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Ciências Sociais e Humanas

Sexuality, Intimacy and Sexual Behavior of Elderly People with Dementia in Residential Care: The Perspective of Healthcare Professionals and Family Caregivers in Portugal

Sarah Angélica Almeida Simões Pinho

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Orientador: Prof. Doutor Henrique Pereira

Coorientadora: Prof (a). Doutora Rosa Marina Afonso

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For all those who are reading this study, please remember:

"A resident may perform poorly on a mental status test but his or her preference for a special friend or lover may be quite evident."

(Kuhn, 2002)

Resumo

No âmbito do Mestrado em Psicologia Clínica e da Saúde, a presente dissertação é organizada em formato de artigo, o qual, conforme indicado no regulamento de Mestrado em Psicologia da Universidade da Beira Interior, a sua redação aproxima-se de um artigo publicável numa revista científica revista. Este artigo pretende descrever a pesquisa realizada no ano letivo de 2017/2018 na Unidade Curricular de Dissertação. O estudo apresenta uma investigação de uma análise empírica, fundamentado teoricamente e que contribui de forma pertinente para a área da Psicologia Clínica e da Saúde.

A sexualidade é considerada uma dimensão que diz respeito à saúde humana e está presente em todas as idades. Apresenta profundas implicações não só nos domínios biológicos e psicológicos, como também nas dimensões sociais e culturais. Da mesma forma, o crescente envelhecimento e o aumento expectável de casos de demência têm e terão um profundo impacto na sociedade, afetando não apenas o indivíduo diagnosticado com demência como também os seus cuidadores e entes queridos. O tema da sexualidade na terceira idade, particularmente aqueles com demência, não é um tema habitualmente aprofundado pelos psicólogos em Portugal.

O objetivo deste estudo é duplo, sendo que pretende por um lado (1) explorar e compreender as perspetivas dos profissionais de saúde e cuidadores familiares em relação à sexualidade, intimidade e comportamento sexual de idosos com demência e por outro, (2) explorar como é que os participantes gerem as necessidades sexuais dos residentes com demência em contexto residencial.

No estudo foi implementada uma abordagem de metodologia mista, por forma a aprofundar os objetivos delineados. Desta forma, foram desenvolvidos dois estudos, um de natureza qualitativa e outra de natureza quantitativa. No Estudo 1 (qualitativo), forma realizadas entrevistas presenciais de forma aprofundada com um total de 32 participantes. No Estudo 2 (quantitativo), participaram 69 profissionais de saúde e 40 cuidadores familiares, que responderam exclusivamente a um questionário online. Os dados da análise qualitativa foram analisados usando a análise temática por forma a analisar o conjunto de dados, através da identificação de padrões repetidos de significado. Quanto aos dados quantitativos, estes foram sujeitos a uma análise estatística.

Os resultados qualitativos demonstram que: (1) os participantes validam a existência sexualidade, intimidade e comportamento sexual em idosos com demência, que resulta de uma necessidade fisiológica e devem ser encarada como algo natural / normal; (2) sexualidade considerada como uma importante manifestação de amor, afetividade e proximidade, em vez de presença exclusiva de relacionamentos sexuais; (3) os participantes hipotetizaram que as crenças sociais e a educação tem influência no manutenção de tabus acerca da sexualidade na demência; (4) Os participantes referem estar atentos e lidar da forma mais natural e discreta às necessidades dos idosos em relação às manifestações

sexuais; (5) Perceção dos participantes de que é necessário mais formação e orientação institucional , especialmente se os idosos apresentarem comportamentos inapropriados (6) A tomada de decisão é determinada pelos idosos, se estes apresentarem capacidades preservadas para a manifestação dos seus interesses, sem que este coloque em causa os seus direitos.

Quanto à pesquisa quantitativa, conclui-se que: (1) um elevado número de participantes discorda da inferência de que à medida que as pessoas envelhecem vão-se tornando menos interessadas em sexo ou na expressão sexual (2) os participantes concluirão que os idosos deveriam de ter a liberdade de se expressarem sexualmente e intimamente de uma forma natural e espontânea. No entanto, é sentido pelos participantes (3) falta de tempo para responder às manifestações de sexualidade e intimidade e (4) expressam preocupação nas respostas dos parceiros, bem como dos cuidadores familiares face aos comportamentos sexuais.

Neste sentido, e de acordo com os resultados obtidos é necessário que se sensibilize as entidades governamentais e as entidades institucionais, no sentido de estabelecerem políticas e padrões de orientação para aqueles que lidam com esta população envelhecida, que apresenta necessidades específicas. Tanto os profissionais de saúde quanto os cuidadores familiares beneficiariam de uma formação por forma a melhor compreenderem a expressão sexual na demência. Esta formação aperfeiçoaria tanto a forma de atuação e tomada de decisões éticas, como contribuiria para a desmistificação de tabus e promoção de qualidade de vida nos idosos. É fundamental ainda, considerar políticas de inclusão social, que possibilitem debates e normalização da temática.

Na seção final desta dissertação, os anexos são apresentados, incluindo todo o material usado durante a investigação assim como a teoria que fundamentou a base do conhecimento do fenómeno.

