review
This chapter was conducted to analyze the actual state of the art of Smartphone
applications for RA self-management and includes all the information about the search strategy and its results.

Chapter 5. Study 2: Needs assessment
This chapter describes the methodology used for the realization of the questionnaire and the results obtained from the questionnaire’s analysis.

Chapter 6. Study 3: Development of a Smartphone application
This chapter provides the description of the stages of Smartphone application development.

Chapter 7. General conclusion
This chapter presents the general conclusions of this work.

Chapter 8. Future Work
This chapter presents and discusses the future work.
Scientific and Financial Results

With regard to scientific contributions, the following papers were submitted to a scientific journal with international circulation:


- Rita Azevedo, Miguel Bernardes, João Fonseca, Aurea Lima. **Smartphone application for Rheumatoid Arthritis self-management: cross-sectional study revealed the usefulness, willingness to use and patients’ needs.** 2014. Original article. [Submitted]

The idea of this M.Sc. work was submitted to the 5th edition of the “Fraunhofer Portugal Challenge”, an idea contest promoted by Fraunhofer AICOS with the objective of motivating and rewarding research of practical utility, through the attribution of a scientific prize to M.Sc./Ph.D. Students and Researchers from Portuguese Universities in the areas of ICT, Multimedia and other related Sciences. The idea reached to 2nd phase (in 3 phases) of this challenge.

The work of this dissertation did not received financial or scientific funding from any organization.
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# Acronyms & Abbreviations

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<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>3G</td>
<td>Third Generation</td>
</tr>
<tr>
<td>ACR</td>
<td>American College of Rheumatology</td>
</tr>
<tr>
<td>ADR</td>
<td>Adverse Drug Reactions</td>
</tr>
<tr>
<td>ADT</td>
<td>Android Development Tools</td>
</tr>
<tr>
<td>API</td>
<td>Application Programming Interface</td>
</tr>
<tr>
<td>b/min</td>
<td>Beats for Minute</td>
</tr>
<tr>
<td>DAS28</td>
<td>Disease Activity Index 28</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>European Quality of Life Five Dimensions</td>
</tr>
<tr>
<td>EULAR</td>
<td>European League Against Rheumatism</td>
</tr>
<tr>
<td>EuroQoL</td>
<td>European Quality of Life</td>
</tr>
<tr>
<td>HAQ</td>
<td>Health Assessment Questionnaire</td>
</tr>
<tr>
<td>HAQ-DI</td>
<td>Health Assessment Questionnaire - Disability Index</td>
</tr>
<tr>
<td>IDE</td>
<td>Integrated Development Environment</td>
</tr>
<tr>
<td>JDK</td>
<td>Java SE Development Kit</td>
</tr>
<tr>
<td>kg</td>
<td>Kilogram</td>
</tr>
<tr>
<td>m</td>
<td>Meter</td>
</tr>
<tr>
<td>mg/dl</td>
<td>Milligrams for Deciliter</td>
</tr>
<tr>
<td>mHealth</td>
<td>Mobile Health</td>
</tr>
<tr>
<td>mmHg</td>
<td>Millimeters of Mercury</td>
</tr>
<tr>
<td>NUTS III</td>
<td>Nomenclatura Comum das Unidades Territoriais Estatísticas – Nível III</td>
</tr>
<tr>
<td>OS</td>
<td>Operating System</td>
</tr>
<tr>
<td>PDF</td>
<td>Portable Document Format</td>
</tr>
<tr>
<td>RA</td>
<td>Rheumatoid Arthritis</td>
</tr>
<tr>
<td>RAID</td>
<td>Rheumatoid Arthritis Impact of Disease</td>
</tr>
<tr>
<td>RAQoL</td>
<td>Rheumatoid Arthritis Quality of Life</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>SDK</td>
<td>Software Development Kit</td>
</tr>
<tr>
<td>SMS</td>
<td>Short Message Service</td>
</tr>
<tr>
<td>UML</td>
<td>Unified Modelling Language</td>
</tr>
<tr>
<td>URL</td>
<td>Uniform Resource Locator</td>
</tr>
<tr>
<td>VAS</td>
<td>Visual Analog Scale</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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1. Introduction
1. Introduction

This introductory chapter provides a brief description of Rheumatoid Arthritis, explains the role of self-management interventions in this disease, and exploits the applicability of Smartphone applications for Rheumatoid Arthritis self-management.

1.1 Rheumatoid Arthritis

Rheumatoid Arthritis (RA) is a complex, systemic autoimmune disease, typically characterized by a chronic and symmetric inflammation of multiple peripheral joints, which leads to destruction of cartilage and bone, progressive deformity and severe disability (Imboden et al., 2006; Smith et al., 2011).

The worldwide prevalence of RA is relatively constant ranging from 0.3% to 1.1% (Myasoedova et al., 2010; Silman & Pearson, 2002) and the incidence rates vary from 9 to 60 cases per 100,000 inhabitants (Carbonell et al., 2008; Myasoedova et al., 2010). In Portugal, the prevalence of this disease is 0.36% and the incidence is not known, still should follow the same trend of Southern European countries (9 to 24 cases per 100,000 inhabitants) (Branco & Canhao, 2011; Carbonell et al., 2008). RA affects more the feminine gender, with a gender ratio from about 2:1 to 3:1 (Alamanos & Drosos, 2005), and the peak disease onset occurs at the fifth decade of life (Rindfleisch & Muller, 2005).

RA usually affects up to 80% of patients within one year of diagnosis (Aletaha et al., 2010; McInnes & Schett, 2011). The distinct pattern of bone and joint destruction is translated in pain, stiffness (worse in morning) and swelling of involved joints, which difficult the routine activities (Imboden et al., 2006; Smith et al., 2011). In fact, RA patients are less physically active than general population (Hootman et al., 2003). Nevertheless, physical activity is crucial for maintain physical health and wellness and reduce pain (Cooney et al., 2011; Vliet Vlieland & van den Ende, 2011), which is positively related to several psychological factors (e.g. self-esteem, pain coping and self-efficacy) (Creamer et al., 1999). Additionally, there is also a persistent systemic inflammatory state present that may promote a number of other extra-articular manifestations such as lung fibrosis, osteoporosis, rheumatoid nodules, infections and cardiovascular, hematologic and gastrointestinal diseases (Smith et al., 2011; Tobon et al., 2010). These systemic complications related to the underlying disease process impact the average life expectancy of patients with RA, which is reduced by ten years in the female gender whereas in male gender is diminished by four years, and are responsible for increased morbidity (Akil & Amos, 1995). No less important is the fact that about 20% of patients with RA have approximately 2-fold to 4-fold higher risk of developing affective disorders (e.g. depression and anxiety) than general population (Margaretten et al., 2011).
Introduction

Given the characteristics of RA, there is a need for patient's long-term monitoring in order to minimize the negative impact of the disease on patient's quality of life (Rindfleisch & Muller, 2005). There are several patient-centered methods used for self-monitoring the disease that take into account the quantification of the disease activity, and of the health-related quality of life impact (Bruce & Fries, 2003; Leeb et al., 2008). The ability to effectively measure health-related quality of life longitudinally is central to describing the impact of disease or treatment (Bruce & Fries, 2003).

RA affects not only the patient but also the society in general, since the disease represents great economic losses mostly caused by work withdrawal due to failure or pain associated with the disease, loss of work productivity and constant use of health care services (Kvien, 2004). An earlier detection of RA, a rapid effective therapeutic institution and treatment compliance are crucial factors to achieve the disease remission (Smolen et al., 2014). Nevertheless, treatment non-compliance is a common, complex and costly problem in RA (Elliott, 2008; Neame & Hammond, 2005; van den Bemt et al., 2009; van den Bemt & van Lankveld, 2007). In fact, average non-compliance rate to chronic medication therapy is about 50%, mostly because RA is a chronic condition that often requires multiple drug regimens (Iihara et al., 2004; van den Bemt et al., 2009). Non-compliance can be intentional or unintentional and is influenced by patient characteristics (e.g. educational levels and socioeconomic levels), treatment factors (e.g. multiple drug regimens and chronic medication) and patient-rheumatologist issues (Elliott, 2008; Neame & Hammond, 2005). Intentional non-compliance reflects a rational decision-making process by the patient to not take the drugs or make a different dosage as instructed based on perceptions, feelings or beliefs that drugs will not relieve symptoms, improve quality of life and/or will cause adverse drug reactions (ADRs) or dependence (Elliott, 2008; Lehane & McCarthy, 2007; Neame & Hammond, 2005). On the other hand, unintentional non-compliance involves intending to take a medication as instructed but failing to do so for some reason (e.g. forgetfulness or carelessness) (Elliott, 2008; Neame & Hammond, 2005). The unintentional non-compliance is the most common type of non-compliance (Table 1) (Wilson Health Information & The J. Scott Group, 2006).

<table>
<thead>
<tr>
<th>Reason for non-compliance</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td><strong>Unintentional</strong></td>
<td></td>
</tr>
<tr>
<td>Forgot to take</td>
<td>79.0</td>
</tr>
<tr>
<td>Ran out of medication</td>
<td>19.0</td>
</tr>
<tr>
<td><strong>Intentional</strong></td>
<td></td>
</tr>
<tr>
<td>Too costly</td>
<td>9.0</td>
</tr>
<tr>
<td>Patient-perceived lack of need</td>
<td>9.0</td>
</tr>
<tr>
<td>Side effects</td>
<td>7.0</td>
</tr>
<tr>
<td>No improvement seen</td>
<td>3.0</td>
</tr>
</tbody>
</table>

Adapted from reference (Wilson Health Information & The J. Scott Group, 2006)
RA treatment is not only based in pharmacologic strategies. Nowadays, the large majority of patients have been told to try at least one type of non-pharmacologic treatment, such exercise therapy, physical modalities (e.g. thermotherapy and massage) and self-management interventions (Li et al., 2004).

1.2 Self-management interventions

Self-management has been defined as the “patient ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (Barlow et al., 2002). It is characterized by several subcomponents such as self-education (e.g. goal setting and problem solving), self-monitoring, self-measurement, self-evaluation, self-treatment and self-comparison.

Self-management interventions, besides being problem-focused and action-oriented, emphasize patient-centered care plans that include educational, behavioral and cognitive approaches, in order to influence health knowledge, attitudes, beliefs and behaviors (K. R. Lorig & Holman, 2003). These are seen as key components of rheumatologic care (Kendall et al., 2011), aimed to directly and/or indirectly improve health-related quality of life of the most important health domains for RA patients (e.g. pain, disability, depression and global disease severity (Figure 1)), healthcare utilization (total clinical visits to physicians and rheumatology-related visits) and perceived self-efficacy (reflection of patient confidence to exercise control over the disease) (Goeppinger et al., 2007; Nour et al., 2006, 2007; Patel et al., 2009). To achieve these patient- and healthcare-related improvements, RA self-management interventions cover several subjects, as follow: 1) educational and psychosocial interventions; 2) lifestyle interventions; and, 3) treatment interventions (Figure 2) (Goeppinger et al., 2007; Goeppinger et al., 2009; K. Lorig et al., 2005; K. R. Lorig & Holman, 2003; K. R. Lorig et al., 2008; Nour et al., 2006, 2007; Patel et al., 2009).

Figure 1. Most important health domains for Rheumatoid Arthritis patients. Adapted from reference (Laure Gossec, 2010).
Figure 2. Self-management interventions in Rheumatoid Arthritis.
Recent literature suggests that traditional RA self-management interventions such as face-to-face or internet-delivered can empower patients to become effective health-care consumers in addition to improving clinical outcomes (Bernatsky et al., 2012; Dures & Hewlett, 2012; Foster et al., 2007; Garnefski et al., 2013; Goepfinger et al., 2007; Goepfinger et al., 2009; K. Lorig et al., 2005; K. R. Lorig et al., 2008; Nour et al., 2006, 2007; Patel et al., 2009; Reid et al., 2008). In addition, these programs are both important and satisfying to patients (K. R. Lorig et al., 2001). Nevertheless, there are several problems in these self-management interventions that include the difficulty in involving patients, physicians and organizations; issues in evaluating them; and, their limited success both in terms of content, timing and economic and social impacts (Glasgow et al., 2008; Kendall et al., 2011; Lind-Albrecht, 2006; Riemsma et al., 2004) (Subchapter 1.3.2 Importance of Smartphone Applications for Self-management). One economically and socially viable solution to mitigate some of these problems is exploiting the benefits of modern technologies, using Smartphone applications.

1.3 Smartphones in self-management

Internet technologies have yielded advances in telemedicine and teleHealth and, subsequently, are now used in every modern health care organizations (Mariani & Pego-Fernandes, 2012). Due to the advances of these technologies, barriers of space and time between healthcare providers and patients have been broken and a new term in the field of teleHealth emerged: mobile health (mHealth) (El Khaddar et al., 2012). As defined by the World Health Organization (WHO), mHealth, a component of electronic health (eHealth), is a “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants and other wireless devices” (Martinez-Perez et al., 2013). Although personal digital assistants experienced a growth between 1990s and early 2000s, they have been replaced by other mobile devices with new functions and utilities, such as Smartphones (Martinez-Perez et al., 2013).

1.3.1 Smartphone: An Emerging Technology in Health

Smartphones are defined as mobile telephones with computer features that may enable them to interact with computerized systems, send e-mails and access the web (Mosa et al., 2012). The Smartphone market is growing quickly and there are already more than 1.20 billion Smartphones of a total of 5 billion mobile phones around the world, with women taking the lead (56% owning a Smartphone) (Figure 3) (GO-Gulf.com Web Design Company, 2012; Mosa et al., 2012; Ogilvy Action, 2012; Statista, 2014). These have the advantages of being personal, intuitive, user-friendly, computationally powerful, with larger and higher resolution display screens, sensor-rich (e.g. high quality cameras, recording devices, accelerometers and geo-positioning systems), connected and portable (Fogg & Adler, 2009; Patrick et al., 2008). The internal sensors offer diverse possibilities such the ability to infer context (user location, movement and emotion) and the connectedness facilitates the sharing of health data with health professionals or peers (Patrick et al., 2008).
As portable devices, they are highly valued by individuals, tend to be switched on and, remain with the owner throughout the day and everywhere, which offers the opportunity of bring interventions into real life context (Patrick et al., 2008; Venta et al., 2008). Moreover, the capability of Smartphones to support software programs, known as applications (“apps”), has stimulated significant attention in recent years and since Smartphones global acceptance is increasing quickly, there is a great opportunity for mHealth in using these applications.

Similarly to Smartphone owing, women take the lead when it comes to using health applications, with greater use in certain life events (e.g. pregnancy) (Oglivy Action, 2012; Rotheram-Borus et al., 2012). There is already a growing body of evidence that supports the use of Smartphone applications in health interventions. Many thousands of commercial applications may provide cheaper, more convenient, continuous, automated tracking of health and timely interventions for specific contexts without users special training (Patrick et al., 2008). Those aiming to improve health, tend to provide information, advice, instruction, prompts, support, encouragement, and interactive tools for individuals to monitor, record and reflect (Patrick et al., 2008). Smartphone applications may address a wide variety of purposes and contexts, such as for promoting behavior changes, for example smoking cessation (Abroms et al., 2011; Buller et al., 2014), weight management and physical activity promotion (Allen et al., 2013; Bexelius et al., 2011; Carter et al., 2013). These provide a unique opportunity to help users stay healthy, while potentially playing a key role in helping to prevent disease onset (Dennison et al., 2013; Wac, 2012). Moreover, applications may improve diseases tracking and monitoring process, for example, melanoma screening (Rosado et al., 2012) and quantitative assessment of the curvature in diagnosis of scoliosis (Qiao et al., 2012). In addition, applications can be applied for the self-management of diseases, mainly chronic, such as Diabetes mellitus (Quinn et al., 2008), Asthma (Marcano Belisario et al., 2013) and RA (Shinohara et al., 2013; Yamada et al., 2012).

Figure 3. Global Smartphone shipments from 2009 to 2014 (in million units) and forecast until 2018. Adapted from reference (Statista, 2014).
1.3.2 Importance of Smartphone Applications for Self-management

Smartphone applications have several advantages compared to traditional RA self-management interventions because they allow:

1) Long-term self-monitoring of symptoms, activity of disease and health-related quality of life, which are central to describe the impact of disease or treatment (Bruce & Fries, 2003) and minimize the negative impact of disease on patient’s quality of life (Rindfleisch & Muller, 2005) and, of treatment compliance, which is of great importance since non-compliance rate is about 50% in RA (van den Bemt et al., 2009);
2) “In moment” information, to take any doubt instantaneously at any moment and place without needing to wait for periodic traditional interventions;
3) Constant perception by patients of self-efficacy in disease managing, which can reduce the development of affective disorders (more incident in RA patients than in general population (Geenen et al., 2012));
4) Incorporation of medication reminding systems that involve the patient in the self-medication process and provide them access to their compliance data or other educational information (Harbig et al., 2012);
5) Incorporation of step-by-step techniques and tips for e.g. teach how to do appropriate exercise, maintain an adequate nutrition and healthy behavior and manage disease complications, with the possibility for patients to turn back and re-read.

As previously referred, Smartphone applications have potential to mitigate traditional self-management interventions problems’, as briefly reviewed below.

Achieving engagement of patients, physicians and organizations with self-management programs is challenging (Glasgow et al., 2008). Particular patient groups are less engaged with traditional programs such as patients with low levels of health literacy and low socioeconomic status, or patients from culturally and linguistically diverse communities (Glasgow et al., 2008). Smartphone applications can partially solve this problem since these applications can be utilized without special training, contain user-friendly visual graphics and speech in animations, can be provided in all languages with minor modifications to the intervention and reach almost all communities (Patrick et al., 2008). In fact, applications that use animation are particularly gaining popularity in patient education and other self-management interventions because they can improve the delivery and presentation of the content (Jibaja-Weiss & Volk, 2007). Nevertheless, the Smartphone applications engagement may also vary according to age, gender and socioeconomic levels. For example, many patients do not have Smartphones or do not fully understand how to use them (Wayne & Ritvo, 2014).

Access to self-management programs is an issue for some patients, especially those working full time or living in rural and remote communities. Most programs are face-to-face interventions, which may be difficult for those who work full-time to attend a program during the day (Lind-Albrecht, 2006). Although some programs offer evening sessions,
participation can be hindered by fatigue after a long workday (Lind-Albrecht, 2006). Also, for those living in rural and remote areas, such programs may not be readily available. Smartphone applications provide good flexibility for delivering health information and resources at a time and place chosen by the individual (Patrick et al., 2008). Other advantage is that they allow the easy sharing of daily health and activity information among the patient and health professionals without the need to travel (Shinohara et al., 2013).

Evaluation of self-management interventions has problems in terms of frequency and methodology. Since the evaluation occurs in stages before, during and after intervention, it represents a range of snapshots along a continuum, which may miss the full impact on the patient (Lind-Albrecht, 2006). In addition, differences in outcome data may occur depending on who has asked questions and how questions were asked (Lind-Albrecht, 2006). Smartphone applications offer a promising method for delivering a variety of medical and psychosocial treatments and for prospectively assessing treatment outcomes in patients’ typical environment, by a continuous way, rather than depending on a return clinic visit for post-treatment assessment (Bromberg et al., 2013).

While health professionals embrace self-management education, because these programs are standardized, concerns have been raised that traditional self-management programs lack the flexibility to incorporate individuals’ existing self-management skills, life circumstances and resources (Kendall et al., 2011). In fact, evidence demonstrates that those who benefit from structured self-management programs tend to have a higher education level (Newbould et al., 2006). Moreover, a study in adolescents with chronic rheumatic diseases suggests that these may need additional support to achieve independence in self-management (Lawson et al., 2011). This suggests that structured programs may not be sufficient for all patients. Smartphone applications can be useful for this issue because more and more they are reaching to all, independently of age, education level or socioeconomic environment (GO-Gulf.com Web Design Company, 2012; Mosa et al., 2012). In accordance, one study demonstrated that elderly patients with no previous experience with information and communication technologies were capable of effectively using a Smartphone application (Mira et al., 2014).

Another issue is the timing of self-management interventions. Most self-management programs were tested in patients five to ten years after diagnosis (Riemsma et al., 2004). The advantage of offering these interventions to patients who are early diagnosed has not been fully explored. Still, sociopsychological research suggests that after a major life experience (e.g., having a child) or a health event (e.g., a disease) people tend to be more amenable to adopt healthy behaviors (Blanchard et al., 2003). This “teachable moment” is thought to be the ideal time for self-management interventions because people are more motivated (Grindrod et al., 2010). Although the mechanism of this behavior change was unclear, the diagnosis of RA may present a “teachable moment” for engaging patients in self-management behaviors. Smartphones can be very helpful in that moment by capturing in the moment reports and provide immediate feedback and recommendations targeting symptom reduction and improved functioning (Bromberg et al., 2013). For instance, Smartphone applications could teach patients in-the-moment coping techniques and prompt practice in response to current symptoms (Bromberg et al., 2013).
2. Objectives
2. Objectives

This chapter presents the main and secondary objectives of this work.

The main objective of this work was to develop a Smartphone application for supporting in RA self-management by Portuguese with this disease. The application should actively endow patients to develop and maintain skills to effectively self-manage the disease and, ultimately, to directly and/or indirectly improve health-related quality of life, healthcare utilization and perceived self-efficacy.

As secondary objectives, the present work included the following studies:

- **Study 1: Literature review** - Exploitation of the actual state of the art of Smartphone applications for RA self-management.