Palavras-chave

Envelhecimento, demência, sexualidade, intimidade, comportamento sexual, técnicos, cuidadores, instituições.

Abstract

In the scope of the Master's Degree in Clinical and Health Psychology, this dissertation is organized in an article format, which, as indicated in the Master's Degree in Psychology regulation of University of Beira Interior, is written similar to a publishable article in a journal scientific journal. This scientific paper intends to describe the research carried out in the academic year 2017/2018 in the Dissertation Curricular Unit. The research presents a psychological investigation of an empirical study theoretically based which contributes in a pertinent way to the area of Clinical Psychology and Health.

Sexuality is considered a dimension that concerns human health and is present in all ages. It has profound implications not only on biological and psychological aspects, but also on social and cultural dimensions. Likewise, the significant increase in population aging and the expected increase in dementia cases have and will have a profound impact on society, affecting not only the individual diagnosed with dementia but also their caregivers and loved ones. The theme of sexuality in the third age, particularly those with dementia, is not a subject commonly investigated by psychologists in Portugal.

The objective of this study is twofold: (1) it aims to explore and understand the perspectives of family health professionals and caregivers regarding sexuality, intimacy and sexual behavior in elderly people with dementia, and (2) explore how participants manage the sexual needs of residents with dementia in a residential care context

The current research used a mixed methodology approach. Two studies were conducted, one using quantitative and the other quantitative research tools. In Study 1, face-to-face in-depth interviews were conducted with a total of 32 participants. In Study 2, 69 health professionals and 40 family caregivers participated, responding exclusively to an online questionnaire. The qualitative analysis data was analyzed using thematic analysis to help identify repeated patterns of meaning in the dataset. As for the quantitative data, these were subjected to a statistical analysis.

Qualitative results demonstrate that: (1) participants identified the presence of sexuality, intimacy and sexual behavior in elderly people with dementia, that result of a physiological need and should be faced as natural/normal as possible; (2) Sexuality is mostly considered as an important manifestation of love, affectivity and proximity, rather than exclusive presence of sexual intercourse; (3) Participants hypothesized that the social beliefs influence on mentality and education given to date and that has an influential factor in the rooting of existing taboos about the subject of sexuality in the third age, specifically in dementia; (4) Participants refer to be attentive and try to deal in the most natural and discreet way to the to the needs of the elderly concerning sexual behaviors; (5) It is perceived a general limitation on training and institutional orientations barriers, especially if

the elderly manifests inappropriate sexual behaviors and (6) Decision-making is determined by the elderly if he reunites the ability and capacity to manifests what his wishes are, without it calling into question his rights.

As for the quantitative research it is concluded that:(1) high percentage of participants disagree with the inference that as people age, they become less interested in sex and on sexual expression (2) they should have the freedom to express themselves sexually and intimately in a natural and spontaneous way. However, there is felt a (3) lack of time that the caregivers dedicate to respond to the situations of sexuality and intimacy (4) expressing concerns in the responses of the partners as well as the family caregivers to the sexual expressions.

In this sense, and in accordance with the results obtained, it is necessary to sensitize governmental and institutional entities to establish policies and standards of orientation for those dealing with this aging population that have sexual needs. Both health professionals and family caregivers would benefit from training to better understand sexual expression in dementia. This training would improve both the way of acting and making ethical decisions, as it would contribute to the demystification of taboos and promotion of quality of life in the elderly. It is also essential to consider policies of social inclusion, which allow debates and normalization of the topic of sexuality in elderly people with dementia.

In the final section of this dissertation, the annexes are presented, including all the material used during the investigation, such as the theory underlying the knowledge base of the analyzed phenomenon that provided theoretical and empirical insights and a better understanding of the analysis theme.

Keywords

Aging, dementia, sexuality, intimacy, sexual behavior, healthcare professionals, family caregivers, residential care.

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List of Acronyms

UBI	University of Beira Interior
ISB	Inappropriate Sexual Behavior
RCF	Residential Care Facilities

Chapter 1: Introduction

This dissertation is submitted in order to meet the academic requirements for the degree of Masters in Clinical and Health Psychology, from the School of Social and Human Sciences, University of Beira Interior. The purpose of this study is twofold: (1) to explore and understand the perspectives of healthcare professionals and family caregivers towards sexuality, intimacy and sexual behaviour in elderly with dementia; (2) explore how participants manage the sexual needs of residents with dementia in a residential care context.

Sexuality is a dimension that concerns human health and it's present in all ages. It has profound implications not only in biological and psychological aspects, but also on the social and cultural ones (Abdo, 2013). Likewise, the growing phenomena of the aging population and the projected increase of dementia continues to have a great impact on society, affecting not only the elderly individual diagnosed with dementia but also their caregivers and loved ones. For older people with dementia, sexuality implies a continued involvement with life (Bauer et al., 2014), a source of emotional support and a validation of self-worth and self-esteem (Mahieu & Gastmans, 2012).

In the context of nursing home settings and as we verify across this study, many manifestations of intimacy and sexuality in elderly with dementia take essentially the form of affection, romance, presence, companionship, personal preparing, touch, and the need to feel attractive, which is perceived to be a positive replacement of sexual intercourse (Lightbody, 1993; Mulligan & Palguta, 1991; Nogueira, Brasil, de Sousa, Santos, & Dourado, 2013).