- **Study 2: Needs assessment** of RA patients for a Smartphone application for RA self-management. Development of a questionnaire based in standard and validated questionnaires in area and literature for the analysis of the following:
  
  2.1. Usefulness of a Smartphone application to support RA self-management;
  2.2. Willingness of RA patients to use and pay for a Smartphone application to support RA self-management;
  2.3. Functional features the application should have to support self-management of RA.

- **Study 3: Development of a Smartphone application** by the following steps:
  3.1. Definition of functional requirements using the questionnaire’s results and literature and non-functional requirements;
  3.2. Creation of use-cases diagrams, event list, and identification of system stakeholders;
  3.3. Interface design.
3. Justification
3. Justification

This chapter describes all the facts and knowledge that supported/justified this investigation work arising from the literature review.

Patient-directed Smartphone applications have great potential to support RA self-management interventions. This potential stems from Smartphone having now achieved such a pervasive presence in society, it is a personal device and it assists its user throughout different daily life activities and environments persistently, and provides several advantages compared to traditional interventions. Although, at this moment, and despite all the advantages, there is lack of literature exploring this sort of applications and the few existing are in prototype stage. There are innumerous Smartphone-based medical applications available in online application stores (e.g., Apple’s App Store) directed for RA not described in the literature. Nevertheless, most of these applications fail to: 1) provide a solid evidence-based approach to ensure applications’ credibility, because almost anyone can write and post a Smartphone application, and thus, most applications do not adhere to evidence-based literature; 2) certify that there is sufficient health professional and target-users involvement in applications’ design and content; 3) guarantee that applications are provided in a reliable way, since it influences their usability; 4) make sure that concerns in relation to security and privacy are attended; and, 5) indicate all possible conflicts of interest, since, in some cases, applications are industry-driven, hence exposing bias in information provided, including bias towards particular types of treatment or intervention procedures. Therefore, all the potential of these Smartphone applications is not being completely well explored. So it is extremely important to develop more applications for self-management of RA, preferentially considering these five key challenges, which will determine the success or the failure of such applications. In line with this, and since the today’s digital age patients will be the tomorrow patients, the main objective of this work was to develop a Smartphone application for supporting in RA self-management by Portuguese with this disease. The development of such Smartphone application is a novel approach to assist in self-management of Portuguese patients with RA.
4. Study 1: Literature review
4. Study 1: Literature review

This chapter was conducted to analyze the actual state of the art of Smartphone applications for RA self-management and includes all the information about the search strategy and its results.

4.1 Search strategy & selection criteria

The search was performed using the PubMed database and bibliographies of retrieved articles were screened for cited references to identify additional publications not indexed in the search database. In addition, the search was performed in the online official stores, e.g. Apple store and Android market. The search strategy included one or a combination of the following terms: “application”, “app”, “compliance”, “disease activity”, “management”, “medical”, “mobile applications”, “mobile phone”, “monitoring”, “Rheumatic Diseases”, “Rheumatoid Arthritis”, “self-management”, “self-monitoring”, “Smartphone”, “treatment” and “therapy.”

Studies and Smartphone applications were selected according to the following criteria:

- Were written in English or Portuguese languages;
- Were aimed for RA or Rheumatic Diseases in general;
- Analyzed strategies of self-management in health (e.g. self-monitoring, self-tracking, self-learning);
- Had the involvement of Smartphone technology (studies);
- Had full version available;
- Freely available or with a free short demo version (applications);
- Applications were excluded if had country constraints or had technical problems (applications).

4.2 Results

The results of the search strategy about the theme resulted in a review article (Annex 10.1 and Scientific and Financial Results) that demonstrated the importance of developing a Smartphone application for Rheumatic Diseases self-management. Information of this review was included whenever relevant in the introductory chapter of this dissertation (Chapter 1). In this subsection it is only presented the state of the art of Smartphone applications for RA self-management obtained from search strategy.
Recently, there has been an increase in the use of digital media technologies (e.g., websites, Smartphone applications and social networking tools) to deliver self-management interventions (Goeppinger et al., 2009; K. R. Lorig et al., 2004; K. R. Lorig et al., 2008; Shinohara et al., 2013; Yamada et al., 2012).

4.2.1 Literature

In literature, only two applications were aimed for RA self-management. Shinohara et al. developed a sharing system for Android platform that gathers objective data from RA patients on a daily basis via Smartphone (self-monitoring) and shares this data with health professionals (Shinohara et al., 2013). The shared data comprised in gait pattern analysis by sensors and self-evaluations of the modified health assessment questionnaire (HAQ), tender joint count and swollen joint count (in accordance with the 49 or 46 joints used by the American College of Rheumatology - ACR), pain visual analog scale and quantification of daily activity (Figure 4) (Shinohara et al., 2013). The application for Smartphone was evaluated only in terms of feasibility and results demonstrated that the rate of patient usage was very high, even though some patients had no experience in using Smartphones (Shinohara et al., 2013).

Yamada et al. created a Smartphone application for self-assessment of gait patterns for Android platform and analyzed it in terms of utility for RA (Yamada et al., 2012). The Smartphone have to include an acceleration sensor, a recording device and a computer program, for processing the acceleration signals, and have to be attached to the L3 spinous process using a semi-elastic belt. Trunk linear accelerations were measured using the Smartphone while the subject walks on the walkway. The results suggested that some gait parameters recorded using the Smartphone represent an acceptable assessment tool for gait in patients with RA (Yamada et al., 2012).

At the moment these two applications are still in the prototype stage.

Figure 4. Sharing system overview.
Left: Main menu of Smartphone application with English translation. Center: Gait measurement screen after 8 seconds. Right: Screen of inputting the number of tender joints and swollen joints by touching the pertinent joints on the screen. Adapted from reference (Shinohara et al., 2013).
4.2.2 Application’s online stores

In online stores, there were several Smartphone-based medical applications directed for RA (Table 2 and Table 3).

Table 2. Smartphone applications for self-management of Rheumatoid Arthritis in online stores

<table>
<thead>
<tr>
<th>Application</th>
<th>Version</th>
<th>Platforms</th>
<th>Type of intervention</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>MyRA®</td>
<td>1.6</td>
<td>iOS</td>
<td>Educational &amp; Psychosocial</td>
<td>- Flag and make notes on various body parts where there are symptoms.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Generates reports for symptom tracking and sharing with physicians.</td>
</tr>
<tr>
<td>RheumaTrack ®</td>
<td>2.0.4</td>
<td>Android and iOS</td>
<td>Educational &amp; Psychosocial + Lifestyle + Treatment</td>
<td>- Records pain based on the Visual Analogue Scale.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Symptom check with simple functional ability assessment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Clear representation of the pain diary over time.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Tracks morning stiffness, sporting activities, times of infection and inability to work.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Reminder functions for recording pain, use of medication, checks &amp; doctors’ visits.</td>
</tr>
<tr>
<td>RA Helper ®</td>
<td>1.0.1</td>
<td>Android and iOS</td>
<td>Educational &amp; Psychosocial + Treatment</td>
<td>- Tracks disease activity.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Reminder functions for use of medication, doctor appointments and laboratory controls.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Store laboratory results.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Set goals for disease activity score.</td>
</tr>
<tr>
<td>Rheumatoid Arthritis ®</td>
<td>1.0</td>
<td>Android</td>
<td>Educational &amp; Psychosocial</td>
<td>- Inform about Rheumatoid Arthritis</td>
</tr>
<tr>
<td>My Pain Diary ®</td>
<td>1.2</td>
<td>Android and iOS</td>
<td>Educational &amp; Psychosocial + Lifestyle + Treatment</td>
<td>- Keep an accurate record of your condition for your doctor.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Compare multiple conditions and metrics on a single, interactive graph which makes finding correlations easy.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Learn how much you are affected by humidity, barometric pressure and more.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Identify triggers, remedies, patterns and trends.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Track complex medical condition multiple times a day.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Track pain condition as it occurs.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Inform and track nutrition, fitness, sleep, medication and mood and compare it to arthritis pain.</td>
</tr>
<tr>
<td>Track+React ®</td>
<td>1.2</td>
<td>Android and iOS</td>
<td>Educational &amp; Psychosocial + Lifestyle + Treatment</td>
<td>- Inform about diagnosis, classification, and management of Rheumatoid Arthritis.</td>
</tr>
<tr>
<td>Rheumatoid Arthritis Diagnosis and Management ®</td>
<td>1.0</td>
<td>iOS</td>
<td>Educational &amp; Psychosocial</td>
<td>- Teach about how to manipulate joints to prevent problems and relieve pain with step-by-step video demonstrations.</td>
</tr>
<tr>
<td>Learn Arthritis Prevention ®</td>
<td>1.2</td>
<td>Android</td>
<td>Educational &amp; Psychosocial</td>
<td>- Teach about how to manipulate joints to prevent problems and relieve pain with step-by-step video demonstrations.</td>
</tr>
</tbody>
</table>
Table 3. Screens of Smartphone applications for self-management of Rheumatoid Arthritis in online stores

<table>
<thead>
<tr>
<th>MyRA®</th>
<th>RheumaTrack®</th>
<th>RA Helper®</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatoid Arthritis ©</td>
<td>My Pain Diary ©</td>
<td>Track+React ©</td>
</tr>
<tr>
<td>Rheumatoid Arthritis Diagnosis and Management ©</td>
<td>Learn Arthritis Prevention ©</td>
<td></td>
</tr>
</tbody>
</table>

[Images of phone screens showing various applications and options]

Note: The applications listed in the table are examples and may vary in actual availability and features.
4.3 Discussion

For those with chronic disease such as RA, patient self-management is especially important because the person who can be accountable for his or her everyday care over the length of the disease is only the patient. Therefore, we can say that patient self-management is a lifespan task for those patients who have such chronic condition. Self-management interventions are typically provided through traditional intervention approaches, which are designed to improve health-related quality of life, healthcare utilization and perceived self-efficacy.

The future of "wireless mHealth technologies" is a new and evolving topic in healthcare services, with a great potential for supporting self-management interventions in RA. The Smartphone seems to be a platform suitable to support these procedures, as it has now achieved such a pervasive presence in society, it is a personal device and it assists its user throughout different daily life activities and environments persistently, and presents several advantages compared to traditional interventions. Still, the state of the art suggests that research on development of Smartphone applications for RA self-management is very sparse and the existing applications described in literature are only in prototype stage. In addition, although the several applications found in online stores, most failure to meet the five key challenges described in Chapter 3. Justification. Therefore, all the potential of these Smartphone applications is not being completely well explored. Moreover, there are any applications in Portuguese from Portugal for RA self-management. Since the today’s digital age patients will be the tomorrow patients, it is important to start now developing such applications, preferentially by meeting of the five key challenges. Nevertheless, it is imperative to be aware of possible limitations from the use of Smartphone applications. Patients’ engagement is limited by age, gender and socioeconomic levels (Wayne & Ritvo, 2014). The overuse of such applications may result in several problems easily seen in today’s society. For example, Smartphones can interfere with school or work, decrease real-life social interaction, decrease academic ability, cause relationship problems, and cause physical health-related problems including blurred vision and pain in the wrists or the back of the neck (Hope, 2010; Kuss & Griffiths, 2011; Kwon et al., 2013).
5. Study 2: Needs assessment
5. Study 2: Needs assessment

This chapter describes the methodology used for the realization of the questionnaire and the results obtained from the questionnaire's analysis.

5.1 Methodology

5.1.1 Study design & population

A descriptive cross-sectional study was conducted in 100 patients diagnosed with RA from Rheumatology Service of the São João Hospital Center, Porto. Patients were excluded of the study if did not have Portuguese nationality or complete knowledge of Portuguese language, had less than 18 years and were diagnosed with other rheumatic diseases than RA. It was explained the study objectives and requested to all patients to sign an informed consent according to the Declaration of Helsinki (Reynolds, 2000) (Annexes 10.2-10.4).

All procedures were according to the principles applied by the Ethical Committee for Health of São João Hospital Center (reference 303/2013).

5.1.2 Data collection

A questionnaire to RA patients was conducted for the analysis of usefulness of a RA self-management application, patients’ willingness to use and pay for it and the features the application should have to support in RA self-management. In order to define the features of the application it was analyzed: 1) patients’ opinion about the most important features for self-management; 2) aspects/problems described in literature (including risk of developing affective disorders, treatment non-compliance prevalence and reasons, relation patient-rheumatologist); 3) patients’ motivation for having a more active role in self-management and their self-management skills; and, 4) technology ownership and skills.

The questionnaire was constructed based in the information obtained in the literature (Chapter 1. Introduction), and in validated questionnaires in the area. It was constituted by questions of dichotomous response, Likert scales, multiple choice, rank in order of preference and free response.

The questionnaire was divided in seven sections as follow:

1) **General patient characteristics**, including gender, age, presence or absence of motor or visual incapacities, smoking habits, actual living sub-region, formal education, work status and income.

2) **Relation patient-disease**, including disease duration, diagnosis age and disease
impact on patients’ quality of life, both physically - evaluated by the Stanford Health Assessment Questionnaire 8-Item Disability Scale (HAQ-DI 8-items) (Pincus et al., 1983; Santos et al., 1996) and the Self-Rated Health Scale (K. Lorig et al., 1996) - and psychologically.

3) **Relation patient-treatment**, including the number of drugs that patients use for RA treatment and in global, treatment compliance and reasons for non-compliance based on the 8-item Morisky Medication Adherence Scale (MMAS-8) (de Oliveira-Filho et al., 2013).

4) **Relation patient-rheumatologist**, including the number of programmed and non-programmed clinical visits per year, the frequency that patients question the rheumatologist and how patients evaluated their disease monitoring by the rheumatologist.

5) **Level of knowledge** regarding RA and treatment and reasons for patients’ lack of knowledge.

6) **Relation patient-self-management** to assess patients’ ability and opinion about participating in RA self-management.

7) **Relation patient-technologies** to assess if patients have Smartphone, laptop or a desktop computer or Internet access and their skills in using technologies.

8) **Perception of usefulness and willingness to use and pay for a RA self-management application** to assess if a RA self-management application would be useful and if patients were willing to use and pay for it.

9) **Patients’ opinion about RA self-management application features** regarding what patients’ think necessary/useful for RA self-management, if an automatic notification to rheumatologist it would be helpful and if patients’ would use an application that implied Smartphones had an Internet connection.

The questionnaire (Annex 10.5) was applied by interview at the end of patients’ scheduled clinical visits.

### 5.1.3 Statistical Analysis

Statistical analysis was performed using the IBM® SPSS® Statistics for Windows, version 20.0 (IBM Corp., Armonk, NY, USA) program. It was mainly used descriptive statistics. Results were expressed in the form of frequencies and percentages for categorical variables, as mean and standard deviation for normally distributed continuous variables or scores, and median and range for non-normally distributed continuous variables.

One sample t tests were used to compare the mean of scores with the central value of the score, i.e. in a score mean ranges from 1 to 5 the central value to compare the population mean is 3 (no alteration). A probability was considered as statistically significant if was less than or equal to 5%.

For the rank in order of preference question, the score was constructed by multiplying sequentially the value from 1 to 5 with the number of times the value was chosen to a determined sentence of that question. Then, all the values were summed and the sentence with the higher score was the most preferable.
5.2 Results

The results of this chapter resulted in an original article (Scientific and Financial Results). Information about these results was described hereafter.

5.2.1 Study population

Table 4 demonstrates the characteristics of the 100 patients enrolled in the study. This study clearly included more females (91.0%) and the mean age was 57.3 ± 11.9 years. Sixty-two percent of patients were from Grande Porto, 61.1% were retired, 66% had one to six years of formal education and 67.2% have reduced incomes (<500€).

Table 4. Sociodemographic characteristics of the studied population

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, n (%).</td>
<td>91 (91.0)</td>
</tr>
<tr>
<td>Male, n (%).</td>
<td>9 (9.0)</td>
</tr>
<tr>
<td>Age, mean ± SD, years</td>
<td>57.3 ± 11.9</td>
</tr>
<tr>
<td>With motor incapacity, n (%)</td>
<td>5 (5.0)</td>
</tr>
<tr>
<td>With visual incapacity, n (%)</td>
<td>3 (3.0)</td>
</tr>
<tr>
<td>Current smokers, n (%)</td>
<td>12 (12.0)</td>
</tr>
<tr>
<td>Actual living sub-region*, n (%)</td>
<td></td>
</tr>
<tr>
<td>Grande Porto</td>
<td>62 (62.0)</td>
</tr>
<tr>
<td>Tâmega</td>
<td>20 (20.0)</td>
</tr>
<tr>
<td>Ave</td>
<td>6 (6.0)</td>
</tr>
<tr>
<td>Others**</td>
<td>12 (12.0)</td>
</tr>
<tr>
<td>Formal education, n (%)</td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>3 (3.0)</td>
</tr>
<tr>
<td>≥1 year and ≤6 years</td>
<td>66 (66.0)</td>
</tr>
<tr>
<td>&gt;6 years and ≤12 years</td>
<td>25 (25.0)</td>
</tr>
<tr>
<td>&gt;12 years</td>
<td>6 (6.0)</td>
</tr>
<tr>
<td>Employment situation***, n (%)</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>44 (61.1)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>7 (9.7)</td>
</tr>
<tr>
<td>Employed</td>
<td>21 (29.2)</td>
</tr>
<tr>
<td>Income***, n (%)</td>
<td></td>
</tr>
<tr>
<td>&lt;500€</td>
<td>47 (67.2)</td>
</tr>
<tr>
<td>500€-1000€</td>
<td>15 (21.4)</td>
</tr>
<tr>
<td>1000€-5000€</td>
<td>8 (11.4)</td>
</tr>
</tbody>
</table>

*Sub-regions that divide Portuguese territory where defined according to “Nomenclatura Comum das Unidades Territoriais Estatísticas – Nível III” (NUTS III) and all correspond to North of the Portugal Continent. **Other actual living sub-regions include Alto Trás-os-Montes, Cârvo, Entre Douro e Vouga, Minho-Lima and Douro. ***Employment situation and income presented 28 missings and 30 missings, respectively. SD: Standard deviation.

5.2.2 Relation patient-disease

Table 5 represents the patients’ characteristics concerning to their disease. In the studied population, the mean age at diagnosis was 39.3 ± 15.3 years and the median disease duration was 16.0 (1.0-56.0). The mean HAQ-DI 8-items was 1.58 ± 0.71 and 23.0% of
patients had mild disability (0<HAQ-DI≤1), 54.0% had moderate disability (1<HAQ≤2) and 23.0% had severe disability (2<HAQ≤3). In relation to the psychological distress, patients significantly reported a high fear of disease lack of control (p=0.038) and difficulty in dealing with feelings of sadness (p=0.005). The Self-Rated Health Scale demonstrated that patients evaluated their global health as bad (p<0.001).

Table 5. Disease characteristics of the studied population

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis, mean ± SD, years</td>
<td>39.3 ± 15.3</td>
<td>-</td>
</tr>
<tr>
<td>Disease duration, median (range), years</td>
<td>16.0 (1.0-56.0)</td>
<td>-</td>
</tr>
<tr>
<td>HAQ-DI 8-items (0 - mild disability to 3 – severe disability), mean ± SD</td>
<td>1.58 ± 0.71</td>
<td>0.254</td>
</tr>
<tr>
<td>Psychological distress (1 – none to 5 – very), mean ± SD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty in getting a good night of sleep</td>
<td>3.14 ± 1.24</td>
<td>0.261</td>
</tr>
<tr>
<td>Fear of disease lack of control</td>
<td>3.30 ± 1.42</td>
<td><strong>0.038</strong></td>
</tr>
<tr>
<td>Difficulty in dealing with feelings of sadness</td>
<td>3.39 ± 1.35</td>
<td><strong>0.005</strong></td>
</tr>
<tr>
<td>Self-Rated Health Scale (1 – bad to 5 - excellent), mean ± SD</td>
<td>2.62 ± 1.04</td>
<td>&lt;<strong>0.001</strong></td>
</tr>
</tbody>
</table>

*p value ≤0.05 was considered to be of statistically significance (highlighted in bold). HAQ-DI: Health Assessment Questionnaire - Disability Index; SD: Standard deviation.

5.2.3 Relation patient-treatment

Table 6 represents the reported attitudes in relation to medication and reasons for non-compliance. The median number of drugs used for RA was 5.0 (2.0-15.0) and in total was 8.0 (2.0-18.0). Forty patients (40%) reported that did not always take their medication as prescribed by the rheumatologist (non-compliance rate) and the most frequent reason stated for non-compliance was forgetfulness/distraction (67%).