However, it has been documented that dementia may lead to an extensive variety of sexual problems/barriers (Garrett, 2014; Hajjar & Kamel, 2003) specially the decision-making task. The elderly with dementia may lose interest in sexual activities, or alternatively, may express unsuitable sexual behavior, causing frustration to their partner and to themselves (Alzheimer Scotland, 2011). To determine the condition of the elderly they have to pass through a process of assessment for family members and technician consider the different levels of neurocognitive impairment that he presents. Consequently, people need to consider how to care about individual specifies and to adequate assess to their behavior towards them (Schulz & Mann, 2016).

It's important to validate that sexuality and intimacy have the potential to contribute to the quality of life and in the systems evolved, like health and well-being of people with dementia, their family and caregivers (Jones & Moyle, 2016).

The topic of sexuality in the third age, particularly those with dementia, is not a theme commonly researched by Psychologists in Portugal, primarily because of the cultural, stereotypical behavior and ethical dilemma's surrounding the issue. This study aims to address this knowledge gap. Due, to the rise in the average life expectancy and increasing cases of dementia, it is an interesting topic to explore, particularly when you consider its impact and the potentials to improve the quality of life of these vulnerable individuals.

Thus, the current research, centers on an in-depth analysis of the different aspects of sexuality in the elderly with dementia, aiming to demystifying the existing myths that prevail in today's society and obtaining a more profound understanding in this area, in order to contribute to current knowledge. Since it is not possible to collect data from the elderly diagnosed with dementia, due to their condition, the sexuality, intimacy and sexual behavior of this particular population group were analyzed through the perspectives of healthcare professionals/technicians and family caregivers.

In the next section, Chapter 2, a literature review is undertaken, followed by a discussion on the methodology approach used. Two separate studies, utilizing quantitative and qualitative research tools are discussed in-depth. In study 1, data is analyzed using thematic analysis to help identify repeated patterns of meaning in the dataset. In Study 2, the quantitative data is subjected to a confidentiality and statistical analysis. The findings and analysis of the data are analyzed next, followed by an overall discussion of the research topic, its limitations and conclusion.

In the next section, Chapter 3, the scientific article submitted for publication is presented includes a brief introduction on the subject under consideration, a description of the methods used, the results obtained and the discussion thereof. Subsequently a general discussion is presented where several themes are addressed, these include; a reflection on the results, the application of this research to Psychology and also a brief reflection on the conclusion of the 2nd cycle in Clinical and Health Psychology undertaking.

The last section of the dissertation contains the annexes. Annex 1 includes the Theoretical Annex (Annex 1), followed by the evidentiary of submission for publication. In the theoretical annex, all the variables of the present study are explored and discussed in-depth for a better understanding about the research topic. This section also includes all the material used during the research process, which was elaborated across the study and its respective management. The theoretical and empirical insights that are explained based on the review of the current literature.

Chapter 2: Sexuality, Intimacy and Sexual Behavior of Elderly People with Dementia in Residential Care: The Perspective of Healthcare Professionals and Family Caregivers in Portugal

This chapter is based on the paper:

Pinho, S., Pereira, H., Afonso, M. (submitted). Sexuality, Intimacy and Sexual Behavior of Elderly People with Dementia in Residential Care: The Perspective of Healthcare Professionals and Family Caregivers in Portugal. *Sexuality and Disability* (see Annex 2).

Abstract

Aims and Objectives: The purpose of this study is twofold: (1) to explore and understand the perspectives of healthcare professionals and family caregivers towards the theme: sexuality, intimacy and sexual behavior in the elders with dementia; (2) explore how participants manage the sexual needs of residents with dementia in a residential care context

Background: The growing phenomena of the aging population and the projected increase in dementia cases have impact on society, affecting not only the elderly individual diagnosed with dementia, but also their caregivers and loved ones. Nowadays, little information is available to understand the perceptions of the caregivers and how they can help these vulnerable individuals to maintain quality sexual life, despite of facing particular physical and mental challenges. The elderly with dementia may, over the years, lose interest in sexual activities, causing frustration to their partner and themselves, which potentially affects their quality of life, or either intimacy and sexuality in elderly with dementia can take the form of affection, romance, presence, companionship, personal preparing, touch, and the need to feel attractive, which is perceived to be a positive replacement of sexual intercourse (Lightbody, 1993; Mulligan & Palguta, 1991; Nogueira, Brasil, de Sousa, Santos, & Dourado, 2013).

Design: The methodology used is based on a mixed method approach, using both qualitative and quantitative research tools.

Methods: The data collection methods used were semi-structured interviews and an online closed ended questionnaire. The research was conducted in Portugal, using two separate studies. In Study 1, face-to-face in-depth interviews were conducted with a total of 32 participants. In Study 2, the participants consisted in 69 healthcare professionals and 40 family caregivers, responding exclusively to the online questionnaire. The qualitative data was analyzed using thematic analysis to help identify repeated patterns of meaning in the dataset, and the quantitative data was subjected to a confidentiality and statistical analysis.