Table 6. Attitudes in relation to medication and reasons for non-compliance

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of drugs used for RA treatment, median (range)</td>
<td>5.0 (2.0-15.0)</td>
</tr>
<tr>
<td>Number of drugs used in total, median (range)</td>
<td>8.0 (2.0-18.0)</td>
</tr>
<tr>
<td>Attitudes in relation to medication, n (%)</td>
<td></td>
</tr>
<tr>
<td>Took always</td>
<td>60 (60.0)</td>
</tr>
<tr>
<td>Took immediately when remember</td>
<td>17 (17.0)</td>
</tr>
<tr>
<td>Took in the next day</td>
<td>12 (12.0)</td>
</tr>
<tr>
<td>Did not take and communicated to doctor at next visit</td>
<td>4 (4.0)</td>
</tr>
<tr>
<td>Did not take and not reported to doctor</td>
<td>7 (7.0)</td>
</tr>
<tr>
<td>Reasons for non-compliance*, n (%)</td>
<td></td>
</tr>
<tr>
<td>Forgetfulness/distraction</td>
<td>27 (67.5)</td>
</tr>
<tr>
<td>Fails to take when feel sick</td>
<td>6 (15.0)</td>
</tr>
<tr>
<td>Fails to take when goes to travel/vacations because forgets to bring the drugs</td>
<td>6 (15.0)</td>
</tr>
<tr>
<td>Believes that drugs will cause adverse effects, side effects or undesirable effects</td>
<td>4 (10.0)</td>
</tr>
<tr>
<td>Believes that drugs will not improve quality of life</td>
<td>2 (5.0)</td>
</tr>
<tr>
<td>Only take when feel sick</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Fails to take because does not want to take too many drugs</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Reduces the dose when feel better</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Believes will cause addiction</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Others</td>
<td>2 (5.0)</td>
</tr>
</tbody>
</table>

* Patients could select more than one answer. The patients that took the drugs always did not respond to this question.
5.2.4 Relation patient-rheumatologist

Patients reported a median number of programmed rheumatology visits of 4.00 (1.00-24.00) per year and of non-programmed rheumatology visits of 0.00 (0.00-7.00) per year. Considering patient-rheumatologist relation, patients inquired the rheumatologist often about doubts relative to disease and therapy (mean score of 3.51 ± 1.55; \( p=0.001 \)). But when the doubts were about personal problems, patients demonstrated to be more reserved (mean score of 3.31 ± 1.74; \( p=0.079 \)). Moreover, patients reported a good management of their disease by the rheumatologist (mean score of 4.68 ± 0.65, \( p<0.001 \)).

5.2.5 Patients’ knowledge

Table 7 presents the reported knowledge and the reasons for the lack of knowledge about the disease and therapy. From the questions evaluating the patients’ level of knowledge, there was a relatively good knowledge. The most frequent reason for the lack of knowledge was because patients trusted in the decisions of the rheumatologist (74.0%).

Table 7. Knowledge and reasons for the lack of knowledge about the disease and therapy

<table>
<thead>
<tr>
<th>Knowledge about:</th>
<th>Mean ± SD</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>RA (1 – none to 5 – very)</td>
<td>3.59 ± 0.91</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>General therapies in RA (1 – none to 5 – very)</td>
<td>3.51 ± 1.02</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Therapeutic effects of medications (1 – none to 5 – very)</td>
<td>3.70 ± 1.02</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>General adverse drug reactions or secondary effects of medications (1 – none to 5 – very)</td>
<td>3.33 ± 1.11</td>
<td>0.004</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reasons for the lack of knowledge*</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trusted in the decisions of the rheumatologist</td>
<td>74 (74.0)</td>
</tr>
<tr>
<td>Lack of time in clinical visits for more explanations</td>
<td>15 (15.0)</td>
</tr>
<tr>
<td>Did not know how to find information</td>
<td>7 (7.0)</td>
</tr>
<tr>
<td>Lack of patients’ interest</td>
<td>5 (5.0)</td>
</tr>
<tr>
<td>Preferred not to know certain things</td>
<td>4 (4.0)</td>
</tr>
<tr>
<td>Did not want to think about the disease</td>
<td>3 (3.0)</td>
</tr>
<tr>
<td>The rheumatologist did not clarify about RA and therapy</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Did not know to write or read</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Forgot to ask to rheumatologist</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Did not know to use the computer and so did not search</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>There is few information</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Due to the rapid innovations in the area and the disease complexity</td>
<td>1 (1.0)</td>
</tr>
</tbody>
</table>

\( p \) value ≤0.05 is considered to be of statistically significance (highlighted in bold).

* Patients could select more than one answer.

RA: Rheumatoid Arthritis; SD: Standard deviation.

5.2.6 Relation patient-self-management

The vast majority of patients (94.0%) believed that they could have a more active role in self-management. Half of RA patients (50.0%) reported that immediately after diagnosis they did not made changes or tried to make changes to some aspects of their life, such as starting to lose weight and exercise. Of these, 28 patients (56.0%) reported that the reason
for not changing their behaviors were related to, at that time, didn’t give importance to self-management and 22 patients (44.0%) answered that they did not know what they should change.

5.2.7 Relation patient-technology

Figure 5 represents the technologic devices ownership and reported utilization. Considering the technology owning, of the 98 patients that had mobile phones, only 18 patients (18.4%) owned a Smartphone, of these, 13 patients (72.2%) demonstrated a high usage of their Smartphone. Sixty-seven patients (67.0%) owned a laptop or a desktop computer. Sixty-five patients (65%) had a private Internet access but only 27 patients (41%) used the Internet.

![Bar chart showing technology ownership and patient-relation with it.](chart.png)

**Figure 5.** Technology ownership and patient-relation with it.
A) Representation of the number of RA patients that owned a mobile phone clustered by the use of SMS and of the patients having a private Internet access clustered by the use of the Internet and, of these, by the use of the email services. B) Representation of the number of RA patients that owned a Smartphone clustered by the frequent use of these devices, and of the patients that owned laptops or desktop computers clustered by patients frequently using these devices.

E-mail: Electronic Mail; SMS: Short Message Service.

Fifteen patients (83%) reported to use applications (agenda, social networks, games and alerts) on their Smartphone: 6 patients (40%) used four or three types of applications simultaneously, 4 (27%) used at least two types of applications and 5 patients (33%) reported to use at least one application. None ever used an application for health purposes.
5.2.8 Perception of usefulness & willingness to use and pay for a RA self-management application

The vast majority of patients (86%) reported that it would be useful to develop a Smartphone application for RA self-management. The remaining patients said that preferred a Web page (6%) or to use paper (6%) as methods to support self-management. Only 2% said that did not need any method to assisting them in self-management tasks.

Of the patients that reported the usefulness of developing an application for self-management, 71 patients (83%) said that were willing to use it. In order to better analyze the importance of developing an application for this purpose, it was asked if patients would pay for it and how much they were willing to pay for that self-management application. Fifty-eight patients (82%) were willing to pay for it. The mean price was 8.05 ± 14.62€, the median price was 5.00€ and the highest price reached 100.00€.

5.2.9 Patients’ opinion about RA self-management application features

Table 8 exhibits the requested features that would better support RA patients to develop self-management skills. The feature with the highest rank was the information about the disease and treatment in a simple format.

<table>
<thead>
<tr>
<th>What it's more important for RA self-management?*</th>
<th>Value (maximum of 490 points)</th>
<th>Decreased rank order by importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Inform about the disease and treatment in a simple format</td>
<td>327</td>
<td>1st</td>
</tr>
<tr>
<td>b. Monitor and record the disease activity and quality of life over time</td>
<td>312</td>
<td>2nd</td>
</tr>
<tr>
<td>c. Alerts for taking medication or other tasks such as clinical visits</td>
<td>297</td>
<td>3rd</td>
</tr>
<tr>
<td>d. Register of therapeutic, adverse and side effects of medication</td>
<td>296</td>
<td>4th</td>
</tr>
<tr>
<td>e. Register the medication and its compliance</td>
<td>234</td>
<td>5th</td>
</tr>
<tr>
<td>f. Others, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practical tips to improve the disease condition and quality of life</td>
<td>7 (77.8)</td>
<td>-</td>
</tr>
<tr>
<td>Actualizations of the recent scientific articles in area</td>
<td>1 (11.1)</td>
<td>-</td>
</tr>
<tr>
<td>Chat for contacting peers</td>
<td>1 (11.1)</td>
<td>-</td>
</tr>
</tbody>
</table>

* For this question 2 patients said that did not want to respond because they needed no assistance in self-management.

Sixty-four percent would like an automatic sending of data to the rheumatologist by the application and half of patients (50%) would use an application even it required the Smartphone would need to have an access to the Internet (Figure 6).
Study 2: Needs assessment

Figure 6. Answers to the question “Would you like if the application could send an automatic notification of your inputted data to the rheumatologist?”

The answered was not applicable for the patients that answered “No” to the question “Can an application for Smartphone be useful for aiding in strategies you indicated as most important for RA self-management?” and said that the method should be in paper or should be any method.

5.3 Discussion

Needs assessment should be a necessary first step to develop successful applications for patient-centered care (Wright et al., 1998). Still, to our best knowledge, this is the first study assessing the needs of patients with RA of a self-management application. Therefore, it was evaluated the usefulness and willingness to use and pay for a Smartphone application for supporting RA self-management and the functional features the application should have.

This study suggests that an application for RA self-management is considered useful by the RA patients and that these are willing to use and pay for it. This is in accordance to previously studies in other chronic diseases (Fonseca et al., 2006; Parker et al., 2013), which suggested that patients were more willing to use communication technologies such as mobile phones to help them self-manage their disease. We are aware that in our population only one in five RA patients had a Smartphone. Although, those with access to Smartphones were all willing to use a RA self-management application and about two thirds of patients without a Smartphone were also willing to use it. In addition, of the 18 patients having Smartphones, none used a health-related application and, thus, are not familiarized by this type of applications. Nevertheless, Smartphones are being increasingly adopted (Statista, 2014) and the “technological generation” could became the near-future RA patients, so these problems should be significantly reduced.

The most requested features for self-management were information about disease and treatment in a simple format and long-term monitoring of disease. In fact, and despite the patients’ reported good knowledge, an application for self-management could provide
information to eliminate doubts about disease and treatment, as also to provide a long-term monitoring of disease activity and quality of life required for keeping a good management by rheumatologist. Bruce and Fries suggest that the long-term monitoring of disease provides continuous information about the impact of disease or treatment in patients’ quality of life (Bruce & Fries, 2003). This can be used for the rheumatologist decide better about therapeutic strategies for each patient and minimize the RA burden (Rindfleisch & Muller, 2005). In addition, 64% patients would like an automatic sending of application data to rheumatologist and half of patients would use the application even that the Smartphone needs to have an access to the Internet. Besides these functional specifications, results on patients’ characteristics highlighted some problems that can be important to consider for a RA self-management application.

Accordingly, patients reported their global health as poor in the Self-Rated Health Scale but this was not observed for HAQ-DI 8-items. Since the HAQ-DI 8-items does not evaluate the psychological impact and patients reported having fear of disease lack of control and difficulty in dealing with feelings of sadness, the Self-Rated Health Scale captured the psychological negative impact of disease and possibly a great risk for developing affective disorders (e.g. depression and anxiety), very frequent in chronic patients and, particularly, in RA patients (Geenen et al., 2012; Margaretten et al., 2011). Therefore, the development of a self-management application could be useful for strengthen patients’ confidence and motivation to use their own skills and knowledge to take effective control over their life, even with this chronic illness, and, perhaps, reduce the development of affective disorders.

In addition, the studied population had a typical multiple drug regimen seen in RA (Elliott, 2008; Neame & Hammond, 2005). Patients demonstrated a non-compliance rate of 40% and the most frequent reason for non-compliance was unintentional due to forgetfulness/distraction, as reported by literature (Elliott, 2008; Neame & Hammond, 2005). The development of a self-management application can reduce this type of non-compliance by the possibility of integrating alerts for medication and long-term monitoring of compliance. Since the registry of the medication and its compliance was the last chosen feature for self-management, it seems that patients unknown the implications of non-compliance in their disease and the importance of monitoring it. Therefore, a self-management application can reduce this perception by the incorporation of an information section about pharmacological therapy.

Additionally, half of patients reported an inexistent ability to engage in self-management behaviors after diagnosis due to lack of understanding of the importance of self-management or lack of knowledge about what to do. The development of a self-management application can be important for motivating and aiding patients to change behaviors and to perform self-management tasks as also to add more and better knowledge, appropriate to the needs of each patient.

Despite the potential of these results, this work has several limitations. The design of this study was cross-sectional, which is limited by the fact that it was carried out at one time point and the situation may provide differing results if another time-frame had been chosen. For an instance, the question about the importance of the application could have a
higher number of positive responses if the questionnaire was conducted at time of diagnosis, a “teachable moment” where patients would be more motivated for any type of help or intervention (Blanchard et al., 2003). Also, as in all studies assessing opinions, the results need to be interpreted with caution as expressed opinions are different of what participants may think and do. For example, 58% of patients were willing to pay for a self-management application and the named prices reached as high as 100€. These extremely high values can be explained by the fact that the majority of the patients asked to the interviewer which price an application normally costs. To not interfere with the answers the interviewer did not responded to that. So, it is possible that patients responded to these high values due to their perception of usefulness and necessity of an application for self-management and not to the value that the patient would actually pay for it. Additionally, this study included RA participants from a single center within North of Portugal where the sample had more females (91%) that the expected female/male ratio (Alamanos & Drosos, 2005), presented in majority an established RA (disease duration superior or equal to 6 months) (Singh et al., 2012) and a reduced economic and educational level, thus, the generalization of results obtained from this study is limited. Therefore, additional studies should be conducted in other geographical areas with bigger samples to confirm or not our results.

In conclusion, this study suggests the usefulness of a smartphone application for RA self-management and that most RA patients were willing to use and pay for it. The RA self-management application should include the most requested features (e.g. information in a simple format and long-term disease monitoring) and try to resolve the problems observed in the population such the psychological factors impact on quality of life, the typical multiple drug regimens, the high treatment non-compliance rate and type and the reduced ability to engage in self-management behaviors.
6. Study 3: Development of a Smartphone application
6. Study 3: Development of a Smartphone application

This chapter provides the description of the stages of Smartphone application development.

The Smartphone application process of development followed a waterfall model (Figure 7) (Royce, 1987).

6.1 Requirements & Analysis

Requirement specification is an invaluable part of software engineering, which defines the requirements in a formal way to avoid problems of ambiguities along the development process. In this section, it are identified the functional and non-functional requirements of the application, it is presented an events list and use-cases, and identified the different stakeholders.

6.1.1 Functional requirements

The functional requirements were defined based on questionnaire (Study 2: Needs assessment) concerning the patients’ opinion about the functional features of RA self-management application and the problems observed in the population, observed in the questionnaire, combined with literature.

- **Requirement 1:** Inform about the disease and treatment in a simple format and actualize about the recent scientific articles in area

**Justification:** This requirement was the patients’ first choice expressed in the questionnaire regarding features most important to support RA self-management.
**Functional requirement specifications:** Provide a section with information about what is RA, causes, diagnosis, pharmacological and non-pharmacological therapeutic, and several links for several Portuguese societies/institutions/associations and for the “*Acta Reumatológica Portuguesa*”, a Portuguese scientific journal about RA and other rheumatic diseases.

- **Requirement 2:** Record and monitor the disease activity and quality of life over time

  **Justification:** Record and monitor the disease activity and quality of life over time was the patients’ second choice and it is central to describe the impact of disease on patient's quality of life (Bruce & Fries, 2003; Rindfleisch & Muller, 2005).

  **Functional requirement specifications:** Record user’s data and generate reports in Smartphone’s memory for tracking and sharing with rheumatologists/physicians by email. Since only 64% of patients said that they would like an automatic notification to rheumatologist, the application will allow patients to take the decision of sending their data or not, which data, when and to whom (Figure 6). Data include responses to questionnaires of quality of life impact of disease and flags on various key joints as defined by the Disease Activity Score 28 (DAS28), where there are symptoms of pain. The joints include: 2 in shoulder, 2 in elbow, 2 in wrist, 10 metacarpophalangeal, 10 proximal interphalangeal and 2 in knee (Englbrecht et al., 2010). The application should calculate and show the questionnaires’ results in real-time.

  The questionnaires used for evaluating the health-related quality of life impact of RA include two validated Portuguese versions:

  ✓ **HAQ-DI** (Santos et al., 1996) - because is one of the most widely used comprehensive, validated, patient-oriented outcome assessment instruments and is relatively short (Bruce & Fries, 2003). It is an easy to administer self-questionnaire which comprises eight categories of functioning: dressing, rising, eating, walking, hygiene, reach, grip, and usual activities (Bruce & Fries, 2003; Santos et al., 1996). The Aides and Devices are assigned to the specific HAQ categories as follows:

    o Dressing and Grooming: Devices used for dressing (button hook, zipper pull, shoe horn, etc.)
    o Rising: Special or built up chair
    o Eating: Built up or special utensils
    o Walking: Cane, Walker, Crutches, Wheelchair
    o Hygiene: Bathtub bar, Long-handled appliances in bathroom, Raised toilet seat
    o Reach: Long-handled appliances for reach
    o Grip: Jar opener for jars previously opened

  The HAQ-DI Portuguese version is in Annex 10.6. The score is calculated as:

  1) Choose the highest score between the questions of each eight categories, i.e. if one question is scored 1 and another 2, then the score for category is 2.
2) Sum of the scores of the eight categories.
3) If an aide or device is used or if help is required from another individual, then the minimum score for that category is 2. If the category score is already 2 or more then no modification is made.
4) Divide by 8 the sum of the scores of the eight categories to give a value between 0 and 3.
5) If $0<\text{HAQ-DI}\leq 1$, mild disability; $1<\text{HAQ}\leq 2$, moderate disability; and $2<\text{HAQ}\leq 3$, severe disability.

✓ RA impact of disease (RAID) (EULAR; L. Gossec et al., 2011) - due to its shortness and completeness compared to other standard questionnaires in the area since it’s the one that includes more domains or areas of health considered to be important for RA patients (Table 9 and Figure 1) (Laure Gossec, 2010; Gullick & Scott, 2011). This patient-derived composite response score is based on the patients’ perception of the impact of the disease on domains of health. The score includes seven domains prioritized by patients. The domains of highest importance are pain, functional disability, and fatigue; the four other domains are emotional and physical well-being, sleep disturbance and coping (EULAR; L. Gossec et al., 2011; Gullick & Scott, 2011). The Portuguese version of RAID is in Annex 10.6.

The score is calculated by the following formula:

$$RAID = \left(pain \text{ (scale } 0 - 10) \times 0.21 \right) + \left(functional \text{ disability} \text{ (scale } 0 - 10) \times 0.16 \right) + \left(fatigue \text{ (scale } 0 - 10) \times 0.15 \right) + \left(physical \text{ well – being} \text{ (scale } 0 - 10) \times 0.12 \right) + \left(sleep \text{ disturbance} \text{ (scale } 0 - 10) \times 0.12 \right) + \left(emotional \text{ well – being} \text{ (scale } 0 - 10) \times 0.12 \right)$$

### Table 9. Health domains assessed by disease impact questionnaires in Rheumatoid Arthritis

<table>
<thead>
<tr>
<th>Domain</th>
<th>RAID</th>
<th>RAQoL</th>
<th>EuroQoL (EQ-5D)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Functional capacity</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Fatigue</td>
<td>✓</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>Physical well-being</td>
<td>✓</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sleep</td>
<td>✓</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>Coping</td>
<td>✓</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>Ability to work</td>
<td>-</td>
<td>✓</td>
<td>-</td>
</tr>
<tr>
<td>Global score</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

RAID: Rheumatoid Arthritis Impact of Disease; RAQoL: Rheumatoid Arthritis Quality of Life; EuroQoL: European Quality of Life; EQ-5D: European Quality of Life Five Dimensions.
Adapted from reference (Gullick & Scott, 2011).
• **Requirement 3:** Alerts for taking drugs or other tasks such as clinical visits and register the medication and its compliance

**Justification:** Treatment non-compliance rate was 40.0% in this population mainly due to forgetfulness/distraction (67.5%), mostly because RA is a chronic condition that often requires multiple drug regimens (median number of medications used for RA was 5.00 (2.00-15.0)) *(Table 6)*, in accordance to literature (Iihara *et al.*, 2004; van den Bemt *et al.*, 2009).

**Functional requirement specifications:** Reminder functions for use of medication, doctor appointments or other tasks. Track the medications compliance with update of the medication quantity and alert when it’s finishing and record it in history, for viewing past actions in the future or sent by email.

• **Requirement 4:** Register of therapeutic, adverse and side effects of medication

**Justification:** Continuous monitoring of therapeutic, adverse and side effects of medication is central to describe the impact of treatment on patient's quality of life (Bruce & Fries, 2003).

**Functional requirement specifications:** Track and record the adverse drug reactions as mild, moderate and severe and possibility of viewing past actions in the future and sent by email.

• **Requirement 5:** Practical advices to improve the disease condition and quality of life

**Justification:** A variety of simple changes in patients’ lifestyle can help them better manage RA and have a better life style (Arthritis Self-management).

**Functional requirement specifications:** Incorporation of step-by-step advices for teaching what patients can modify in their life for staying healthy, live better with RA and improve their prognosis at the same time.
**Table 10** presents a summary of the functional features of the Smartphone application for RA self-management.