Results: Qualitative results demonstrate that: (1) participants identified presence of sexuality, intimacy and sexual behavior in elderly people with dementia, that result of a physiological need and should be faced as natural/normal as possible; (2) Sexuality is mostly considered as an important manifestation of love, affectivity and proximity, rather than exclusive presence of sexual intercourse; (3) Participants hypothesized that the social beliefs influence on mentality and education given to date and that has an influential factor in the rooting of existing taboos about the subject of sexuality in the third age, specifically in dementia; (4) Participants regarding to the health care professionals' performance, refer to be attentive and try to deal in the most natural and discreet way to the to the needs of the elderly concerning sexual behaviors; (5) It is perceived a general limitation on training and institutional orientations barriers, especially if the elderly manifests inappropriate sexual behaviors and (6) Decision-making is determined by the elderly if he reunites the ability and capacity to manifests what his wishes are.

As for the quantitative research it is concluded that:(1) high percentage of participants disagree with the inference that as people age, they become less interested in sex and on sexual expression (2) considering they must have the freedom to express themselves sexually and intimately in a natural and spontaneous way. However, there is felt a (3) lack of time that the caregivers dedicate to respond to the situations of sexuality and intimacy (4) expressing concerns in the responses of the partners as well as the family caregivers to the sexual expressions.

Conclusion: There is a need for the Portuguese government to setup policies and guidance’s to better meet the needs of those living with dementia, specifically covering areas of sexuality, intimacy and sexual behavior. Both healthcare professionals and family caregivers would benefit from having a better understanding of sexuality in dementia. This will enable them to adequately access the decision-making capacity of the elderly with dementia whilst managing risk appropriately when ethical dilemmas arise.

Keywords: aging, dementia, sexuality, intimacy, sexual behavior, healthcare professionals/technicians, family caregivers, residential care.

Introduction

The physical and mental health of people is a concern for everyone. The aging population in Portugal represents one of the main demographic and social phenomena of Portuguese society (de Sousa, 2013), due to the improvement and dissemination of pharmaceutical, medical and health benefits and consequently the development in social, economic, cultural and political conditions (Silva, 2003). It is also an emerging topic of research.

Aging has been defined as a process that is progressive and dynamic. Several adjustments occur in morphological, physiological and psychological ways, which may result in a gradual loss of the person's ability to adapt to their surroundings (Moreira, 2012). However, 'Active aging' has emerged as a paradigm to respond to individual and collective trials that arise from this particular population (Veloso, 2015). According to Bárrios & Fernandes (2014), the active aging process intends to optimize, as much as possible, the opportunities for health and to develop 'quality of life' during the process of aging, as it's considered an important research area in the present study.

As a consequence of aging, clinical expressions of several pathological entities may arise, one of which can be dementia, especially Alzheimer. Dementia is a clinical syndrome, caused by neurodegeneration. It is considered as one of the main chronical illnesses in the elderly due to the cognitive loss they suffer (Mascayano, Tapia, & Gajardo, 2015). This pathology has been defined as an increased and permanent state of global deficit of mental faculties (Mental Health First Aid Australia, 2015; Nogueira et al., 2013), bringing loss of memory and other cognitive abilities (including sensory perception and communication), changes in behavior and in personality (Devesa, Cruz, & Simões, 2013; Harris, 2009) and, with time, results in a loss of the capacity to have an independent life (Prince et al., 2013). Santana, Farinha, Freitas, Rodrigues, and Carvalho (2015), suggest that dementia develops almost exponentially with age, doubling approximately every 5 years, consequently it is estimated by 2030, there would be approximately 65.7 million people affected and 115.4 million by 2050. According to Harris (2009), Alzheimer's disease is predominantly diagnosed in the elderly and is considered the most common of dementia accounting for 50% to 70% of the cases. Furthermore, as Campos, Ferreira, & Vargas (2015), suggest, there are multidimensional layers that integrates the various domains of an individual's personal and social life, the current study focuses on the sexuality, intimacy and sexual behavior of the elderly diagnosed with dementia.

According to Sobral & Paúl (2015), the deterioration of cognitive and functional facilities associated with aging and dementia, does not occur in the same manner in all elderly people, since it does not follow a fixed pattern. Instead, it differs from person to person and depends on an individual´s aptitude to deal with challenges and solve the tasks of

daily life. In marital situations, specific life events, such as; the birth of children, the purchase of a first home and retirement - all shape the relationships over the course of life and can make inherent changes in the dynamic of the couple. Furthermore, a couples' ability to cope with major life changes and stresses is often a determining factor of how they will manage changes, such as dementia, later in life.

However, according to Seng (2017), the human desire for intimacy, endures despite the cognitive decline of dementia. According to Kalra, Pinto, & Subramanyam (2011), the changes that occur, (which are inherent to aging), can affect sexual functioning, it is difficult to disentangle their individual effects. However, according to Rowntree & Zufferey´s (2015) study, there is no question that people's sexual desire and activity can continue well into later life.