<table>
<thead>
<tr>
<th>Type of intervention</th>
<th>Description</th>
</tr>
</thead>
</table>
| Educational & Psychosocial + Lifestyle + Treatment | - Track health-related quality of life according to pain, functional disability, fatigue, emotional and physical well-being, sleep disturbance and coping based on Visual Analogue Scales.  
- Flag on various body parts where there are symptoms.  
- Teach about how to live well with RA with step-by-step advices.  
- Reminder functions for use of medication, tasks & doctors’ clinical visits.  
- Track medication’s quantity and alert when finishing.  
- Track compliance and adverse drug reactions.  
- Inform about Rheumatoid Arthritis and therapy with external links to more information and scientific articles of “Acta Reumatológica Portuguesa”.  
- Track health-related quality of life according to 8 categories of functioning: dressing, rising, eating, walking, hygiene, reach, grip, and usual activities and considering the aides and devices used.  
- Real-time calculation and exhibition of health-related quality of life questionnaires’ results.  
- Keep an accurate record of the health-related quality of live, flagged painful joints, adverse drug reactions and compliance and clear representation as a list, figure or as a graphic over time.  
- Generate reports for sharing with rheumatologists by email. |

### 6.1.2 Event list

An event list was made to count the functional requirements systematically. The below event list (**Table 11**) includes all the possible inputs from patient and outputs from application and the events that can occur in the application.
Table 11. Event list

<table>
<thead>
<tr>
<th>Event name</th>
<th>Input</th>
<th>Output</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Open the application for the 1st time</td>
<td>Select “Create a profile” – Event 2</td>
<td>Alert box for inserting personal data</td>
<td>Open the application and then the screen shows an alert box for inserting personal data or close the box</td>
</tr>
<tr>
<td>OR “Close” – Event 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Create a profile</td>
<td>Insert personal data and “Save”</td>
<td>Fields for inserting the data and “Save” button</td>
<td>Choses to create a profile and inserts the personal data (name, birth date, gender, weight, height, disease duration, smoking status, arterial blood pressure, cardiac frequency, capillary blood glucose, total cholesterol and triglycerides) in the correspondent fields and “Save” to go to main screen</td>
</tr>
<tr>
<td>3 Open the main screen/Open the application after the 1st time</td>
<td>-</td>
<td>Welcome message, date, next-to-date events scheduled and buttons for navigating in the application</td>
<td>Open the application main screen and then the screen shows a welcome message, date, next-to-date events scheduled and buttons for “Profile”, “Disease Monitoring”, “Medication”, “Information”, “Health Questionnaire”, “Historical” and “Options”</td>
</tr>
<tr>
<td>4 Select “Profile”</td>
<td>Edit/Insert personal data</td>
<td>Fields for inserting the data</td>
<td>Edit or insert data to personal profile</td>
</tr>
<tr>
<td>5 Select “Disease Management”</td>
<td>Select “Menu”</td>
<td>Shows 4 options: “Functional Impact”, “Clinical visits and Other Tasks”, “Practical Advices” and “Menu”</td>
<td>Open a screen with 4 options: “Functional Impact”, “Clinical visits and Other Tasks”, “Practical Advices” and “Menu” to return to main screen</td>
</tr>
<tr>
<td>6 Select “Functional Impact”</td>
<td>Answer the questions by selecting the response</td>
<td>Shows several screens with questions to select the response</td>
<td>Opens several screens with questions that patients can answer</td>
</tr>
<tr>
<td>7 Save results of the functional impact questionnaire</td>
<td>Choose “Save” results</td>
<td>Shows results</td>
<td>At the end of the questionnaire the application gives a result that patient must save to return to “Disease Management” screen</td>
</tr>
<tr>
<td>8 Select “Clinical visits and Other Tasks”</td>
<td>Select “Save”</td>
<td>Shows agented tasks, an option to add or edit a task, and the possibility to select the symbol to update the task state or “Save”</td>
<td>Open a screen with agented tasks and with buttons for adding a task, update the task state, edit the task and “Save” to return to “Disease Management” screen</td>
</tr>
</tbody>
</table>
Table 11. Event list (continuation)

<table>
<thead>
<tr>
<th>Event name</th>
<th>Input</th>
<th>Output</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Add/Edit a task</td>
<td>Select “New”/“Edit” task, insert data and “Save”</td>
<td>Fields for inserting the data</td>
<td>Open a screen with fields for inserting/editing task name, start and end data of the task, place and notes and for selecting if want to receive a notification and “Save” to return to “Clinical visits and Other Tasks” screen</td>
</tr>
<tr>
<td>Manually update task state</td>
<td>Select the symbol to it change for a green right symbol and “Save”</td>
<td>Shows a right symbol without color in each task and possibility to “Save”</td>
<td>Open a screen with tasks presenting a right symbol without color and if patient want to actualize the task state they have to select the symbol to it change for a green right symbol (indicating that effectuated the task). Select “Save” to return to “Disease Monitoring” screen</td>
</tr>
<tr>
<td>Select “Practical Advices”</td>
<td>Read the information and click in “Next” and “Back” buttons</td>
<td>Shows information and “Next” and “Back” buttons</td>
<td>Open several screens with information that patient can read with “Next” and “Back” buttons</td>
</tr>
<tr>
<td>Select “Medication”</td>
<td>See list of medications and “Save”</td>
<td>Shows list of medications, an option to add or edit or eliminate a medication, register adverse effects and the possibility to select “Take/Delay/Ignore” or “Save”</td>
<td>Open a screen with a list of medications added and with buttons for adding or editing or eliminate a medication, register adverse drug reaction, select “Take/Delay” or “Save” to return to main screen</td>
</tr>
<tr>
<td>Add/Edit a medication</td>
<td>Select “New”/“Edit” medication, insert data and “Save”</td>
<td>Fields for inserting the data</td>
<td>Open a screen with fields for inserting/editing medication name, changing/eliminating the medication image (if changing, turns on the camera to take a picture), inserting units, actual quantity, method of taking, frequency, time, dose, after or before the meal and for selecting if want to receive a notification and “Save” to return to “Disease Monitoring” screen</td>
</tr>
<tr>
<td>Manually update medication state</td>
<td>Select “Take/Delay/Ignore” and select/insert data and “Save”</td>
<td>Shows a screen with fields for selecting “Take”, “Delay” or “Ignore” and insert the real date and quantity taken and notes and “Save”</td>
<td>Open a screen with fields for selecting “Take”, “Delay” or “Ignore” and inserting the real date and quantity taken and making notes and “Save” to return to “Medication” screen</td>
</tr>
</tbody>
</table>
Table 11. Event list (continuation)

<table>
<thead>
<tr>
<th>Event name</th>
<th>Input</th>
<th>Output</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eliminate a medication</td>
<td>Select “Eliminate”</td>
<td>Shows the option “Eliminate”</td>
<td>In “Medication” screen, there is an option to “Eliminate” the medication.</td>
</tr>
<tr>
<td>Add an “Adverse Drug Reaction”</td>
<td>Select the answer, write notes and “Save”</td>
<td>Open a screen with the answers, a field of notes and “Save” button</td>
<td>Open a screen with 4 possibilities of answer: none, mild, moderate and severe and a field for making notes and “Save” to return to “Medication” screen.</td>
</tr>
<tr>
<td>Select “Information”</td>
<td>Read the information about the topic chosen</td>
<td>Shows the text relative to the topic chosen</td>
<td>Click the topic of interest and the application shows the text of interest.</td>
</tr>
<tr>
<td>Select “Health Questionnaire”</td>
<td>Answer the questions by selecting the response</td>
<td>Shows several screens with questions to select the response</td>
<td>Opens several screens with questions that patients can answer.</td>
</tr>
<tr>
<td>Save results of the health questionnaire</td>
<td>Choose “Save” results</td>
<td>Shows results</td>
<td>At the end of the questionnaire the application gives a result that patient must save to return to main screen.</td>
</tr>
<tr>
<td>Select “Options”</td>
<td>-</td>
<td>Shows fields for selecting if patients want to receive notifications, if want to protect the application with a pin code, “Save” or export the data from a determined time space by email and “Save” to return to main screen.</td>
<td></td>
</tr>
<tr>
<td>Enable notifications</td>
<td>Select enable notifications and “Save”</td>
<td>Shows a field for selecting notifications and “Save” option</td>
<td>Enable to receive notifications boxes of the medications and tasks even when the application is closed.</td>
</tr>
<tr>
<td>Enable pin protection</td>
<td>Select enable pin protection, write a pin number and “Save”</td>
<td>Shows pin status and a field for introducing it and “Save” option</td>
<td>Enable pin protection at application opening and “Save” to return to main screen.</td>
</tr>
<tr>
<td>Export data</td>
<td>Write the email, select data interval and click “Send”</td>
<td>Shows fields for selecting and writing and “Send”</td>
<td>Enable exporting of recorded data of questionnaires, adverse drug reactions and historical.</td>
</tr>
<tr>
<td>Close the application</td>
<td>Exit using the Smartphone button</td>
<td>Closes but system of notifications works</td>
<td>If closing the application, the notifications (if selected) will appear wherever necessary.</td>
</tr>
<tr>
<td>Notification</td>
<td>See the received notification</td>
<td>Sent a notification</td>
<td>Notification box for taking the medications or going to accomplish tasks.</td>
</tr>
</tbody>
</table>
Table 11. Event list (continuation)

<table>
<thead>
<tr>
<th>Event name</th>
<th>Input</th>
<th>Output</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>27 Open the application</td>
<td>Select “See” and introduce the pin</td>
<td>Automatically opens the application and asks for pin</td>
<td>Application automatically re-routs for the corresponding screen if patients select “See” in the notification box (if select “Ignore” the notification box closes and the application does not open)</td>
</tr>
<tr>
<td>28 Close the application</td>
<td>Turn off the notifications</td>
<td>Inactive application</td>
<td>Closing the application</td>
</tr>
</tbody>
</table>

### 6.1.3 System stakeholders

Identifying system stakeholders is an important aspect of the software development as it guides the requirements engineering process. The identified stakeholders included patients and rheumatologists.

- **Patients**: These stakeholders are able to introduce/register data, access to recorded data, learn about RA and therapy, set notifications, set pin protection and send recorded data via email.

- **Rheumatologists**: These stakeholders are the probable receivers of the recorded data sent by patients.

### 6.1.4 Use-case diagrams

Unified Modelling Language (UML) use-case diagrams were built by using the event list above to outline the scope of the application. Use-case diagrams were developed to describe the behavior of the application when the user interacts with it to achieve a goal in one or more possible scenarios. Some examples of possible interactions between the different stakeholders are drawn in the below figures. Figure 8 presents the use-case representative of the profile’s creation and edition stages after the first time the application is started. When the application is started it will be requested a pin (if the RA patient enables the pin protection at “Options” section) after the main screen appear.
At main screen, the options the RA patient can choose are: “Disease Management”, “Medication”, “Information”, “Health Questionnaire”, “Options” and “Profile”. If the “Disease Management” section is selected, the patient can respond to the “Functional Impact” questionnaire, which is constituted by the RAID questionnaire and by a figure constituted by various key joints defined by the DAS28 that will allow flagging the painful joints, as previously described in this chapter. The application should at the end of the “Functional Impact” questionnaire give the results and save the responses at Smartphone internal memory or memory card (Requirement 2). The RA patient can also use in this section the “Clinical visits and Other Tasks” functionality and add or edit a task or clinical visit, change the state of the task/clinical visit i.e. when the task is accomplished or skipped the patient can select the task symbol to change it. If the patient enables the notifications, it will receive a notification box one hour before the task, at the time of the task and 1 hour after the task (if the task was skipped and/or the task symbol was not changed) (Requirement 3). In addition, the “Disease Management” section also presents “Practical Advices”, which gives practical information about several details the patient can change in his life to live better with RA (Requirement 5, Figure 9).
In a scenario were the RA patient chose the “Options” section of the application, he can enable/disable the pin protection and notifications for tasks and medications, and can send recorded data (questions and answers to “Functional Impact” questionnaire and “Health Questionnaire”, medication compliance and ADRs) in PDF format to rheumatologist via email (Requirements 2, 3 and 4, Figure 10).
6.1.5 Non-functional requirements

Considering the non-functional requirements, the application must be:

- **Secure**: Only the user themselves should be able to access their account because health-related information is confidential so it should be treated very carefully. Usually a mobile phone is regarded as a personal belonging and the applications and messages in the phone are only possessed by the owner. In addition, the application will allow the user enable a pin protection that should block its unsolicited use.

- **Simple to use**: A user should be able to use the application without requiring training.

- **Fast**: The interaction process should not take an unreasonable amount of time.

- **Accurate**: Produces accurate data from tasks.

- **Reliable**: There should be a high success rate for finishing the tasks.

- **In simple and clear Portuguese from Portugal**.

Further to these requirements, it was selected a single operating system (OS) for the initial proof of concept work. The selected OS for this work was the Android, developed by Google, due to the follow factors:

1) **A distinct dominance** at 81% of market share in the third quarter of 2013 (IDC, 2013).

2) **Openness**, i.e. the Application Programming Interface (API) is licensed with the Apache License 2.0 that allows free and open distribution of the source code (Android).
3) **Forward compatibility**, i.e. applications developed for an older or current version (API level) of the OS will likely work also in future versions of Android, prolonging application’s lifetime (Android).

4) **Low cost and easiness of the development environment.**

5) **Easy access to investigator** of Android devices on which tested the application.

However, the choice of Android does not limit the future applicability on other OS. In addition, this project has few specific hardware requirements and all that was required was internet connection, an Android Smartphone and a portable computer.

### 6.2 Design

After carefully considering the requirements of the application and the technologies available, it was effectuated the design of the interface using the online software Fuid UI® (fuid) in a portable computer.

The design process started by checking the guidelines teaching how to create interfaces (Benyon, 2010) prior to designing the interface. They help the designer to make good choices during the design stage. The design principles are divided into three main topics: 1) learnability; 2) effectiveness; and, 3) accommodation. The topics are summarized below.

- **Learnability**, to make sure everything is visible so the users can easily see what functionality the program offers. Use symbols and language that the intended users should be familiar with. Make everything clear to the user by organizing objects and their properties in the interface so it can be related with their functionality and how it should be used.

- **Effectiveness**, provide support for users to navigate through the interface and make it easy to understand when and where the user is in control with the help of good feedback.

- **Accommodation**, make the interface flexible, stylish and attractive. The overall design should always be aimed to be polite to the user.

#### 6.2.1 System architecture

**Figure 11** shows the overall picture of the system architecture of the proposed application for self-management of RA.

The Smartphone application – named as “Diário da AR” - should access to email service using a third generation (3G) mobile network or a local wireless network when the patient deliberately chooses to export its recorded data from a determined time space in the “Options” section. The data is possibly delivered to the email of patient’s rheumatologist. The application also has links to external Internet pages with more information about a determined subject and whenever the patient selects them it is redirected for his web browser and the Uniform Resource Locator (URL) of the selected page is loaded if the Smartphone is connected to a 3G mobile network or a local wireless.
6.2.2 Screens for profile’s creation/edition

After launching the “Diário da AR” application for the first time, the user will receive a notification box from application to create a profile as demonstrated in Figure 12.
If the user presses the “Create” button, it will appear the section for creating/editing the profile. This section contains fields for text introduction such as “Name”, “Height” (meters - m), “Weight” (kilograms - kg) and “RA disease duration” (years). In addition, text fields such as “Arterial blood pressure” (millimeters of mercury - mmHg), “Cardiac frequency” (beats for minute – b/min), “Capillary blood glucose” (milligrams for deciliter – mg/dl), “Total cholesterol” (mg/dl) and “Triglycerides” (mg/dl) also make part of this section and can be easily obtained with medical equipment at home or in a pharmacy. The “Birth date”, “Date that started smoking” and “Date that stopped smoking” fields allow the response by selecting the answer in drop-down lists, “Gender” and “Smoking status” by selecting a button while “Number of cigarettes per day” by selecting the plus or the minus signs, in this section (Figure 13). If the user selects the “Close” button at left screen of Figure 12 or presses the arrow button in the third screen of Figure 13, the main menu screen appears.

Figure 13. Profile’s creation/edition screens.

6.2.3 Screens for disease management

In the “Diário da AR” application main screen, once the “Disease Management” is selected it will appear a screen with three options – “Functional Impact”, “Clinical visits and other tasks” and “Practical advices” (Figure 14). If the user selects “Functional Impact”, it will appear one question for each seven domains of RAID (pain, functional disability, fatigue, emotional and physical well-being, sleep disturbance and coping). The response for these questions can be given by two ways – using a Visual Analog Scale (VAS) illustrated with happy and sad faces with different colors depending of the degree chosen or the plus and minus signs to add or eliminate the number of painful joints. After the pain domain question, it will appear a screen with a mannequin with eight black circles. This screen is to select the painful joints. If the user selects the circles they will turn in to orange color except for the hands circles, which after being selected, a screen with the hand zoom will appear with eleven black circles for painful joints choice. Is sufficient one circle selection in the hand for the global mannequin presents the big hand circle in orange color.
Counting that the large circle in both hands is represented by the eleven circles when zoomed, the selection of painful joints only will occur in a maximum of twenty-eight joints (twenty-two from hands when zoomed and six from the mannequin), according to DAS28. **Figure 15** demonstrates some “Functional Impact” screens. After this question the remaining screens (questions for functional disability, fatigue, emotional and physical well-being, sleep disturbance and coping) will be presented and at end the result is given as demonstrated in **Figure 16**, according to the previously described formula (**Requirement 2 - RAID**). If result is between 0 and 3 points it will be presented “Little impact” at green color and a happy green face. If result is between 4 and 6 points it will be demonstrated “Medium impact” at yellow color and an unhappy yellow face. If result is between 7 and 10 it will be presented “High impact” at red color and sad red face.

![Main menu screen (Left) and “Disease Management” screen (Right).](image1.png)

**Figure 14.** Main menu screen (Left) and “Disease Management” screen (Right).

![“Functional Impact” screens.](image2.png)

**Figure 15.** “Functional Impact” screens.

Left: Pain domain screen of the “Functional Impact” questionnaire. Middle: Screen with joints for selecting the painful ones. The selected joints are represented in orange color circles while the non-selected are black circles. Right: If a hand circle is selected it will appear a screen with the zoom of that hand.
At “Disease Management” section, if the user selects “Clinical visits and other tasks” or receives a notification box it will be redirected to “Clinical visits and other tasks” screen, where is presented a list of the agented tasks and their status. If the user selects the gray symbol it will turn into green and the task will disappear from the list when the screen is changed to another one. If selecting the “Add task” button it will be possible to add a task to the list and if selecting a task from the list it will be possible to edit it. The information for each task includes the “Task name”, “Start date/hour”, “End date/hour”, “Place name” and “Notes” for any details that need to be remembered such which analyses must be shown to rheumatologist in that clinical visit or any questions to be made. Because “Clinical visits and other tasks” screen have only the purpose of alerting, it will be allowed to enable/disable notifications for these in this screen (Figure 17).

Figure 16 “Functional Impact” result’s screen.

Figure 17. “Clinical visits and other tasks” screens.
The “Functional Impact” section also presents the “Practical advices” option. These advices are summarized in the following screens/themes: use Velcro on clothing, use more the arms, use a basket, line hand tools, use technology in your favor, prevent falls and ask for help when you need. Some of these screens are presented in Figure 18. Text in these screens is described in Annex 10.7.

6.2.4 Screens for medication

The main screen also presents a “Medication” section that allows the user to add/edit a medication by filling the “Medication name” field, taking a camera picture of the medication box (it is easiest to patients remember the box than the medication name) and choosing in drop-down boxes the “Units” (ampules, capsules, cups, drops, grasses, injections, liter, micrograms, milligrams, milliliters, packages, pills, sprays, tablets, tea spoons, soup spoons), “Actual quantity”, “How to take” (oral, intramuscular, subcutaneous, sublingual, other), “Frequency” (single event, every day, every x days (if selecting this should give a place to write the number of days), weekly, monthly, every x hours (must give a place to write the number of hours) and as needed), “Hours” and “Instructions” (after or before eating). The “Quantity” is defined by selecting the plus or minus symbols. Notifications to take medication can be enabled or disabled. Each time a medication is taken the quantity is discounted to the introduced total number of pills or other administrable types and when running out the application displays an alert symbol. Figure 19 presents the screens relative to add/edit medications in “Medication” section. If the notifications are enable, the user receives a notification box at the time of taking the medication that redirects it to a screen where he can select if the medication was taken or if he wants to delay it or ignore it (the selected option turns to orange) and input the real data and quantity taken (Figure 20). Another feature of this section is the subsection for adding ADRs (select mild, moderate or severe ADRs that user could be experiencing – the selected option turns to orange - and add more specific notes such as spot of pain or what the user was doing when felt bad) (Figure 21).
Figure 19. “Medication” screens for add/edit medications.

Figure 20. Notification box for take the medications (left) and screen for editing medication status (right).

Figure 21. Adverse drug reactions registry screen.
6.2.5 Screens for information

The “Information” section could be selected from main menu screen. This section presents several informational topics including: “What is Rheumatoid Arthritis?”, “Causes”, “Diagnosis”, “Pharmacological therapy”, “Non-pharmacological therapy” and “Want to know more!”. The last section has several external links to informative sites of several Portuguese societies/institutions/associations to the Portuguese scientific journal about Rheumatic Diseases: “Acta Rheumatológica Portuguesa”, as previously referred (Figure 22). Text in these screens is presented in Annex 10.7.

![Figure 22. “Information” screens.](image)

6.2.6 Screens for health questionnaire

The “Health questionnaire” section, which could be assessed from main screen, incorporates the HAQ-DI (the selected options turn to orange) in an illustrative form, as previously described (Subchapter 6.1.1. Functional requirements – Requirement 2 – HAQ-DI). If result is $0 < \text{HAQ-DI} \leq 1$ it will be presented “Mild disability” at green color and a happy green face. If result is $1 < \text{HAQ-DI} \leq 2$ it will be demonstrated “Moderate disability” at yellow color and an unhappy yellow face. If result is $2 < \text{HAQ-DI} \leq 3$ it will be presented “Severe disability” at red color and sad red face (Figure 23). Additionally to the result from the 8 categories, the score for the aides and devices was also indicated at results screen, as previously described (Bruce & Fries, 2003; Santos et al., 1996):

- 0 = No assistance is needed.
- 1 = A special device is used by the patient in his/her usual activities.
- 2 = The patient usually needs help from another person.
- 3 = The patient usually needs BOTH a special device AND help from another person.
6.2.7 Screens for historical

The “Historical” section at main screen presents the registered data of the used drugs, the two questionnaires and ADRs in form of list. The graphics in this section present the results from both questionnaires and the representation of the selected painful joints over time (Figure 24).

6.2.8 Screens for options

At “Options” section the enable/disable of notifications and pin protection occur by selecting them. The notification in this screen is for the both medication and tasks and if the user wants to receive only notifications for one of them has to go to the corresponding
section and enable the notifications. At this screen is possible to export data by email from a selected data. All the screens in application present an information button (i format), as exemplified in Figure 25, that explains the importance or functionalities of each section. This information button also appears at the main menu for explaining the purpose of the application.

Figure 25. “Options” screens.

### 6.3 Implementation & Testing

Implementation (coding) and testing on real user in terms of measuring the usability of the “Diário da AR” application were beyond the scope of this research due knowledge limitations of investigator to perform the implementation and the limited time of the dissertation. However, a testing method is presented in Chapter 9. Future Work.

### 6.4 Discussion

The application “Diário da AR” was designed considering the questionnaire and literature review and included several sections/functions for providing the best help in self-management for RA patients as follow: 1) record and monitor disease activity, by flagging on painful joints, and quality of life over time in log-term with real-time calculation and exhibition of health-related quality of life questionnaires’ results; 2) step-by-step advices for teaching what patients can modify in their life for staying healthy, live better with RA and improve their prognosis at the same time; 3) alerts for taking medication or other tasks such as clinical visits and register the medication and its compliance; 4) register ADRs; 5) inform about the disease and treatment in a simplified form and actualize about the recent
sciences in area; and, 6) enable viewing past actions in the future and sharing with rheumatologists by email. In literature, only one study relatively similar to this, developed an application that gathers objective data from RA patients and shares this data with health professionals (Shinohara et al., 2013). Some of the shared data comprised self-evaluations of the mHAQ, tender joint count and swollen joint count (in accordance with the 46 or 49 joints used by the American College of Rheumatology), pain visual analog scale and quantification of daily activity (Shinohara et al., 2013). This application evaluated the disease activity and health-related quality of life over time using different questionnaires than those used by the “Diário da AR” application. While the Shinohara et al. application used the mHAQ for measuring health-related quality of life over time, a version of HAQ-DI with fewer questions, in “Diário da AR” application the HAQ-DI and the RAID were used, which allowed a more comprehensive analysis of quality of life impact. For the disease activity, the Shinohara et al. application used tender joint count and swollen joint count in accordance with the 49 or 46 joints used by the ACR, pain visual analog scale and quantification of daily activity “Diário da AR” application it was used only the tender joint count according to DAS28. Nevertheless, the “Diário da AR” application explored much more functions then Shinohara et al. application (Shinohara et al., 2013) and the majority of the applications in online application stores.

The major challenges during application development were minimizing the information displayed, finding a way to include all the functionalities organized, develop an interface intuitive with pleasant colors, reduce the number of screens as possible and display all the sections for users selecting, such as buttons, with large selectable areas (the most difficult section was the “Medications”).

Despite the potential of the application, it presents several limitations. The application was designed only for Android OS, therefore, any implications or conclusions derived from this study concerning the design of the application was limited to this device. The application has too many screens, which could difficult the navigation of the user. There were sections that may be too small to user select.
7. General conclusion
7. General conclusion

This chapter presents the general conclusions of this work.

Self-management interventions are typically provided through traditional intervention approaches such as face-to-face or internet-delivered. Nevertheless, these self-management interventions present several problems’ and one solution is to explore the technologies such as Smartphone application. This area seems to be very promising since Smartphones have potential to mitigate such problems and additionally provide several advantages compared to traditional interventions due to their widespread adoption combined with their increasingly powerful technical capabilities and portability. Still, the potential of RA self-management applications is not being completely well explored and there are no applications for this purpose in Portugal. Therefore, the development of such applications seems to be important and so it was conducted a needs assessment of a RA self-management application for the RA patients. This study suggested the usefulness of a smartphone application for RA self-management and that most RA patients were willing to use and pay for it. Additionally, highlighted that the RA self-management application should include the most requested features (e.g. information in a simple format and long-term disease monitoring) and try to resolve the problems observed in the population such the psychological factors impact on quality of life, the typical multiple drug regimens, the high treatment non-compliance rate and type and the reduced ability to engage in self-management behaviors. Considering this, “Diário da AR” was developed/design to aid self-management and solve these problems by including the functionalities of long-term record and monitor of disease activity, providing step-by-step advices for living better with RA and alerts for taking medication or other tasks, registering ADRs of medication and enabling viewing past actions and sharing with rheumatologists.

The opinions of RA patients support the potential of a smartphone application to be an innovative medium to empower patients to develop self-management skills. However, more research is required to optimize the potential of this delivery-mode in self-management interventions.
8. Future Work
8. Future Work

This chapter presents and discusses the future work.

8.1 Application testing

First of all, after the application implementation (coding), the most important work to develop in future is the evaluation of the “Diário da AR” application in terms of usability and usefulness.

The usability or user-friendliness of a product or system is defined in the International Organization for Standardization standard as the degree to which a group of users are able to achieve specific goals using it, within a specific context (International Organization for Standardization, 2013). It is also broken down into effectiveness, efficiency and satisfaction, which are defined as how well the goals are achieved, how much resources are required and the users' comfort and attitude towards the system, respectively. A fourth aspect of usability that is often added is learnability, relating to the time and effort required to learn how to use the system (Jeng, 2005). Henceforth, when user-friendliness is used it includes all four of these aspects.

A cross-sectional study should be conducted to evaluate the usefulness and usability of “Diário da AR” application. The participant sample size must be determined using the Problem Discovery Rate Model (Hwang & Salvendy, 2010; Nielsen, 2012; Nielsen & Landauer, 1993).

The usability of the application should be tested by the System Usability Score (SUS), a “quick and dirty”, reliable tool for measuring the usability (Aaron Bangor et al., 2009; Aaron Bangor et al., 2008). The SUS is a 10-item Likert-type measure of usability with 5 response options (strongly disagree, disagree, neutral, agree and strongly agree). In addition to SUS, the questionnaire should evaluate the time spent using the application, if patients think the application is useful, if they would like to use it when available and the parts of the application they like/unlike more and what they would better. The questionnaire was developed considering this and other additional usability questions, although not used in this work due to time restraints (Annex 10.8).

After this evaluation, future investigations of “Diário da AR” application usability should consider adopting new technologies, such as eye tracking methodologies applied to mobile devices, to quantitatively measure user interaction and engagement. Eye tracking can provide valuable information, such as how well a graphical interface works, where on the mobile device the user looks for certain options (such as buttons) and how the user’s attention shifts between the different parts of the phone when interacting with it. Eye tracking on Smartphones is a new and unexplored area of research that may provide a
more sophisticated quantitative approach to measuring usability.

The low socioeconomic level of the population and the reduced number of patients with Smartphone are potential barriers to the testing of application. Still, with the increasing of Smartphones, higher access to Internet and technologies acceptance in society, these limitations have tendency to be reduced over time.

8.2 Effectiveness evaluation

Secondly, if the application demonstrates to be useful and usable, their effectiveness to influence self-management and directly and/or indirectly improve health-related quality of life, healthcare utilization and perceived self-efficacy must be analyzed in a prospective interventional study. Smartphones integrated into interventions have the potential to be an efficacious, scalable, and cost-effective prevention and treatment option, with significant capability for public health impact. However, for this potential to be realized much more research needs to be conducted. The feasibility of Smartphone applications as an assistant tool is not well established and self-management interventions are typically provided through traditional intervention approaches such as face-to-face or internet-delivered. To date there has been no research published on the theoretical fundamentals of using Smartphone applications in self-management interventions. Smartphone technology differs to these other approaches, with both advantages and disadvantages, and it is necessary for future investigators to test this.

8.3 Extension for others OS

In this work it was selected a single OS for the initial proof of concept work due to several factors such a distinct dominance at 81% of market share, openness, forward compatibility, low cost and easiness of the development environment and easy access to investigator of Android devices (Android; Android; IDC, 2013). Still, in order to reach the biggest number of patients the application must be developed for running in other OS such as iOS.

8.4 Application improvement

Several characteristics to aid self-management can be implemented in the developed application in order to significantly improve it. These are discussed below.

8.4.1 Gait pattern measure

RA leads to functional disability and possible changes in normal gait pattern, a common but clinically serious problem that substantially affects quality of life in RA patients (Sakauchi et al., 2001). Previous studies have demonstrated that RA may lead to a decreased
Future Work

walking speed, shortened stride length, and increased double-stance period, indicative of a limitation in lower limb function (Laroche et al., 2006; O’Connell et al., 1998). Because of day-to-day variations in inflammatory activity and gait pattern in RA patients, self-management by self-monitoring becomes very important for controlling abnormal gait. Since the two applications in literature for RA measure gait patterns (Shinohara et al., 2013)(Yamada et al., 2012), it seems important to analyze this feature in future studies and possibly include it in the application.

8.4.2 Detection of drug interactions

In future work, the application must detect and update information on drug interactions. In fact, medication errors increase when the number of medications being administered increases (Aronson, 2009), as in case of RA (Elliott, 2008; Neame & Hammond, 2005). These errors can be prevented by developing such functionality in the developed application.

8.4.3 Advices and track physical activity

The distinct pattern of bone and joint destruction in RA is translated in pain, stiffness (worse in the morning) and swelling of involved joints, which difficult the routine activities (Imboden et al., 2006; Smith et al., 2011). In fact, RA patients are less physically active than general population (Hootman et al., 2003). Nevertheless, physical activity is crucial to maintain physical health and wellness and reduce pain (Cooney et al., 2011; Vliet Vlieland & van den Ende, 2011), which is positively related to several psychological factors (e.g. self-esteem, pain coping and self-efficacy) (Creamer et al., 1999). Therefore, it is extremely important to add advices on how to perform physical exercises without damage the affected joints and track physical activity as functionalities to application.

8.4.4 Goal setting

Goal setting involves establishing specific, measurable, achievable, realistic and time-targeted goals (Mendelson et al., 2011). On a personal level, setting goals helps people work towards their own objectives and perform better the tasks assigned (Mendelson et al., 2011). Therefore, setting self-management goals in the application may increase the patients’ interest in using it and improve their self-efficacy.

8.4.5 Contacting peers

Living with RA is about more than just managing joint pain and stiffness — it’s a condition that can affect your whole life. That’s why RA symptoms can also include depression and anxiety. According to a research review on psychological well-being with RA, it’s become increasingly evident over the past few years that emotional support is a key component to managing RA (Gettings, 2010). Although there’s no one-size-fits-all solution for RA support, the best fit could be an arthritis support group. People with RA may find it hard to open up, but in a good support group, they can find a place to learn and safely share experience with others. Therefore, adding to application the possibility of accessing
the chat rooms with peers could be an important step for helping RA patients learning more about self-management options.

8.5 Extension for others languages

The application was only developed in Portuguese from Portugal. In order to extend to other countries, it should be analyzed the applicability of the application in other populations and created other language versions.

8.6 Integration with the Hospital Information System

The integration of mobile applications with other aspects of patient care including use of electronic health records and patient portals will be one of the pivotal steps on the application maturity journey to facilitate the widespread prescription of mobile healthcare applications. Therefore, in a last step, the application must be integrated with the Hospital Information System. Still, for now there is a need of a considerable work and of guidelines to standardize applications after they could be integrated.
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9. References


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10. Annexes
10. Annexes

10.1 Review article about the importance of developing a Smartphone application for Rheumatic Diseases self-management

10.2 Proof of acceptance by the Ethics Committee for Health of São João Hospital/Faculty of Medicine of University of Porto

10.3 Information about the study delivered before the questionnaire

10.4 Informed consent according to the Declaration of Helsinki

10.5 Questionnaire delivered to RA patients

10.6 Portuguese versions of HAQ-DI and RAID

10.7 Text on the “Diário da AR” application screens

10.8 Application usability and usefulness questionnaire
10.1 Review article about the importance of developing a Smartphone application for Rheumatic Diseases self-management
Future perspectives of Smartphone applications for rheumatic diseases self-management

Ana Rita Pereira Azevedo · Hugo Manuel Lopes de Sousa · Joaquim António Faria Monteiro · Aurea Rosa Nunes Pereira Lima

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Abstract Rheumatic diseases (RD) self-management interventions are designed to improve health-related quality of life, health care utilization, and perceived self-efficacy. Despite these demonstrated good results, there are several issues that hinder or render less appealing these interventions. One economically and socially viable solution is exploiting the potential of Smartphone technology. This potential comes from Smartphones pervasive presence in actual society, combined with the advantages of being personal, intuitive, and computationally powerful, with capability to support applications and assist its user throughout different activities of daily living and environments persistently. With their global acceptance increasing quickly, there is a great opportunity for mobile health in using Smartphone applications for RD self-management. Besides the potential of such applications, research on the development and evaluation of such applications is in the early stages. Therefore, it is important to foresee its future applicability in order to meet the needs of the twenty-first century.

Keywords Smartphone applications · Self-management · Rheumatic diseases · Mobile devices · Mobile health

Introduction

Rheumatic diseases (RD) are non-traumatic functional disorders of musculoskeletal system (bones, joints, muscles, and/or tendons) with a wide spectrum of conditions with diverse pathophysiology, signs, symptoms, and duration time (acute onset, short duration, or chronic progressive course) [1–3]. The RD include more than one hundred diseases that can be classified into (1) non-inflammatory: degenerative spine diseases, osteoarthritis, osteoporosis, and fibromyalgia; (2) inflammatory: rheumatoid arthritis, juvenile idiopathic arthritis, ankylosing spondylitis, spondyloarthritis, reactive arthritis, connective tissue diseases, rheumatic polymyalgia, early stages. Therefore, it is important to foresee its future applicability in order to meet the needs of the twenty-first century.

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Introduction

Rheumatic diseases (RD) are non-traumatic functional disorders of musculoskeletal system (bones, joints, muscles, and/or tendons) with a wide spectrum of conditions with diverse pathophysiology, signs, symptoms, and duration time (acute onset, short duration, or chronic progressive course) [1–3]. The RD include more than one hundred diseases that can be classified into (1) non-inflammatory: degenerative spine diseases, osteoarthritis, osteoporosis, and fibromyalgia; (2) inflammatory: rheumatoid arthritis, juvenile idiopathic arthritis, ankylosing spondylitis, spondyloarthritis, reactive arthritis, connective tissue diseases, rheumatic polymyalgia,
Rheumatic diseases self-management

Self-management interventions are seen as key components of rheumatologic care, in particular of chronic RD [8]. These are aimed to directly and/or indirectly improve health-related quality of life (HRQoL) of the most important health domains for RA patients (e.g., pain, disability, depression, and global disease severity), health care utilization (total visits to physicians and rheumatology-related visits), and perceived self-efficacy (reflection of patient confidence to exercise control over the disease) [13–19]. These interventions promote independence, maintain or adjust social life roles, and address the psychological impact of disease [12]. To achieve these patient- and health care-related improvements, RD self-management interventions cover several subjects, they are as follows: (1) educational and psychosocial interventions; (2) lifestyle interventions; and (3) treatment interventions (Fig. 1).

Educational and psychosocial interventions

Education should constitute the initial step in self-management of RD and, whenever possible, should be combined with psychosocial interventions in order to influence behavior and induce self-efficacy perception [20, 23]. Self-efficacy perception is essential to reduce the development of affective disorders (e.g., depression and anxiety), commonly present in chronic RD patients [23]. Affective disorders are manifested in worrying, tenseness, avoidance behavior, and in feelings of sadness and helplessness and can reach to such an extent that can affect how well people are able to manage their disease (e.g., anxious avoidance of physical activity may increase functional impairment, and pessimistic thoughts may lead to poor compliance to pharmacological treatment) [29]. Thus, this will be translated in increased health care consumption, medical costs, sickness leave, and job loss [29–31]. Educational and psychosocial self-management interventions have demonstrated effective results in the improvement of patients’ HRQoL and perceived self-efficacy [13, 23, 24, 29, 32, 33]. In addition, these interventions combined with other strategies such as Yoga, Tai Chi, massage, and music therapy resulted in a median pain reduction of 23 % and an improvement in disability score of 19 % [22].

Lifestyle interventions

Lifestyle interventions are of great importance since due to pain and other symptoms, patients with RD are less physically active than general population [34]. Ongoing studies have shown that avoiding unhealthy behavior, maintaining optimal weight, having an adequate nutrition and sleep, and engaging in physical activities are self-management strategies recommended to improve and maintain periarticular muscle strength, flexibility and endurance, joint range of motion and protection, promote self-esteem, pain coping and self-efficacy, and improve HRQoL [20, 35–37]. Of particular interest is the participation in these interventions of overweight and obese individuals in self-management strategies, given that this population experiences more severe symptoms and impaired HRQoL when compared to those who maintain a healthy weight [38, 39] and, therefore, they are more likely to benefit of these strategies. In fact, a
systematic review and meta-analysis of weight reduction in obese patients with osteoarthritis showed that a 5% reduction in weight was associated with improved disability and pain [40].

Treatment interventions

Treatment non-compliance rate is about 50% in RD patients and can be of two types—intentional or unintentional [41–43]. The intentional non-compliance reflects a rational decision-making process of patient to not take the drugs or make a different dosage as instructed, whereby the benefits of pharmacological treatment are weighed against perceptions, feelings, or beliefs that drugs will not relieve symptoms, will cause serious adverse drug reactions or dependence [44–46]. On the other hand, unintentional non-compliance involves intending to take a medication as instructed but failing to do so for some reason (e.g., forgetfulness or carelessness) [45, 46]. Non-compliance is influenced by patient characteristics (e.g., educational and socioeconomic levels), treatment factors (e.g., multiple medication regimens and chronic therapy), and patient–health provider issues [45–47]. It contributes to the failure of therapeutic outcome, greater number of drug-related hospitalizations, and higher costs in health care services [45, 46, 48]. Therefore, compliance monitoring should be performed routinely to ensure drug effectiveness, avoid unnecessary dose and regimen changes, and contain health care costs [49]. Currently, there have been interventions specifically designed to improve compliance, mainly based on patient education, development of reminders, counseling, family therapy, psychological therapy, telephone follow-up, supportive care, and teaching techniques of disease self-management [45, 48, 50]. These traditional reminder systems are helpful compliance auxiliaries, especially when non-compliance is unintentional, but minimally involve the patient in the self-medication process and do not provide them access to their compliance data or other educational information [50].

Smartphone: an emerging technology in health

Internet technologies have yielded advances in telemedicine and teleHealth. Subsequently, they are now used in every modern health care organizations [51]. Due to the
advances of these technologies, barriers of space and time between health care providers and patients have been broken and a new term in the field of teleHealth emerged: mHealth [52]. As defined by the World Health Organization, mHealth, a component of electronic health (eHealth), is a “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices” [53]. Although personal digital assistants experienced a growth between 1990s and early 2000s, they have been replaced by other mobile devices with new functions and utilities, such as Smartphones [53].

The Smartphone market is growing quickly, and there are already more than 1.08 billion Smartphones of a total of 5 billion mobile phones around the World, with a greater penetration between ages of 25–34 and with females taking the lead (56% owning a Smartphone) [54–56]. These have the advantages of being personal, intuitive, user-friendly, computationally powerful, with larger and higher-resolution display screens, sensor-rich (e.g., high-quality cameras, recording devices, accelerometers, and geo-positioning systems), connected, and portable [57, 58]. The internal sensors offer diverse possibilities such the ability to infer context (user location, movement, and emotion), and the connectedness facilitates the sharing of health data with health professionals or peers [58]. In addition, as portable devices, they are highly valued by individuals, tend to be switched on, and remain with the owner throughout the day, which offers the opportunity of bringing interventions into real-life context [58]. Moreover, the capability of Smartphones to support software programs, known as applications (“apps”), has stimulated significant attention in the last years, and since Smartphones global acceptance is increasing quickly, there is a great opportunity for mHealth in using these applications.

Smartphone applications in health

Similarly to Smartphone owning, females take the lead when it comes to using health applications, with greater use in certain life events (e.g., pregnancy) [55, 59]. There is already a growing body of evidence that supports the use of Smartphone applications in health interventions. Many thousands of commercial applications may provide cheaper, more convenient, continuous, automated tracking of health and timely interventions for specific contexts without users special training [58]. Those aiming to improve health tend to provide information, advice, instruction, prompts, support, encouragement, and interactive tools for individuals to monitor, record, and reflect [58]. Smartphone applications may address a wide variety of purposes and contexts, such as for promoting behavior changes, for example, smoking cessation [60, 61], weight management, and physical activity promotion [62–64]. These provide a unique opportunity to help users stay healthy, while potentially playing a key role in helping to prevent disease onset [65, 66]. Moreover, applications may improve diseases tracking and monitoring process, for example, melanoma screening [67] and quantitative assessment of the curvature in diagnosis of scoliosis [68]. In addition, applications can be applied for the self-management of diseases, mainly chronic, such as diabetes mellitus [69], asthma [70], and RD [71–73].

Smartphone applications for rheumatic diseases

Importance of Smartphone applications

Recent literature suggests that RD self-management interventions can empower patients to become effective health care consumers in addition to improving clinical outcomes [13–24]. Moreover, these programs are both important and satisfying to patients [25]. Nevertheless, there are several problems in RD self-management interventions, including difficulty in involving patients, physicians, and organizations; issues in evaluating them; and their limited success both in terms of content, timing, and economic and social impacts [8, 26–28]. One economically and socially viable solution to mitigate some of these problems is exploiting the benefits of new technologies, using Smartphone applications.