Sexual relations and intimacy are physiognomies that define an individual and often affect their way of living and the aging of each human being. Moreover, they can contribute to the conservation of healthy interpersonal relationships, self-concept and a sense of integrity (Benbow & Beeston, 2012; Dourado & Silva, 2016; Nogueira et al., 2013). Current research developed by Chen, Jones and Osborne (2017), indicates that sexual relations and intimacy remain important to older people and can improve their overall quality of life. Therefore, for older people, sex implies a continued involvement with life (Bauer et al., 2014), a source of emotional support and an authentication of self-worth and self-esteem (Mahieu & Gastmans, 2012). Likewise, sexuality and intimacy have the potential to contribute to the quality of life, health, and well-being, of people with dementia, their family and caregivers (Jones & Moyle, 2016).

The diagnosis of dementia can have a great impact in many aspects of a patient's life, (Harris, 2009; Tsatali & Tsolaki, 2014). Orgasms and/or masturbation may be limited, physically challenging, painful or even unsafe due to pathology, social circumstances and other factors such as occasions for sexual relationships (Miller, Sehgal, & Dziegielewski, 2011). In cases where sex is not desirable or even possible, the sexual needs of the elderly don't have to be disregarded. Many older people find pleasure in the expression of affection, through touch, kissing, hugging and listening to words of love and affection (Devesa et al., 2013). It can simply involve caresses and gentle touching as well as emotional sharing of joy and values (Chen et al., 2017). According to Spece, Hilton, and Younggren (2013), the above describe techniques and approaches to sex are considered elder-friendly and can positively replace by sexual intercourse.

Although recognized as a fundamental driving force, human sexuality is frequently misunderstood and often neglected in the elderly, especially the ones who have dementia (Frankowski & Clark, 2009; Kalra et al., 2011). In particular, residents with dementia in nursing homes, are often viewed as asexual or incapable of being sexually active (Devesa et al., 2013; Vandrevala, Chrysanthaki, & Ogundipe, 2017). Having pejorative views of later life

sexuality, may affect according to Chen et al (2017), the attitudes of care workers, who provide assistance to the aged, specifically when responding to residents' sexual expression.

Contrary to society beliefs, sexual and intimate behaviors are exhibited by older adults in nursing home settings, and by those that have dementia-related diseases (Syme et al., 2017). Several studies concluded, that whilst the frequency of sexual intercourse tends to decrease with age, the level of interest and the necessity to engage in sexuality and intimacy remains (Kalra et al., 2011; Miller et al., 2011). This is supported by Benbow & Beeston's (2012) study, which found that as adults, elderly people with dementia also feel the need to express their sexuality. Nevertheless, Nogueira et al. (2013) suggest intimacy and sexual activity in those with dementia are negatively influenced by the level of care that the illness demands.

Consequently, the managing of sexual behavior is central and should be made across time. To manage the sexual behaviors of the elderly in residential care many decisions should be made, following an ethical decision-making process and considering their specific situations. Thus, healthcare professionals and family members dealing with individuals with cognitive deficit/dementia may be attentive when dementia progresses, in order to adequately meet their patient's needs (Devesa et al., 2013). As suggested by Devesa et al. (2013), new relationships can arise and desire may fluctuate, moreover it is the right of every adult to remain sexually active, if it is their wish to do so and one cannot violate the rights of another, regardless of their age, ability or sexual preference.

As previously mentioned, when seeking to meet resident requests or managing their sexual behavior, both the people involved and the situation must be considered prudently. Nevertheless, if a resident engages in a sexual act or requests a worker's assistance in an immoral act, they have to consider not only the elderly but also the ones that surround him. It is therefore fundamental, that the dignity of the patient is always be considered. If this principle is denied, then a direct violation is made, which can undermine the elderly patient's sense of security and potentially their health condition (Seng, 2017).

Despite advances that have been made in Portugal with regards to research on sexuality and intimacy in the elderly population, few studies have explored the underlying issue with those who are diagnosed with dementia. The current study aims to address this gap in research. Two studies were undertaken to enrich the analyses process; study 1 focused on a qualitative research approach and in study 2 a quantitative study is presented.

Methods

Design and Procedures

A quantitative and qualitative methodology was applied. In multivariate analysis approach is more likely to notice a greater insight into the research study (Breton & Taffler, 2001). The field of geriatrics is complex, especially the subject of sexuality in elderly with dementia, as it requires a specific and comprehensive process in order to provide the best care for the elderly (quality of life). The development and application of qualitative research studies in sexual areas are appropriate as they provide a better understanding of different perspectives of healthcare professionals and family caregivers in different contexts. The basis of the qualitative method comes from individual face-to-face, semi-structured in-depth interviews, selected due to the sensitive nature of the topic. In contrast to the quantitative inquiry, the goal of the qualitative analysis is to understand the phenomenon, rather than to make generalizations from this study sample based on statistical inference (Forman & Damschroder, 2015).

During the analytical and interpretation phase, content analysis was used as it oscillates between the two poles of the rigor of objectivity and the fecundation of subjectivity (inference). These analytical techniques use systematic procedures and purposes to describe the content of messages (Bardin, 2013). On the other hand, the quantitative analysis has been selected to determine the frequency of the occurrence, in each individual communication, that's why quantitative data was subjected to a confidentiality and statistical analysis.