Engaging patients, clinicians, and organizations

Achieving engagement of patients, clinicians, and organizations with self-management programs is challenging [26]. Particular patient groups are less engaged with “standard” programs such as patients with low levels of health literacy and low socioeconomic status, or patients from culturally and linguistically diverse communities [26]. Smartphone applications can partially solve this problem since these applications can be utilized without special training, contain user-friendly visual graphics and speech in animations, and can be provided in all languages with minor modifications to the intervention and reach almost all communities [58, 74]. Nevertheless, the Smartphone applications use also may vary according to age, gender, and socioeconomic levels, such that, for example, many patients do not have Smartphones or do not fully understand how to use them [75].

Self-management interventions access

Access to self-management programs is an issue for some patients, especially those working full time or living in rural and remote communities. Most programs are
face-to-face interventions, which may be difficult for those who work full time to attend a program during the day [27]. Although some programs offer evening sessions, participation can be hindered by fatigue after a long workday [27]. Also, for those living in rural and remote areas, such programs may not be readily available. Smartphone applications provide good flexibility for delivering health information and resources at a time and place that is chosen by the individual [58]. Other advantage is that they allow the easy sharing of daily health and activity information among the patient and health professionals without the need to travel [72].

**Self-management interventions evaluation**

Evaluation of self-management interventions has problems in both terms of frequency and methodology. Since the evaluation occurs in stages before, during, and after intervention, it represents a range of snapshots along a continuum, which may miss the full impact on the patient [27]. In addition, differences in outcome data may occur depending on who has asked questions and how questions were asked [27]. Smartphone applications offer a promising method for delivering a variety of medical and psychosocial treatments and for prospectively assessing treatment outcomes in patients’ typical environment, by a continuous way, rather than depending on a return clinic visit for post-treatment assessment [71]. Still, the continuous use of these applications may result in several problems, such as interference with school or work; decrease real-life social interaction; decrease academic ability; cause relationship problems; lead to physical health-related problems, including blurred vision and pain in the wrists or the back of the neck; and ultimately, cause addiction [76–78].

**Self-management interventions flexibility**

Concerns have been raised for the lack of self-management programs flexibility to incorporate individuals’ existing skills, life circumstances, and resources [8]. Evidence demonstrates that those who benefit from structured self-management programs tend to have a higher education level [79]. Moreover, a study in adolescents with chronic RD suggests that these may need additional support to achieve independence in self-management [80]. This suggests that structured programs may not include or be sufficiently adequate for all patients with RD. Smartphone applications can be useful for this issue because more and more they are reaching to all, independently of age, education level, or socioeconomic environment [54, 56]. In accordance, one study demonstrated that elderly patients with no previous experience with information and communication technologies were capable to effectively use a Smartphone application [81].

**Self-management interventions timing**

Another issue is the timing of self-management interventions. Most self-management programs were tested in patients 5 to 10 years after diagnosis [28]. Sociopsychological research suggests that after a major life experience (e.g., having a child) or a health event (e.g., a disease), people tend to be more amenable to adopt healthy behaviors [82]. This “teachable moment” is thought to be the ideal time for self-management interventions because people are more motivated. A study demonstrated that about 40 % of RD participants started exercising within the first month after receiving a leaflet on osteoarthritis and completing a self-management program [83]. Although the mechanism of this behavior change is unclear, the diagnosis of a RD may present a “teachable moment” for engaging patients to self-management behaviors. In fact, Smartphones can be helpful in this moment by capturing reports and provide immediate feedback and recommendations [71].

**State of the art**

**Literature search methodology**

In order to evaluate the state of art of Smartphone applications for self-management in RD, a search was performed using the PubMed database. Bibliographies of retrieved articles were screened for cited references to identify additional publications not indexed in the search database. Additionally, the search was performed in the online official stores, e.g., Apple store® (Apple Inc.) and Android market® (Google Inc.). The search strategy included one or a combination of the following terms: “application,” “app,” “compliance,” “disease activity,” “management,” “medical,” “mobile applications,” “mobile phone,” “monitoring,” “Rheumatic Diseases,” “self-management,” “self-monitoring,” “Smartphone,” “treatment,” and “therapy.” The most common RD were added to the search strategy. Studies and applications were selected if were in English or Portuguese, aimed for RD, analyzed strategies of self-management in health, patient-oriented, and had the involvement of Smartphone technology.

**Results**

Recently, there has been an increase in the use of digital media technologies (e.g., Web sites, Smartphone applications, and social networking tools) to deliver self-management interventions [14, 15, 72, 73]. Until now, several
Smartphone applications, not specific to any disease, have been developed as educational, psychosocial, lifestyle, and/or treatment interventions for problems related with RD and, there are only a few specific for RD (Table 1) [61–64, 71–73, 81, 84–87]. The RD-specific Smartphone applications are used to measure symptoms, provide the sharing of gather objective data between patients and health professionals, and self-measure the gait patterns [71–73]. A study in juvenile idiopathic arthritis evaluated the impact of the use of electronic diaries (e-diaries) for Smartphone by children to determine whether disabling symptoms (pain, stiffness, and fatigue) continue to be common despite the use of aggressive treatments [71]. Despite it was concluded that these symptoms persist common although the use of aggressive treatments, this study provided a daily evaluation in pain and symptoms patterns [71]. Another study reported the development of an application that analyzes gait abnormal patterns and gathers self-evaluations of HRQoL and disease activity from rheumatoid arthritis patients and shares it with health professionals [72]. The application for Smartphone was evaluated only in terms of feasibility, and results demonstrated that the rate of patient usage was very high, even though some patients had no experience in using Smartphones [72]. A study evaluated a Smartphone application combined with a sensor regarding its utility for self-assessing the gait patterns of rheumatoid arthritis patients, and results suggested that some gait parameters recorded represent an acceptable assessment tool for gait in those patients [73]. There are also many Smartphone-based medical applications available in online application stores directed for RD but they were not evaluated in any step of application development or discussed in the medical literature and, thus, lack of scientific evidence [88]. Table 2 and Table Supplementary 1 present an overview of these applications and some of their screenshots.

Future perspectives

This area seems to be very promising since Smartphones can provide several advantages compared to face-to-face self-management interventions. For example, the problem of access to self-management programs will no longer be an issue for patients working full time or living in rural and remote communities, since the intervention will be brought to any place and any time by a Smartphone. Nevertheless, for future work, there are various paths to take. There is a need for the development of more Smartphone applications in RD aimed for the self-management of disease-related symptoms; treatment, physical, and psychosocial consequences of disease; and lifestyle changes. Moreover, to develop these Smartphone applications with success is necessary to be aware of key challenges for their widespread adoption. These challenges include the following: (1) provide a solid evidence-based approach for ensuring applications credibility; (2) certify that there is sufficient health professional and target users involvement in applications design and content; (3) guarantee that applications are provided in a reliable way, since it influences their usability; (4) make sure that concerns in relation to security and privacy are attended; (5) indicate all possible conflicts of interest since, in some cases, applications are industry-driven, hence exposing bias in information provided, including bias toward particular types of treatment or intervention procedures; and (6) standardize applications to allow their integration with the hospital information system. The integration of mobile applications with other aspects of patient care, including the use of electronic health records and patient portals, will be one of the pivotal steps on the application maturity journey to facilitate the widespread prescription of mHealth applications, but guidelines are still needed to standardize such applications.

Conclusion

The future of “wireless mHealth technologies” is a new and evolving topic in health care services, with a great potential for supporting self-management interventions in RD, designed to improve HRQoL, health care utilization, and perceived self-efficacy. The Smartphone is a platform suitable to support these procedures, and as it has now achieved such a pervasive presence in society, it is a personal device and it assists its user throughout different activities of daily living and environments persistently. There are no doubts that in a near future, Smartphone applications will have potential to transform health care and clinical interventions. In line with this, and since the today’s digital age patients will be the tomorrow patients, it is important to start now to develop such useful applications. Although there has been much enthusiasm with concern to this, the Smartphone applications use is limited by age, gender, and socio-economic levels and its continuous utilization may result in several problems. The state of the art suggests the existence of more Smartphone applications for self-management directed for rheumatoid arthritis and RD in general, and so most of types of RD remain unexplored by these technologies. Moreover, at this juncture, although the several applications found in online stores, there is a need for scientific research in the development of such applications. As future perspectives, the meeting of the key challenges will accelerate the movement of applications use from that of a novelty into the mainstream of health care. In conclusion, research on the development and evaluation of such applications is in
<table>
<thead>
<tr>
<th>References</th>
<th>Application</th>
<th>Aim/disease</th>
<th>Platform/version</th>
<th>Characteristics</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sposaro et al. [80]</td>
<td>iFall</td>
<td>Full detection/not specific</td>
<td>Android/prototype</td>
<td>An application for fall detection and response. (educational and psychosocial intervention)</td>
<td>Realizable and cost-effective solution to fall detection using a simple graphical interface while not overwhelming the user with uncomfortable sensors</td>
</tr>
<tr>
<td>Bexelius et al. [62]</td>
<td>Physical activity levels (PAL) calculator</td>
<td>PAL measure/not specific</td>
<td>Java/prototype</td>
<td>Measures PAL through questionnaire application. (lifestyle intervention)</td>
<td>A promising tool for assessing the levels of physical activity</td>
</tr>
<tr>
<td>Silva et al. [81]</td>
<td>Fall detector</td>
<td>Full detection/not specific</td>
<td>Android/prototype</td>
<td>A fall detection application for Smartphone with an accelerometer. (educational and psychosocial intervention)</td>
<td>Encouraging and optimistic results regarding the feasibility of this fall detector</td>
</tr>
<tr>
<td>Yarnada et al. [71]</td>
<td>Abnormal gait pattern analysis</td>
<td>Gait analysis/RA</td>
<td>Android/prototype</td>
<td>A gait pattern analysis by an acceleration sensor, a recording device, and a computer program for processing the acceleration signals. Sensors have to be attached using a semi-elastic belt. (educational and psychosocial intervention)</td>
<td>Some gait parameters recorded using the Smartphone represent an acceptable assessment tool for gait in patients with RA</td>
</tr>
<tr>
<td>Allen et al. [61]</td>
<td>Lose it!</td>
<td>Weight loss</td>
<td>Android and iOS/5.0.8</td>
<td>Records food intake and exercise, calculates energy balance in real time, records weight and sets goals for weight loss and exercise. (lifestyle intervention)</td>
<td>A promising tool for self-monitoring as an adjunct to behavioral counseling</td>
</tr>
<tr>
<td>Bronberg et al. [69]</td>
<td>E-diary</td>
<td>Data self-collection/IIA</td>
<td>Microsoft windows/prototype</td>
<td>Measures pain (location, duration, intensity, and unpleasantness), functional limitations, stiffness, and fatigue (intensity and duration). (educational and psychosocial intervention)</td>
<td>Provide a daily evaluation in pain and symptoms patterns</td>
</tr>
<tr>
<td>Carter et al. [60]</td>
<td>My meal mate</td>
<td>Weight management/not specific (overweight)</td>
<td>Android/2.0.1</td>
<td>Goal setting, self-monitoring of diet and activity, and feedback via weekly text message. (lifestyle intervention)</td>
<td>Acceptable and feasible weight loss intervention</td>
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Table 1 continued

<table>
<thead>
<tr>
<th>References</th>
<th>Application</th>
<th>Aim/disease</th>
<th>Platform/version</th>
<th>Characteristics</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hayakawa et al. [79]</td>
<td>Medication self-management system</td>
<td>Medication history storage and reminder/not specific</td>
<td>Android/prototype</td>
<td>Storage and provision of an accurate, portable medication history and medication-taking records of patients. Provision of a reminder to take medication. Real-time medication monitoring. (treatment intervention)</td>
<td>Feasible and provides an innovative solution to encourage medication self-management</td>
</tr>
<tr>
<td>Kristjansdottir et al. [78]</td>
<td>Diaries and daily situational feedback</td>
<td>Data self-collection and sharing/not specific (patients with chronic pain)</td>
<td>Unknown/prototype</td>
<td>Analysis by questionnaire of current level and interference of pain, feelings, and thoughts related to avoidance, catastrophizing and acceptance. (educational and psychosocial intervention)</td>
<td>Can reduce catastrophizing and prevent increases in functional impairment and symptom levels in women with chronic widespread pain following inpatient rehabilitation</td>
</tr>
<tr>
<td>Shinohara et al. [70]</td>
<td>Lifelong sharing system</td>
<td>Gait analysis, data self-collection and sharing/RA</td>
<td>Android/prototype</td>
<td>Gait pattern analysis by an acceleration sensor, a recording device, and an application for processing the acceleration signals and an application to patients measure their daily RA parameters. (educational and psychosocial intervention)</td>
<td>Feasible promising tool</td>
</tr>
<tr>
<td>Buller et al. [59]</td>
<td>REQ-mobile</td>
<td>Smoking cessation</td>
<td>Unknown/prototype</td>
<td>An application for smoking cessation. (lifestyle intervention)</td>
<td>Feasible for delivering cessation support but appeared to not move smokers to quit as quickly as text messaging because it is simple, well known, and delivered to a primary inbox. These advantages may disappear as smokers become more experienced with new handsets</td>
</tr>
<tr>
<td>Mira et al. [75]</td>
<td>ALICE</td>
<td>Medication self-management</td>
<td>Android and iOS/prototype</td>
<td>Personalization of prescriptions and medical advice, showing images of each medication together with alerts and multiple reminders for each alert. (treatment intervention)</td>
<td>Improves compliance, helps reduce rates of forgetting and of medication errors, and increases perceived independence in managing medication</td>
</tr>
</tbody>
</table>

iOS phone operating system, JIA juvenile idiopathic arthritis, PAL physical activity levels, RA rheumatoid arthritis, Ref reference
<table>
<thead>
<tr>
<th>Application</th>
<th>Version</th>
<th>Platforms</th>
<th>Disease model</th>
<th>Type of intervention</th>
<th>Description</th>
</tr>
</thead>
</table>
| My Pain Diary®                      | 1.2     | Android and iOS       | Rheumatic diseases     | Educational and psychosocial + lifestyle + treatment     | Keep an accurate record of patient condition for physician  
Compare multiple conditions and metrics on a single, interactive graph, which makes finding correlations easy  
Learn how much patient is affected by humidity, barometric pressure, temperature, precipitation, and other factors  
Identify triggers, patterns, and trends  
Email or print a report  
Track complex medical condition multiple times a day  
Track pain condition as it occurs  
Inform and track nutrition, fitness, sleep, medication, and mood, and compare it to arthritis pain |
| TRACK + REACT®                       | 1.2     | Android and iOS       | Inflammatory rheumatic diseases | Educational and psychosocial + lifestyle + treatment     | Inform and track nutrition, fitness, sleep, medication, and mood, and compare it to arthritis pain  
Track pain condition as it occurs  
Inform and track nutrition, fitness, sleep, medication, and mood, and compare it to arthritis pain |
| Learn Arthritis Prevention®         | 1.2     | Android               | Inflammatory rheumatic diseases | Educational and psychosocial                              | Teach about how to manipulated joints to prevent problems and relieve pain with step-by-step video demonstrations  
Review quizzes  
Flag and make notes on various body parts where symptoms and/or signs are present  
Generates reports for symptoms/signs tracking and sharing with physicians |
| MyRA®                               | 1.6     | iOS                   | Rheumatoid arthritis   | Educational and psychosocial                              | Flag and make notes on various body parts where symptoms and/or signs are present  
Generates reports for symptoms/signs tracking and sharing with physicians  
Records pain based on the visual analogue scale  
Symptoms/signs check with simple functional ability assessment  
Clear representation of the pain diary over time, as a list or as a calendar  
Tracks morning stiffness, sporting activities, times of infection, and inability to work  
Reminder functions for recording pain values, medication use, checks, and physician visits |
| RheumaTrack®                        | 2.0.4   | Android and iOS       | Rheumatoid arthritis   | Educational and psychosocial + lifestyle + treatment     | Records pain based on the visual analogue scale  
Symptoms/signs check with simple functional ability assessment  
Clear representation of the pain diary over time, as a list or as a calendar  
Tracks morning stiffness, sporting activities, times of infection, and inability to work  
Reminder functions for recording pain values, medication use, checks, and physician visits |
| RHEUMATOID ARTHRITIS®               | 1.0     | Android               | Rheumatoid arthritis   | Educational and psychosocial                              | Inform about rheumatoid arthritis  
Inform about diagnosis, classification and management of rheumatoid arthritis |
| Rheumatoid Arthritis Diagnosis and Management® | 1.0   | iOS                   | Rheumatoid arthritis   | Educational and psychosocial                              | Inform about diagnosis, classification and management of rheumatoid arthritis |
the early stages but there is a great potential of Smartphone applications for RD self-management.

Acknowledgments The authors wish to acknowledge Miguel Bernardes (MD, M.Sc.) from the Rheumatology Department of São João Hospital Center for the helpful comments given during this paper revision.

Conflict of interest The authors declare that they have no potential conflict of interests, according to the Journal’s policy.

References


## Table 1. Screenshots of Smartphone applications for self-management of Rheumatic Diseases

<table>
<thead>
<tr>
<th>MyRA®</th>
<th>RheumaTrack®</th>
<th>RA Helper®</th>
<th>SpA Helper®</th>
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</thead>
<tbody>
<tr>
<td><img src="image1" alt="MyRA® Screen" /></td>
<td><img src="image2" alt="RheumaTrack® Screen" /></td>
<td><img src="image3" alt="RA Helper® Screen" /></td>
<td><img src="image4" alt="SpA Helper® Screen" /></td>
</tr>
</tbody>
</table>

### RHEUMATOID ARTHRITIS®

- My Pain Diary®
- PASQ®
- TRACK+REACT®

### Rheumatoid Arthritis Diagnosis and Management

- Learn Arthritis Prevention®

### SUPPLEMENTARY MATERIAL
10.2 Proof of acceptance by the Ethics Committee for Health of São João Hospital Center/Faculty of Medicine of University of Porto
Exmo. Senhor
Presidente do Conselho de Administração do
Centro Hospitalar de S. João – EPE

Assunto: Pedido de autorização para realização de estudo/projecto de investigação

Nome do Investigador Principal:
Ana Rita Pereira Azevedo

Título do projecto de Investigação:
Aplicação "smartphone" de autogestão da Artrite Reumatoide

Pretendendo realizar no Serviço de Reumatologia do Centro Hospitalar de S. João – EPE o estudo/projecto de investigação em epígrafe, solicito a V. Exa., na qualidade de Investigador/Promotor, autorização para a sua efectivação.

Para o efeito, anexa toda a documentação referida no dossier da Comissão de Ética do Centro Hospitalar de S. João respeitante a estudos/projectos de investigação, à qual endereçou pedido de apreciação e parecer.

Com os melhores cumprimentos.

Porto, 31 de outubro de 2013

O INVESTIGADOR/PROMOTOR

Ana Rita Pereira Azevedo
COMISSÃO DE ÉTICA PARA A SAÚDE DO CENTRO HOSPITALAR DE S. JOÃO - EPE

Parecer

Título do Projecto:     Aplicação “Smartphone” de autogestão da Artrite Reumatoide
Nome do Investigador Principal:  Ana Rita Pereira de Azevedo
                                         - Aluna do Mestrado em Informática Médica da Faculdade de
                                         Medicina da Universidade do Porto em cooperação com a Faculdade
de Ciências da Universidade do Porto
                                         - Licenciada em Bioquímica pelo Instituto Superior de Ciências da
                                         Saúde - Norte

Objective do Projecto:  Dissertação no âmbito do Mestrado em Informática Médica
Local onde decorrerá o Estudo:  Serviço de Reumatologia do Centro Hospitalar de S. João EPE
Orientador:  Prof. Doutor João Almeida Lopes Fonseca

Concepção e Pertinência do Estudo

Este Estudo tem como finalidade desenvolver uma aplicação para smartphone para a autogestão da A.R.
por doentes portugueses.

A A.R. é uma doença reumática crónica caracterizada pela inflamação e progressiva destruição das
articulações e cartilagens atingindo 1% da população mundial adulta com mais incidência no Norte da
Europa e Estados Unidos acometendo três vezes mais o gênero feminino e detectando-se majoritariamente
após os 65 anos de idade.

Em Portugal existem cerca de 40.000 doentes com A.R.

A maioria destes doentes com A.R. entra em declínio de funcionalidade e incapacidade dois anos após o
início da doença, verificando-se uma redução em cerca de 10 anos da esperança média de vida nas mulheres
e 4 anos nos homens. A morte ocorre em consequência de complicações sistémicas decorrentes da doença
nomeadamente doenças cardiovasculares, hematológicas, gastrointestinais, pulmonares e infecções. A
depressão ocorre com frequência duas vezes maior comparando com a população geral, piorando o
diagnóstico. O tratamento da doença deve ser iniciado logo que detectada de modo a proporcionar melhor
qualidade de vida aos doentes.
A fraça adesão ao tratamento deve ser evitada porque existe uma tendência do doente a utilizar uma dosagem diferente da prescrita ou a não tomar medicação em férias.

Trata-se dumha doença que exige um acompanhamento a longo prazo do doente de modo a minimizar o impacto na sua qualidade de vida e por esse motivo tem havido esforços no desenvolvimento de técnicas, baseadas na educação do doente para melhorar a adesão ao tratamento bem como no ensino de técnicas de autogestão da doença.

Entre as várias ferramentas utilizadas para monitorizar a doença destacam-se a avaliação da actividade da doença em 28 articulações (DAS 28) e o questionário de avaliação da doença (HAQ).

Existem limitações para o uso destas ferramentas por um lado devido à presença de outras doenças e também devido à subjectividade do (HAQ) que depende da percepção do doente face ao seu estado de saúde.

Estas limitações podem ser minimizadas se os profissionais de saúde recorrerem a outras ferramentas e promoverem uma melhor informação junto dos doentes sobre a doença e das suas implicações na saúde global do doente.

Procura-se actualmente a utilização dos smartphones com um uso muito mais disseminado na população em geral e com o uso adequado nestes de aplicações especializadas a que os utilizadores podem recorrer e que estão direccionados para a autogestão e monitorização de doenças crónicas não existindo no entanto ainda nenhuma aplicação de autogestão da A.R.

Neste sentido uma aplicação direccionada para a A.R. poderá ser uma nova abordagem para melhorar a adesão ao tratamento, envolver e educar o doente e melhorar a relação médico-doente fornecendo um conjunto de informações adicionais sobre o doente e o seu tratamento específico.

A metodologia consiste na realização de questionário para encontrar as características funcionais ideais para a aplicação. Depois de desenvolvida será entregue a uma amostragem de doentes onde será testada a sua utilidade por questionário, avaliando-se o grau de satisfação e dificuldades do doente no uso da aplicação e as suas críticas tendo em vista a sua melhoria.

Os incómodos para o doente que resultam da sua participação resumem-se à perda de algum tempo no final das consultas de reumatologia no preenchimento de 2 questionários e na utilização da aplicação durante 2-3 meses. A participação é livre, sendo-lhe concedido tempo suficiente para a sua decisão ser tomada podendo a todo o tempo recusar a sua participação no estudo sem consequências para a assistência médica que lhe é prestada.

A confidencialidade e anonimização dos dados estão asseguradas.

O consentimento informado está em conformidade.

A amostra será constituída por 100 doentes seguidos no Serviço de Reumatologia do C.H. de S. João.

Os critérios de inclusão estão definidos.
O estudo será alargado ao Instituto de Oncologia, Francisco Gentil EPE e prevê-se o seu termo em 1 de Novembro de 2014.

**Conclusão:** O Estudo afigura-se pertinente pelo que proponho à CES a sua aprovação.


O Relator

Eng. Rui Barbosa
7. **SEGURO**
   
a. Este estudo/projecto de investigação prevê intervenção clínica que implique a existência de um seguro para os participantes?
   
<table>
<thead>
<tr>
<th>SIM</th>
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<th>NÃO APLICÁVEL</th>
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(Se sim, junte, por favor, cópia da Apólice de Seguro respectiva)

8. **TERMO DE RESPONSABILIDADE**

Eu, Ana Rita Pereira Azevedo, abaixo-assinado, na qualidade de Investigador Principal, declaro por minha honra que as informações prestadas neste questionário são verdadeiras. Mais declaro que, durante o estudo, serão respeitadas as recomendações constantes da Declaração de Helsínquia (com as emendas de Tóquio 1975, Veneza 1983, Hong-Kong 1989, Somerset West 1996 e Edimburgo 2000) e da Organização Mundial da Saúde, no que se refere à experimentação que envolve seres humanos. Aceito, também, a recomendação da CES de que o recrutamento para este estudo se fará junto de doentes que não tenham participado em outro estudo no decurso do actual internamento ou da mesma consulta.

Porto, 31 / Outubro / 2013

[Signature]

O Investigador Principal
10.3 Information about the study delivered before the questionnaire
INFORMAÇÃO AO PARTICIPANTE

Título do Estudo
Aplicação “Smartphone” de autogestão da Artrite Reumatoide

Identificação do estudo
A Artrite Reumatoide é uma doença reumática crónica de etiologia desconhecida, caracterizada pela inflamação e progressiva destruição das articulações e cartilagens. Esta atinge cerca de 1% da população adulta mundial, sendo mais incidente no norte da Europa e nos Estados Unidos da América, acomete cerca de três vezes mais o gênero feminino e surge maioria e dentre após os 65 anos de idade. Em Portugal existem cerca de 40.000 doentes diagnosticados com Artrite Reumatoide. A maioria dos doentes com Artrite Reumatoide experencia um declínio de funcionalidade e incapacidade dentro de dois anos desde o início da doença. Além disso, o desenvolvimento de depressão é cerca de duas vezes superior comparado com a população geral e é responsável por pior prognóstico.

A abordagem terapêutica da Artrite Reumatoide deve ser feita o mais precocemente possível após o diagnóstico, de modo a diminuir a inflamação, controlar a sintomatologia associada à doença, atrasar a sua progressão e proporcionar maior qualidade de vida aos doentes. Por outro lado a não adesão ao tratamento é um problema que deve ser contornado, dado que é muito comum na Artrite Reumatoide e contribui para piores resultados do tratamento, maior número de hospitalizações relacionadas com a medicação e maiores custos de saúde. A fraça adesão ao tratamento pelos doentes com Artrite Reumatoide é maioria e intencional, como, por exemplo, fazer uma dosagem diferente da prescrita ou não tomar o fármaco nas férias. O motivo da não adesão intencional deve-se principalmente a crenças que a medicação não irá aliviar os sintomas nem melhorar a qualidade de vida e que irá causar efeitos secundários graves e dependência, e à pobre relação doente-profissional de saúde. Outros motivos são o nível educacional e socioeconómico do doente. Quanto ao comportamento não intencional, são exemplos o esquecimento da administração do fármaco ou a não compreensão das instruções de tratamento. Atualmente têm existido algumas intervenções especificamente concebidas para melhorar a adesão ao tratamento, majoritariamente baseadas na educação do doente, no desenvolvimento de alertas e no ensino de técnicas de autogestão da doença.

Devido às características da Artrite Reumatoide, esta exige um acompanhamento do
doente a longo-prazo, de modo a minimizar o impacto negativo da doença na qualidade de vida do doente. São várias as ferramentas que permitem efetuar a monitorização da doença. As mais comumente utilizadas pelos médicos reumatologistas incluem a avaliação da atividade da doença em 28 articulações (“Disease Activity Score 28”, DAS28) que permite acompanhar a progressão da doença, a evolução dos doentes, bem como auxilia nas decisões terapêuticas, e o questionário de avaliação de saúde (“Health Assessment Questionnaire”, HAQ), concebido para avaliar a influência, a longo-prazo, do impacto das doenças crónicas e do tratamento na qualidade de vida dos doentes.

Todavia, estas ferramentas possuem limitações, nomeadamente a existência de erros na autoavaliação da atividade da doença, devido à presença de outras doenças, além da variabilidade existente entre os diferentes profissionais de saúde e a subjetividade de alguns parâmetros, como p. ex. do HAQ, que depende da percepção do doente face ao seu estado de saúde. Estas limitações podem ser minimizadas se, por um lado, os profissionais recorrerem simultaneamente a diferentes ferramentas e, por outro lado, promovendo a educação para a saúde junto dos doentes, informando-os mais e melhor acerca da doença e das implicações desta na saúde global do doente.

O uso das ferramentas para a monitorização da Artrite Reumatoide e consequente melhoria na otimização das escolhas terapêuticas, contribuem para: 1) atraso da evolução da doença; 2) atraso ou prevenção de complicações relacionadas com a doença; e, 3) melhoria da qualidade de vida. Para além disso, a possibilidade de participação ativa do doente no controlo da sua própria doença tem sido associada com uma melhoria a nível psicossocial, o que é muito importante dado que esta doença está associada com o desenvolvimento de depressão.

Hoje em dia o acesso a tecnologia é muito facilitado e a maior parte das pessoas têm acesso a “Smartphones”, dispositivos multifuncionais com acesso à Internet que permitem o acesso constante à comunicação e informação e executam variadas tarefas. A maioria das tarefas é executada por aplicações especializadas que os utilizadores podem facilmente fazer o “download” e usar. O crescente uso de “Smartphones” no mundo, devido à sua fácil acessibilidade e baixo custo, tornou as aplicações bastante atraentes para a resolução/melhoria de alguns problemas, o que possibilitou a sua diversificação em áreas distintas como a saúde, nutrição, bem-estar, educação, gestão e vigilância em saúde pública.

Existe já um grande número de aplicações “Smartphone” direcionadas para a autogestão e monitorização de doenças crónicas devido ao carácter progressivo
destas doenças. No entanto, e apesar de todas as vantagens, até agora não existe nenhuma aplicação de autogestão da Artrite Reumatoide descrita na literatura. Neste sentido, o desenvolvimento de uma aplicação para “Smartphone” direcionada para a Artrite Reumatoide poderá ser uma nova abordagem para melhorar a adesão ao tratamento, envolver e educar o doente, melhorar a interação doente-médico, fornecer um repositório de informações sobre o doente e o seu tratamento específico.

Identificação do investigador responsável e forma de ser contactado
Ana Rita Pereira Azevedo, o qual poderá ser contactado a qualquer hora através do seguinte número de telemóvel: 917742956 ou para rita.pereir@hotmail.com.

Objetivo da investigação
De acordo com o descrito anteriormente, este estudo tem como objetivo geral desenvolver uma aplicação para “Smartphone” para a autogestão da Artrite Reumatoide por doentes Portugueses.

Metodologia a utilizar
Dos doentes com Artrite Reumatoide será necessário realizar questionários de forma a analisar quais as características funcionais e gráficas a aplicação para “Smartphone” deverá ter. Posteriormente será desenvolvida a aplicação tendo em consideração os resultados dos questionários, será entregue a aplicação a uma amostragem de doentes e avaliada a sua utilidade por questionário, pela análise de satisfação e dificuldades do doente no uso da aplicação e de críticas para melhoria do sistema.

Benefícios esperados e riscos possíveis
Pretende-se com este estudo desenvolver uma aplicação para “Smartphone” que atenda às necessidades dos doentes e, no geral, aumente o grau de conhecimento dos doentes acerca da doença e as suas competências na autogestão desta, permita que o doente tome atitudes que incrementem a sua qualidade de vida, possibilite uma relação mais próxima entre médico reumatologista-doente, elimine ou diminua a não adesão ao tratamento de forma intencional e não intencional e permita que os doentes assumam um papel mais ativo na gestão da doença de forma a melhorar a qualidade de vida e condição psicossocial. No final do estudo os participantes que forem selecionados poderão ficar com a aplicação sem qualquer custo. Não se espera, com este estudo, qualquer situação de risco.
Incómodos derivados da participação
Os participantes no estudo terão de perder algum tempo no final das suas consultas de rotina ao Serviço de Reumatologia no preenchimento de um questionário. Os doentes que forem selecionados para testar a aplicação desenvolvida, terão de perder algum tempo no preenchimento de um questionário e na utilização da aplicação durante 2-3 meses.

Carácter voluntário da participação
Cabe aos doentes a total liberdade de decisão, no que respeita à sua vontade de inclusão ou não no estudo, bem como tempo disponível para refletir sobre o pedido de participação, inclusive ouvir opinião de familiares e/ou amigos. Mais ainda, cabe-lhes o direito de recusar a todo o tempo a sua participação no estudo, sem que isso possa ter como efeito qualquer prejuízo na assistência que me é prestada.

Garantia da privacidade e da confidencialidade
De forma a garantir a privacidade e confidencialidade dos dados dos participantes será atribuído um número de identificação a cada participante e o acesso aos dados será apenas realizada pelo investigador principal. Os dados recolhidos dos participantes serão apenas usados para este estudo, não tendo qualquer outro destino que não o estudo aqui exposto.

Este trabalho de investigação foi aprovado pela Comissão de Ética para a Saúde do Centro Hospitalar de São João – EPE.
10.4 Informed consent according to the Declaration of Helsinki
DECLARAÇÃO DE CONSENTIMENTO

Considerando a “Declaração de Helsínquia” da Associação Médica Mundial
(Helsínquia 1964; Tóquio 1975; Veneza 1983; Hong Kong 1988; Somerset West 1996 e Edimburgo 2000)

Designação do Estudo:
Aplicação “Smartphone” de autogestão da Artrite Reumatoide

Eu, abaixo-assinado, ____________________________________________________________, declaro não ter participado em nenhum outro projeto de investigação similar, tendo compreendido a explicação que me foi fornecida acerca da investigação que se tencionia realizar. Foi-me ainda dada oportunidade de fazer as perguntas que julguei necessárias, e de todas obtive resposta satisfatória. Tomei conhecimento de que, de acordo com as recomendações da Declaração de Helsínquia, a informação ou explicação que me foi prestada versou os objectivos, os métodos, os benefícios previstos, os riscos potenciais e o eventual desconforto. Além disso, foi-me afirmado que tenho o direito de recusar a todo o tempo a minha participação no estudo, sem que isso possa ter como efeito qualquer prejuízo na assistência que me é prestada. Por isso, consinto que me seja aplicado o inquérito proposto pelo investigador.

Data: ____ / _______________ / 2014

Assinatura: ________________________________________________________________

O Investigador responsável:

 Nome: Ana Rita Pereira Azevedo

Assinatura: Ana Rita Pereira Azevedo
10.5 Questionnaire delivered to RA patients
### QUESTIONÁRIO AO PARTICIPANTE

**Nº ID:**

#### Dados Gerais

<table>
<thead>
<tr>
<th>Data nascimento: <em><strong><strong>/</strong></strong></em>/_______</th>
<th>Género: O Feminino O Masculino</th>
</tr>
</thead>
<tbody>
<tr>
<td>Localidade: ________________________</td>
<td>Défice motor: O Sim O Não</td>
</tr>
<tr>
<td></td>
<td>Défice visual: O Sim O Não</td>
</tr>
<tr>
<td>Grau de escolaridade: O Inferior ao 1º Ciclo O 1º Ciclo (1º-4º) O 2º Ciclo (5º e 6º)</td>
<td>O Ensino Secundário (7º-12º) O Ensino Superior</td>
</tr>
<tr>
<td>Situação Laboral: O Reformado O Desempregado O Trabalhador activo</td>
<td></td>
</tr>
<tr>
<td>Rendimentos: O &lt;500€ O 500€ - 1000€ O 1000€ - 5000€ O 5000€ - 10000€ O &gt; 10000€</td>
<td></td>
</tr>
<tr>
<td>Fumador? O Sim O Não</td>
<td></td>
</tr>
</tbody>
</table>

**Contacto:** ________________

#### Relação doente-Artrite Reumatoide (AR)

1. Em que ano/há quanto tempo foi diagnosticada a AR? ________________

#### HAG-DI 8-item

| 2. A dificuldade em vestir-se sozinho, incluindo apertar botões e atacadores? | O 1 O 2 O 3 O 4 O 5 |
| 3. A dificuldade em entrar e sair da cama? | O 1 O 2 O 3 O 4 O 5 |
| 4. A dificuldade em levantar um copo cheio? | O 1 O 2 O 3 O 4 O 5 |
| 5. A dificuldade em caminhar em terreno plano? | O 1 O 2 O 3 O 4 O 5 |
| 6. A dificuldade em lavar e secar todo o corpo? | O 1 O 2 O 3 O 4 O 5 |
| 7. A dificuldade em baixar-se para apanhar objetos do chão? | O 1 O 2 O 3 O 4 O 5 |
| 8. A dificuldade em abrir e fechar torneiras/portas? | O 1 O 2 O 3 O 4 O 5 |
| 9. A dificuldade em entrar e sair de um carro? | O 1 O 2 O 3 O 4 O 5 |
| 10. A dificuldade em ter uma boa noite de sono? | O 1 O 2 O 3 O 4 O 5 |
| 11. O receio que a doença se descontrole? | O 1 O 2 O 3 O 4 O 5 |

#### Self-Rated Health Scale

13. Em geral, como considera a sua saúde?

#### Morisky Medication Adherence Scale


#### Relação doente-adesão à terapêutica direcionada para a AR

| 2. O cumprimento da medicação prescrita? | O 1 O 2 O 3 O 4 O 5 |
| 3. O cumprimento da dose prescrita? | O 1 O 2 O 3 O 4 O 5 |
| 4. O cumprimento dos dias indicados para a toma? | O 1 O 2 O 3 O 4 O 5 |
5. O que faz mais frequentemente quando não toma? (Selecione uma opção)
   O Toma imediatamente quando se lembra.
   O Toma no dia seguinte.
   O Toma passado dois ou mais dias.
   O Não toma e comunica ao seu médico na próxima visita que não tomou.
   O Não toma e não comunica ao seu médico.
   O Toma sempre. (Se assinalar esta opção não fazer a questão 6)

6. Quais os motivos que justifiquem o incumprimento das indicações do médico? (Pode selecionar várias opções)
   O É muito esquecido/distraído.
   O Não tem quem o lembre.
   O Acredita que não vai melhorar a sua qualidade de vida.
   O Acredita que vai causar-lhe efeitos adversos, secundários ou indesejáveis.
   O Acredita que vai causar-lhe dependência.
   O Só toma quando se sente doente.
   O Deixa de tomar quando se sente melhor.
   O Deixa de tomar quando se sente mal.
   O Outras: ________________________________

7. Toma normalmente a medicação nas férias/viagens?  O Sim  O Não
   Se não quais as razões? ____________________________________________

Relação doente-médico reumatologista

1. Qual o nº médio de consultas de Reumatologia (por ano):
   Numa escala de 1 a 5: Em que 1-nunca e 5-sempre.
   2. Qual a frequência com que questiona o médico sobre dúvidas relativas à doença?  O 1  O 2  O 3  O 4  O 5
   3. Qual a frequência com que conversa sobre os problemas pessoais (relacionados com a doença) com o médico?  O 1  O 2  O 3  O 4  O 5
   4. Como avalia o acompanhamento da doença por parte do médico reumatologista? Em que 1-má e 5-excelente.
      O 1  O 2  O 3  O 4  O 5

Conhecimentos sobre a AR e tratamento
   Numa escala de 1 a 5 como avalia o conhecimento sobre: Em que 1-nenhum e 5-muito.
   1. O que é a AR?  O 1  O 2  O 3  O 4  O 5
   2. Qual o tratamento usado na AR?  O 1  O 2  O 3  O 4  O 5
   3. Quais os efeitos terapêuticos do tratamento?  O 1  O 2  O 3  O 4  O 5
   4. Quais os efeitos adversos e secundários do tratamento?  O 1  O 2  O 3  O 4  O 5
Das questões que se seguem, selecione sim ou não:

5. Sabe o que é o DAS28 ("Disease Activity Score 28")?  
   O Sim  O Não

6. Sabe o que é o HAQ ("Health Assessment Questionnaire")?  
   O Sim  O Não

7. Quais as razões de não saber mais sobre a AR/tratamento?  
   (Pode selecionar várias opções)
   - Falta de tempo nas consultas para explicações.
   - Falta de interesse da sua parte.
   - Falta de interesse do seu médico.
   - Confiar nas decisões do seu médico.
   - Desconhece como aceder a essa informação.
   - Outras:__________________________

Relação doente-tecnologias

1. Tem "Smartphone"?  
   O Sim, com Internet  O Sim, sem Internet  O Não

2. Tem computador?  
   O Sim, com Internet  O Sim, sem Internet  O Não

Numa escala de 1 a 5: (Não responder se não aplicável)  
   Em que 1-nunca e 5-sempre.

3. Qual a frequência com que usa o "Smartphone"?  
   O 1  O 2  O 3  O 4  O 5

4. Qual a frequência com que usa o computador?  
   O 1  O 2  O 3  O 4  O 5

5. Qual a frequência com que consulta a internet?  
   O 1  O 2  O 3  O 4  O 5

6. Qual a frequência com que envia mensagens (SMSs)?  
   O 1  O 2  O 3  O 4  O 5

7. Qual a frequência com que envia E-mails?  
   O 1  O 2  O 3  O 4  O 5

8. Qual a frequência que usa aplicações no "Smartphone"?  
   O 1  O 2  O 3  O 4  O 5

Se aplicável e não selecionar 1 (nunca): (Pode selecionar vários)

Que tipo? O Aplicações na saúde (ex: Fitness, dieta, direcionadas para doenças)  
   O Agenda O Alertas O Redes sociais O Jogos O Outros:__________

Autogestão da doença

1. Após o diagnóstico, mudou algum aspeto no seu estilo de vida (ex. perda de peso, deixar de fumar, exercício físico)?  
   O Sim  O Não

   Se não, porquê? O Não sabe o que mudar O Outro: ____________________________

2. No geral, acha que pode ter um papel importante no acompanhamento da sua doença/autogestão?  
   O Sim  O Não
3. O que acha necessário/útil para a autogestão? **(Selezione por ordem de importância de 1-5)**
   a. Monitorização e registo da atividade da doença e qualidade de vida ao longo do tempo. ______
   b. Alertas para tomada de medicação ou outras tarefas tal como consultas. ______
   c. Registo da medicação e do cumprimento desta. ______
   d. Registo de efeitos terapêuticos, adversos e secundários do tratamento. ______
   e. Informação sobre a doença e tratamento disponível de forma simplificada. ______
   f. Outro: ____________________________________________________________

4. Uma aplicação para “Smartphone” poderá ser útil na autogestão?  
   O Sim  O Não  
   Se não, outro método: O “Website”  O Outro: ____________________________

5. Acha útil uma notificação automática da aplicação ao médico?  
   O Sim, sempre que haja um registo de um parâmetro considerado “fora do normal”.  
   O Sim, um relatório semanal ou mensal.  
   O Sim, sempre que introduzir dados na aplicação.  
   O Não.