Study 1

In the qualitative study, participants were invited to answer questions in face-to-face interviews, which were conducted between November 2017 and February 2018. Content analysis was used as the research method, since it has been currently and widely used in health studies. This type of analysis facilitates the examination of both written and oral communication, providing richer detail, preserving greater context information and in addition it has the potential for grounded theory development (Insch, Moore, & Murphy, 1997). It also enabled the researcher to determined patterns and themes that are directly expressed in the text and that resulted in specific categories (Hsieh & Shannon, 2005).

The researcher identified potential participants through mailing lists and social networks (e.g. organizations that worked with elderly with dementia). In addition, healthcare professionals and family caregivers were identified through internet forums, Facebook and LinkedIn. Written requests were sent to different Portuguese institutions (both

public and private), associations and community centers (such as Alzheimer's Portugal, Stimulation Programs), detailing the purpose of the investigation, objectives of the study, requesting their authorization to conduct interviews with their healthcare providers and soliciting contact information of family caregivers who agreed to participate in the research project. In addition, the researcher also made physical visits inviting organizations and their staff to participate in the study. The latter proved to be the most effective method to obtain consent from institutions, healthcare professionals as well as from family caregivers. In additional, the use of personal contacts and oral transmission were mostly used to find family or caregivers of patients with dementia who were institutionalized. Each institution and all participants in the research were provided with a letter detailing the purpose of the study, a description and explanation of objectives of the research, furthermore all participants were required to provide written consent (see annex 3). Respondents were assured data would be confidential and would be used exclusively for academic research. Once the authorization was obtained, the researcher was able to conduct interviews in several different institution's realities. Each interview lasted around 40 minutes

Study 2

In this study participants were selected online; this selection was conducted between October 2017 and February 2018. A link was made available specifically for this study and distributed to Portuguese institutions (see annex 4). Study 2 used the same approach as study 1 to collect participants. All of them consented to take part in the online survey and acknowledged their voluntary participation. Each questionnaire took around 8 minutes to be complete and included socio-demographic questions as well as specific close-ended questions relating to the current research area

Participants

Berg (2004) defines the 'population' as all individuals that are of interest in the research of a specific study. In this study, these are defined as: healthcare professionals and family caregivers who help elderly people with dementia that live in residential care in Portugal; who speak Portuguese as their native language and; are over the age of 18.

Study 1

The final sample consisted of 20 healthcare professionals and 12 family caregivers. Face-to-face in-depth interviews were conducted with a total of 32 participants. In this sample, 27 participants were female and 5 were male. They have an average age of 38.16 years (SD =13.98), ranging from 18 to 71 years. Around 65.7% of the elderly in this sample have been diagnosed with Alzheimer's disease.

Table 1, describes in greater detail the sociodemographic characteristics of the 32 participants that agreed to participate in the qualitative study.

Table 1: Sociodemographic Characteristics of Study 1 Participants (n=32; Mean Age= 38.16)

	n	%
Nature of the relation		
Technician	20	37,5
Caregiver/Family	12	62,5
Nature of the institution		
Collective Person of a private sector and from an administrative public sector	2	6,3
Social Solidarity Association	7	21,9
Social Solidarity Foundation	1	3,1
Misericordia Holy House	9	28,1
Private	10	31,3
Public	3	9,4
Gender		
Female	27	84,4
Male	5	15,6
Marital Status		
Married	17	53,1
Single	7	21,9
Divorced/Separated	0	0
Widow	0	0
Live together	5	15,6
Relationship/ Affective Commitment	3	9,4
Children		
Yes	16	50
No	16	50

Place of Residence		
Small City	5	15,6
Big City	8	25
Small Urban place	14	43,8
Big Urban place	5	15,6
Education		
Up to 9 years of school	5	15,6
Up to 12 years of school	9	28,1
University Degree (Bachelor)	13	40,6
University Degree (Master/Doctor)	5	15,6
Socio-Economic Status		
Low	3	9,4
Medium- Low	10	31,3
Medium	18	56,3
Medium- High	1	3,1
High	0	0
Professional Status		
Full Time Job	23	71,9
Partial Time Job	4	12,5
Unemployed	1	3,1
Anticipated Pension	2	6,3
Retired	0	0
Non-Anticipated Pension Retired	0	0
Domestic	0	0
Student	2	6,3
Working- Student	0	0
Sexual Orientation	32	
Heterosexual	0	100

Bisexual	0	0
Homosexual (Gay or Lesbian)	0	0
Asexual		0
Relation with the family member		
Son/Daughter	5	15,6
Husband/Wife	2	6,3
Grandson/Granddaughter	5	15,6

Study 2

In total, 109 participants responded to the online questionnaire, 69 were healthcare professionals and 40 were family caregivers, all over the age of 18 years. In this sample, 91 interviewees were female and 18 were male. They have an average age of 38.26 years (SD =15.56), ranging from 17 to 86 years. Around 61.5% of the elderly of this sample has been diagnosed with Alzheimer's disease, and 10.1 % with Parkinson's disease.

Table 2, describes in greater detail the sociodemographic characteristics of the 109 participants that agreed to participate in the quantitative study.