6. Usaria uma aplicação que necessite de acesso à Internet?  
   O Sim  O Não

7. Gostaria de ter uma aplicação deste tipo?  
   O Sim  O Não

8. Pagava por uma aplicação deste tipo?  
   Se sim, quanto? O ___________ €  
   O 1,0 – 5,0 €  O 5,0 – 10,0 €  O 10,0 – 20,0 €  O 20,0 – 100,0 €

**Muito obrigado pela sua colaboração!**

Data: _____/_____/2014
10.6 Portuguese versions of HAQ-DI and RAID
Quadro I  
Versão Portuguesa do HAQ-c

Nome ___________________________ Data __/__/____

HAQ - Versão Portuguesa

Estamos interessados em saber como e que a sua doença afecta no seu dia a dia

Para cada questão numerada assinale uma e só uma resposta, aquela que no seu entender melhor descreve as suas capacidades médias na SEMANA QUE PASSOU.

1. Vestir-se e arranjá-lo-se
Consegue
 sem qualquer dificuldade  com alguma dificuldade com muita dificuldade incapaz

Vestir-se incluindo abotoar a roupa e atar os sapatos?
Lavar o cabelo?

2. Levantar-se

Consegue
Enquanto-se de uma cadeira?
Deitar e levantar-se da cama?

3. Comer

Consegue
Cortar a carne?
Levar a boca em copo ou uma chávena cheios?
Alera pela primeira vez um pacote de leite de caramelo?

4. Caminhar

Consegue
Caminhar fora de casa em terreno plano?
Subir cinco degraus?

Assinale qual destes UTENSÍLIOS usa habitualmente:

- Bengala
- Andarilho
- Muleta ou cadeira
- Cadeiras de rodas

Assinale as actividades para cujo desempenho necessita habitualmente de OUTRA PESSOA:

- Vestir-se e arranjá-lo-se
- Comer
- Caminhar

Para cada questão numerada assinale uma e só uma resposta, aquela que no seu entender melhor descreve as suas capacidades médias na SEMANA QUE PASSOU.

5. Higiene

Consegue
Levar e limpar todo o corpo?
Tomar banho?
Sentar e levantar-se da sanita?

6. Alcançar

Consegue
Alcançar e trazer até si um objecto de cerca de 2.5 kg colocado acima da sua cabeça?
Curvar-se e apanhar roupas caídas?

7. Peculiar

Consegue
Abrir as portas do carro?
Abrir as tampas de frascos que já fecham só abertos?
Abrir e fechar terebentas?

8. Actividades

Consegue
Fazer compras e recolher?
Entrar e sair de um carro?
Fazer a lição da casa (por ex, aspirar o pó, varrer ou fazer jardineira)?

Assinale qual destes UTENSÍLIOS usa habitualmente:

- Sanita maior altura
- Bancos para tomar banho
- Abre-bolhas (para bolhas que já abertos)
- Adaptações com pegas longas para a higiene pessoal

As actividades para cujo desempenho necessita habitualmente de OUTRA PESSOA:

- Higiene pessoal
- Alcançar objectos
- Lida doméstica e compras
Impacto da Doença - Artrite Reumatoide
Questionário RAID

1. Dor
Faça um círculo à volta do número que melhor descreve a dor que sentiu devido à sua artrite reumatoide durante os últimos 7 dias.

Nada 0 1 2 3 4 5 6 7 8 9 10 Extrema

2. Avaliação de deficiência funcional
Faça um círculo à volta do número que melhor descreve as dificuldades que sentiu nas atividades físicas diárias devido à sua artrite reumatoide durante os últimos 7 dias.

Não foi difícil 0 1 2 3 4 5 6 7 8 9 10 Extremas dificuldades

3. Fadiga
Faça um círculo à volta do número que melhor descreve a fadiga que sentiu devido à sua artrite reumatoide durante os últimos 7 dias.

Sem fadiga 0 1 2 3 4 5 6 7 8 9 10 Totalmente exausto(a)

4. Sono
Faça um círculo à volta do número que melhor descreve os distúrbios do sono (ou seja, descansar de noite) que teve devido à sua artrite reumatoide durante os últimos 7 dias.

Não foi difícil 0 1 2 3 4 5 6 7 8 9 10 Extremas dificuldades

5. Bem-estar físico
Tendo em conta o estado geral da sua artrite, como avaliaria o seu nível de bem-estar físico durante os últimos 7 dias? Faça um círculo à volta do número que melhor descreve o seu nível de bem-estar físico.

Muito bom 0 1 2 3 4 5 6 7 8 9 10 Muito mau

6. Bem-estar emocional
Tendo em conta o estado geral da sua artrite, como avaliaria o seu nível de bem-estar emocional durante os últimos 7 dias? Faça um círculo à volta do número que melhor descreve o seu nível de bem-estar emocional.

Muito bom 0 1 2 3 4 5 6 7 8 9 10 Muito mau

7. Convívio com a doença
Tendo em conta o estado geral da sua artrite, como conviveu (enfrentou, lidou) com a sua doença durante os últimos 7 dias?

Muito bem 0 1 2 3 4 5 6 7 8 9 10 Muito mal
10.7 Text on the “Diário da AR” application screens
Practical advices

Text in screens (Portuguese):
Substituir maçanetas e torneiras arredondadas
Uma mudança simples que faz toda a diferença. As torneiras e as maçanetas em “formato de bola” são mais difíceis de serem giradas em virtude de exigirem o movimento de prensa da mão, o qual solicita exatamente as articulações mais prejudicadas. Para abrir maçanetas e torneiras em “formato de cabo” basta um empurrão, para baixo ou para cima, bem mais fácil de realizar. Por isso, substitua as maçanetas e torneiras em “formato de bola” por maçanetas e torneiras em “formato de cabo”!

Usar velcro na roupa
Vestir-se pode ser um desafio para quem tem Artrite Reumatoide. Adquirir roupas com velcro, no lugar de zíperes, botões e/ou laços, aumenta a autonomia do doente, já que exige menos o chamado “movimento de pinça dos dedos”, de difícil execução no caso de Artrite Reumatoide. Por isso, adapte as usas peças de roupa!

Usar mais os braços
Na fase de adaptação à doença é fundamental resguardar articulações comprometidas e tentar utilizar os acessórios (neste caso, o braço) para realizar as atividades de vida diárias. Contudo, é preciso cuidado para não sobrecarregar as articulações saudáveis, ou assumir posturas viciosas, como manter a coluna curvada. Por isso, use mais os braços e proteja as articulações comprometidas!

Usar um carrinho
Os “carrinhos de compras” podem ser ótimos aliados na casa de quem convive com Artrite Reumatoide. O transporte de peso excessivo condiciona o desenvolvimento de lesões musculares e/ou o agravamento da dor nas articulações. Por isso, use os carinhos e evite estas agressões!

Forrar utensílios manuais
Facas, garfos e/ou escova de dentes não precisam de ser um obstáculo para o doente com Artrite Reumatoide. Existem atualmente adaptadores que se encaixam a esses utensílios, garantindo a sua usabilidade. Um simples adaptador colocado no cabo de uma faca pode facilitar a utilização desta e evitar que o doente se sinta incapaz!

Usar a tecnologia a seu favor
Tudo o que ajudar a proteger a articulação comprometida e, desta forma conservar a energia, é uma opção benéfica. Escova de dentes elétrica e facas elétricas são algumas das opções que ajudam a evitar a lesão das articulações - aposte nelas!
Evitar as quedas
O risco de osteoporose é maior nos doentes com Artrite Reumatoide. Por isso, além do acompanhamento médico e avaliação da densidade óssea constantes, é recomendado que sejam feitas algumas adaptações na casa a fim de evitar quedas. Colocar barras no banheiro, preferir sabonetes líquidos (em vez da versão em barra, que pode escorregar e cair no chão) e evitar o uso de tapetes são medidas simples que previnem o problema!

Pedir ajuda quando precisar
Nada substitui a ajuda (e o carinho) que um amigo, um familiar ou mesmo um profissional de saúde pode dar. Todos os que convivem com uma pessoa que tem Artrite Reumatoide devem-se esclarecer sobre as possíveis limitações causadas pela doença e, portanto, melhorar o convívio. Sinta-se confortável em solicitar a ajuda de outros sem sentir constrangimento, pois a exigência de ser independente, às vezes, pode ser excessiva e acabar em frustração!

Information

Text in screens (Portuguese):
O que é a Artrite Reumatoide?
A Artrite Reumatoide é uma doença reumática inflamatória crónica de etiologia desconhecida que pode limitar os gestos diários destes doentes, como abrir uma porta, agarrar uma caneta ou calçar uns sapatos. Ocorre em todas as idades e apresenta, como manifestação predominante, o envolvimento repetido e habitualmente crónico das estruturas articulares e periarticulares. Pode, contudo, afetar o tecido conjuntivo em qualquer parte do organismo e originar as mais variadas manifestações sistêmicas. Quando não tratada precoce e corretamente, a Artrite Reumatoide acarreta, em geral, graves consequências para os doentes, traduzidas em incapacidade funcional e para o trabalho.
Em Portugal existem cerca de 40.000 doentes diagnosticados com Artrite Reumatoide. Tem elevada comorbilidade e mortalidade acrescida em relação à população em geral.

Fatores de risco
- Género - as mulheres são frequentemente mais afetadas (quatro mulheres para um homem).
- Idade - é, sobretudo, uma doença dos adultos jovens e das mulheres pós-menopáusicas.
- Histórico de doença e vacinação - esporadicamente, surgem casos de artrite depois de infeções por parvovírus e vírus da rubéola ou vacinações para a rubéola, tétano, hepatite B e influenza.
Sintomas
O principal sintoma é a inflamação das articulações. Além disso, podem aparecer nódulos duros nos cotovelos, ou na zona dorsal dos dedos das mãos e dos pés; também podem localizar-se nos órgãos internos. Com o tempo, a deterioração progressiva das articulações afetadas pode levar a deformidades.

Sinais e sintomas que se apresentam na Artrite Reumatoide:
- Dor articular;
- Inflamação articular;
- Rigidez articular (sensação de “prisão” dos movimentos), geralmente pela manhã e que vai desaparecendo progressivamente ao longo do dia;
- Febre;
- Cansaço.

Formas de prevenção
Entre os fatores de proteção sugeridos destacam-se a gravidez, o uso de contraceptivos orais e a ingestão moderada de álcool.
O diagnóstico precoce é fundamental, uma vez que esta doença, diagnosticada nos primeiros três a seis meses do seu curso clínico e tratada corretamente, tem grandes probabilidades de não evoluir para a incapacidade funcional para o trabalho, diminuir a comorbilidade e não reduzir a esperança média de vida.
Não podemos evitar o surgimento da doença. A prevenção destina-se, fundamentalmente, a diminuir a gravidade da doença, de forma a reduzir a incapacidade funcional e a melhorar a qualidade de vida.

Causas
A causa da Artrite Reumatoide é desconhecida. Sabemos, no entanto, que o sistema imunitário tem um papel importante na inflamação e na doença. O sistema imunitário é o nosso sistema de defesas contra agressões como vírus, bactérias e outras células estranhas ao organismo. No caso da Artrite Reumatoide existe uma resposta errada do sistema imunitário, que reconhece as próprias células como estranhas e ataca-as causando uma resposta inflamatória nas articulações e outros órgãos.

Diagnóstico
O diagnóstico precoce é feito com base na verificação de:
- Inchaço de três ou mais articulações;
- Envolvimento das articulações metacarpofalângicas e/ou metatarsofalângicas;
- Rigidez matinal superior a trinta minutos;
- Simetria do envolvimento articular.

A história que o doente conta ao seu médico é importante e orienta o médico na descoberta do diagnóstico. O médico irá perguntar pelo tipo de dor (na Artrite
Reumatoide mais de manhã), se existe ou não febre baixa ou cansaço, como começou, se existe ou não uma causa conhecida, se tem ou não rigidez nas articulações de manhã e principalmente em que articulações se sente dor, edema (inchaço), calor ou rubor, ou ainda se existe limitação nos movimentos por causa da artrite. Outras perguntas serão feitas e é importante responder de forma clara e verdadeira.

Para além da história a avaliação das articulações, aspectos como a saúde geral, os reflexos e a força muscular poderão ser avaliados pelo médico. Outras manifestações podem ser avaliadas no exame objetivo que ajuda o médico na procura do diagnóstico.

Uma boa relação com o médico é fundamental pois só assim se pode chegar a um diagnóstico mais correto e preciso.

Não existem análises ou exames que deem 100% o diagnóstico de Artrite Reumatoide, mas alguns testes e exames podem ser úteis. As análises de sangue podem revelar a presença de anticorpos como o fator reumatoide ou os anti-CCP que, podendo estar presentes em população saudável, numa população com queixas sugestivas de Artrite Reumatoide pode ajudar a confirmar o diagnóstico. Ter estes anticorpos não é o mesmo que ter a doença, pois se existem algumas pessoas saudáveis com estes anticorpos no sangue existem doentes com Artrite Reumatoide que não os têm. Outros testes importantes são a velocidade de sedimentação ou a Proteína C-reactiva (PCR) para ver o nível da inflamação. O hemograma, que é a contagem dos glóbulos vermelhos e brancos, também é um exame importante, especialmente para determinar a presença de anemia (baixa dos glóbulos vermelhos/hemoglobina) que é muito comum na Artrite Reumatoide.

As radiografias ou Raio-X são usadas mais para ver o atingimento da doença do que propriamente numa fase inicial. É mais fácil ver se já existe uma alteração importante nas articulações numa fase mais tardia da doença que ver alterações numa fase inicial.

**Terapêutica farmacológica**

Existe um conjunto alargado de estratégias terapêuticas para a Artrite Reumatoide, mas o principal é chegar-se a um diagnóstico o mais rapidamente possível e ser seguido em consultas de reumatologia o mais precocemente possível. Será com o seu médico reumatologista que, em conjunto, chegarão aos medicamentos mais indicados para si. Quanto mais rapidamente forem iniciadas as medicações, maior é a possibilidade de sucesso a longo prazo.

Os objetivos das estratégias terapêuticas são reduzir a dor e a inflamação, atrasar ou parar o envolvimento e a lesão das articulações e, por fim, melhorar a sensação de bem-estar e manter a pessoa ativa e válida para a sociedade.

- Anti-inflamatórios não-esteroides, analgésicos e corticoides (ou corticosteroides)
São fármacos utilizados para reduzir a inflamação (anti-inflamatórios e corticoides) e a dor (analgésicos) e são importantes para o controlo dos sintomas. Existem diversas opções e muitas das vezes, ao longo da doença, assiste-se a múltiplas trocas de tipo ou de formulação para melhor se adaptar o tratamento ao doente ou então por algumas queixas ou efeitos secundários. O papel destes medicamentos é importante e muitos dos efeitos secundários podem ser evitados com uma utilização correta e diversas intervenções que minimizem os riscos.

- Fármacos ou medicamentos modificadores da doença
Os anglo-saxónicos chamam-lhes DMARD’s (Disease Modifying Antirheumatic Drugs), o que, traduzido, significa fármacos antirreumáticos modificadores da doença. São a base da medicação na Artrite Reumatoide, pois são os medicamentos que tentam evitar a progressão ou o desenvolvimento da doença.

- Fármacos ou medicamentos biotecnológicos
São a nova classe de medicamentos. Também são modificadores da doença e existem há cerca de 10 anos. Estes medicamentos são tecnologicamente mais evoluídos e apresentam grandes melhorias no controlo da doença. Existem diversos tipos de administração, como por exemplo através de um soro ou até mesmo em caneta de autoaplicação. É a área de maior desenvolvimento e de maior impacto no tratamento da Artrite Reumatoide. Estes medicamentos são utilizados com regras apertadas, sendo apenas indicados para aqueles cuja doença não se encontre controlada com os DMARD’s tradicionais, ou quando há intolerância ou efeitos secundários importantes com os DMARD’s tradicionais. Pelas suas características, custo para a sociedade e efeitos adversos, são medicamentos que implicam um controlo apertado e uma utilização muito controlada. Estão neste momento disponíveis ou em vias de utilização 6 medicamentos diferentes de biotecnologia.

**Terapêutica não-farmacológica**
A terapêutica da Artrite Reumatoide implica não só a utilização de fármacos mas igualmente o recurso a outras opções, como programas individualizados de medicina física e de reabilitação, termas, exercício físico e cirurgia ortopédica.

Os programas de medicina física e de reabilitação devem ser orientados pelo médico da especialidade (fisiatra) e personalizados relativamente ao seu problema atual. Pode passar por tratamentos com agentes físicos, electroterapia ou prescrição de talas de repouso, canadianas e outros auxiliares de marcha, entre outros. A boa colaboração entre todos os especialistas que seguem o doente com Artrite Reumatoide é fundamental para o sucesso final.

As termas, como período de repouso mais ativo com tratamentos, podem ser úteis, tal como a prática regular de exercício físico poderá ser importante.
Por vezes, quando existe desgaste e destruição articular, é necessário contar com o apoio de um ortopedista que possa propor, entre as diversas opções que existem atualmente, a melhor solução cirúrgica para determinado problema.

Outros especialistas podem no decurso da evolução da doença vir a ser chamados a ajudar na gestão do caso, algo que deverá ser sempre coordenado pelo seu reumatologista e em resposta às suas necessidades e expectativas.

Outras medicações podem ser necessárias, nomeadamente para a osteoporose, que muitas das vezes se associa à Artrite Reumatoide e à terapêutica continuada com corticosteroides, ou para o colesterol e outros lípidos que, quando em maior número, podem implicar um aumento importante de risco de doença cardíaca (ex: enfarte agudo do miocárdio) ou vascular (ex: acidente vascular cerebral-AVC).
10.8 Application usability and usefulness questionnaire
**QUESTIONÁRIO DE USABILIDADE E UTILIDADE**

<table>
<thead>
<tr>
<th>Nº ID:</th>
</tr>
</thead>
</table>

1. Há quanto tempo usa um Smartphone?  
   anos ou meses **Diariamente**

2. Quanto tempo usou a aplicação?  
   horas

**Numa escala de 1 a 5 como avalia:**  
(selecione só uma opção para cada pergunta)

<table>
<thead>
<tr>
<th></th>
<th>Discordo Totalmente</th>
<th>Discordo</th>
<th>Neutro</th>
<th>Concordo</th>
<th>Concordo Totalmente</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acho que usaria a aplicação frequentemente</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Acho a aplicação desnecessariamente complexa</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Acho a aplicação fácil de usar</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Acho que precisaria de suporte técnico para usar a aplicação</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Acho que as várias funções da aplicação estão bem integradas, por exemplo, funcionam todas</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Acho que existe muita inconsistência na aplicação, por exemplo, os botões têm ligações imprevisíveis ou pouco lógicas</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Acho que a maioria das pessoas aprenderiam a usar a aplicação muito rapidamente</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Acho a aplicação muito complexa de usar</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Senti-me muito confiante no uso da aplicação</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Precisava de aprender muitas coisas antes de conseguir usar a aplicação</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
### Numa escala de 1 a 5 como avalia:
(Selecione só uma opção para cada pergunta)

<table>
<thead>
<tr>
<th>Pergunta</th>
<th>Discordo</th>
<th>Discordo</th>
<th>Neutro</th>
<th>Concordo</th>
<th>Concordo totalmente</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Acho o aspeto da aplicação muito agradável</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. A organização da informação é bastante clara</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Acho fácil encontrar o que preciso na aplicação</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Em geral, estou satisfeito com a qualidade da informação na aplicação</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Acho que o Smartphone é o melhor método para ter esta aplicação</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Em geral, acho que a aplicação é muito útil e interessante</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Numa escala de 1 a 5 como avalia:
(Selecione só uma opção para cada pergunta)

<table>
<thead>
<tr>
<th>Pergunta</th>
<th>Útil</th>
<th>Ligeiramente útil</th>
<th>Moderadamente útil</th>
<th>Muito útil</th>
<th>Extremamente útil</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acha a aplicação útil?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Numa escala de 1 a 5 como avalia:
(Selecione só uma opção para cada pergunta)

<table>
<thead>
<tr>
<th>Pergunta</th>
<th>Não</th>
<th>Provavelmente não</th>
<th>Não tenho certeza</th>
<th>Provavelmente sim</th>
<th>Definitivamente sim</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Gostaria de usar a aplicação quando disponível?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
1. Que parte da aplicação gosta mais?

2. Que parte da aplicação gosta menos?

3. Existem partes da aplicação que acha que estão confusas ou difíceis de usar/entender? Quais?

4. Se acha que alguma coisa poderia ser melhorado na aplicação, qual seria?
   - Design geral
   - Cores
   - Tipo de letra
   - Imagens
   - Conteúdo
   - Facilidade de uso
   - Outros:

5. Acha que são úteis os componentes da aplicação (Criação/Edição de Perfil, Gestão da doença, Tratamento, Informação, Questionário de Saúde, Histórico e Opções)?
   - Sim, todos são úteis.
   - Não, nem todos são úteis.

6. Se selecionar “Não” na pergunta anterior responda – Qual a parte que acha menos útil e porque?
   - Criação/Edição de Perfil -
   - Gestão da doença ------
   - Tratamento ------------
   - Informação ------------
   - Questionário de Saúde --
   - Histórico ---------------
   - Opções -----------------