Table 2: Sociodemographic Characteristics of Study 2 Participants (n=109; Mean Age= 38,26)

	N	**%**
Nature of the relation		
Technician	40	36.7
Caregiver/Family	69	63.3
Nature of the institution		
Collective Person of a private sector and from an administrative public sector	6	5.5
Social Solidarity Association	22	20.2
Social Solidarity Foundation	3	2.8
Misericordia Holy House	30	27.5
Private	41	37.6
Public	7	6.4

Gender		
Female	91	83.5
Male	18	16.5
Marital Status		
Married	46	42.2
Single	27	24.8
Divorced/Separated	6	5.5
Widow	2	1.8
Living together	12	11
Relationship/ Affective Commitment	16	14.7
Children		
Yes	55	50.5
No	54	49.5
Place of Residence		
Small City	33	30.3
Big City	21	19.3
Small Urban place	28	25.7
Big Urban place	27	24.8
Education		
Up to 9 years of school	20	18.3
Up to 12 years of school	25	22.9
University Degree (Bachelor)	39	35.8
University Degree (Master/Doctor)	25	22.9
Socio-Economic Status		
Low	6	5.5

Medium- Low	33	30.3
Medium	64	58.7
Medium- High	6	5.5
High	0	0
Professional Status		
Full Time Job	80	73.4
Partial Time Job	5	4.6
Unemployed	6	5.5
Anticipated Pension Retired	2	1.8
Non-Anticipated Pension Retired	6	5.5
Domestic	1	0.9
Student	7	6.4
Working- Student	2	1.8
Sexual Orientation		
Heterosexual	103	94.5
Bisexual	2	1.8
Homosexual (Gay or Lesbian)	2	1.8
Asexual	2	1.8
	0	0
Relation with the family member		
Son/Daughter	9	8.3
Husband/Wife	4	3.7
Grandson/Granddaughter	17	15.6
Niece	4	3.7
Brother/Sister	2	1.8
Son in law/ Daughter in law	2	1.8

Instruments and Process

Study 1

In-depth interviews (semi-structured) were used as the main tool for data collection (see annex 5 and 6). During the interviews, participants vividly described their experiences and perspectives about sexuality and intimacy of elderly with dementia that live in residential care. The study considered the differences between the study sample groups, consequently.

Table 3 Interview questions used in qualitative research – Question Set 1 applied to family caregivers and Question Set 2 applied to healthcare professionals

Table 3. Qualitative research interview questions

Questions made to family caregivers	Questions made to healthcare professionals
What do you think about sexuality in the elderly?	What do you think about sexuality in the elderly?
How long has the person suffered from the disease? What impact does this diagnosis have on the user and the family and on the level of the user's sexuality and intimacy?	Do you consider the elderly with dementia able to decide which sexual behaviors to adopt in a relationship? Please explain in depth the reasons for holding those views
Do you feel you should have an active role in the decision making of the sexual behavior of the elderly under your care? Please provide the reasons which underpin your views	Are you able, in facing a situation of sexual expression, to monitor the cases of elderly people with dementia responding to their needs?
How do you view the future with dementia in general and sexual behavior and intimacy in specific?	What behaviors does the institution adopt to respond to the needs of these residents?

The data collected consists transcriptions made during the in-depth interviews. The main goal was to analyze participants responses to each element of the answered questionnaire (Bardin, 2013). As discussed above, thematic analysis was used to identify repeated patterns of meaning throughout the data sets. This method allows the researcher to identify, analyze and report patterns (themes) within data. In addition, it organizes and describes the data set in (rich) detail, as Braun & Clarke (2006) suggest, it interprets various aspects of the research topic.

Content analysis is one of many qualitative methods that allow researchers to test theoretical issues and enhance understanding of textual data. Through content analysis, it is possible to redefine words into fewer content related categories, to classify patterns across

qualitative data. It is assumed that when classified into the same categories, words, phrases are more likely to share the same meaning (Braun & Clarke, 2006; Elo & Kyngäs, 2007; Forman & Damschroder, 2015).

The objective of using content analyses was to attain a condensed and broad description of the phenomenon that consequently generate concepts or categories which describes the phenomenon. As a known unobtrusive research method, content analysis is sometimes used to study sensitive topics and corroborate the findings arrived by other methods (Elo & Kyngäs, 2007; Lad & Bhaskaran, 2008).

Study 2

The online survey was designed to elicit information that meets the current study's data requirement. Section 'A' focused on sociodemographic questions, which included age, gender, current place of residence, marital status, level of education, economic status, professional status, sexual orientation, whether participants have children or not, and their employment status. Section 'B' focused on questions of the study's main topic and objectives. A set of 12 closed questions, based on the report "The last taboo: A guide to Dementia, Sexuality, Intimacy and Sexual Behavior in Care Homes" (Bamford & Serra, 2011), were used in Section 'B' of the online survey (see Table 4 and annex 7). Respondents were required to select answers based on a 4 Likert Scale (ranging from strongly disagree to strongly agree).

Table 4: Statements Submitted in the electronic questionnaire

1.	The expression of sexuality is important for older people.
2.	There are positive links between health, well-being and sexual expression for older people.
3.	Most people as they age become less interested in sex or in sexual expression.
4.	Residents should be able to express their sexual needs in Institutions/Care homes.
5.	Residents with dementia, compared to residents who have full cognitive capacity, should be encouraged or facilitated to have sexual relationships.
6.	Institutions/Care homes should play an active role in allowing residents to express their sexuality.
7.	I think my duty, as a care worker/ caregiver, is more about looking after the residents than encouraging or facilitating their sexual needs and desires.
8.	I think that the Government should produce legislation that would care for the "best interest" in decision-making regarding the sexual expression of people with dementia in residential care.
9.	I value sexual expression in people with dementia, but I don't have enough time in my daily routine to respond to concrete needs that may arise.
10.	For me, sexual expression in people with dementia is important, but I don´t have enough confidence or support to respond to situations of a sexual nature when they arise.
11.	I see sexual expression as important in people with dementia, but I feel it contradicts or conflicts with my own beliefs or social, cultural and religious norms or values.
12.	I see sexual expression as important in people with dementia, but I worry about the response of the partners as well as relatives of residents.

Ethical requirements

It was emphasized to all participants that their participation was voluntary, and their responses would remain anonymous. Confidentiality was guaranteed however participants were informed that confidentiality would be broken if risk of harm emerged. Interviews were recorded and transcribed with the participant's permission. All names exposed throughout this investigation are fictitious, in order to preserve the identity of the participants.

Results and Theme Discussion

Results from Study 1 (Qualitative research)

The content analysis of the 32 participants resulted in a comprehensive analysis of the interviews, which made it possible to categorize 10 units of meaning encompassing 70 categories that express the essence of the study, (see Table 5). The following analysis consists of the descriptions and discussion of these themes, providing illustrative direct quotes from participants. In this way, we try to understand the experience of dementia and sexuality in elderly people and the factors related to them in the following categories:

Table 5: Key Themes Identified

a) Relationships and social support	Proximity to the patient (C1; C2; C3; C5; C6; C7; C8; C9; C10; C11)
	Distance to the patient (C11)
	Variety of family caregivers for the patient (C1; C2; C6; C7; C8; C9; C11)
	Presence of an affective partner (C1; C3; C8; T2; T5; T6; T7; T10; T11; T13; T15; T17; T12; T19)
	Looking for an affectionate partner (C7; C11; T1; T20)
	Frequent visits at the institution from the caregiver (C1; C3; C4; C6; C9; C11)
	Respect for the other patients (T11; T12; T15; T16; T17)
b) Patient capacities and capabilities	Locomotion limitations (C1; C3; C7; C11; T1; T4; T16)
	Cognitive deficits (C1; C2; C3; C4; T2; T4; T5; T6; T7; T8; T11; T13; T14; T15; T18; T19; T20)
	Dependency (C1; C3; C4: C5; C8; C9; T1; T8; T9; T10; T12; T14)
	Partial dependency (C2; C11; T1; T2; T3; T4; T7;

		T11; T17; T18; T19) Medication (C1; C2; C3; C4; C5, C6, C7; C8; C9; C11; T1; T2; T3; T4; T5; T6; T8; T9; T10; T15; T18; T19)
c)	Reasons for the institutionalization of the elderly in residential care	Lack of conditions (C1; C3; C5; C6; C7; C8; C9; C10; C11; C12) Lack of medication control (C2; C6; C7) Doctor's recommendations (C3)
d)	Positive perceptions of sexuality, intimacy and sexual behavior in dementia	Physiological need (C5; C10; T1; T2; T5; T6; T9; T11; T12; T15; T17; T19) Need for sexual pleasure (C3; T1, T5; T9; T11; T12; T17) Company for the patient (C4; C7; C11; T3; T4; T12; T13; T19) Sexuality as something normal/natural (C4; C8; C10; C11; T1; T6; T7; T9; T11; T15; T18; T19; T20) Family acceptance (C8; C11) Makes users happier/ promotes well-being (C3; C4; C7; C11; T1; T4: T6; T9; T10; T11; T12; T13; T17; T19; T20) Sexual activity or intimacy with the partner (C3; C11; T5) Sexuality as an important manifestation of love/ affectivity/proximity (C1; C3; C4; C8; C10; C11 T1; T3; T4; T6; T7; T8; T9; T10; T11; T12; T13; T15; T16; T17; T19; T20) Positive reactions about new relationships (C5, C6, C8, C11) Promote some delay in the development of the disease/ rejuvenation (C6; C11; T1; T12) Sexuality as a right (C5, C6; C11; T13; T16) Funny (T1; T6; T8) A way for the patient to feel active/functional (T3; T8; T12; T17) Cute/beautiful (C6; C10; T1; T4; T10; T12)
e)	Negative Perceptions of sexuality, intimacy and sexual behavior in dementia	Reduction/ End of sexual activity (C2; C3; C4; C7; T8; T10) Man, as more interested in sexuality (C1; C2; T6) Oppression of catholic religion (C2; C5; C6; C8; C11; T1; T17) Oppression of the family (C1; T3; T12; T16; T17) Pejorative society/education (C3; C8; C11; T7; T8; T9; T11; T12; T15; T16; T19) Sex and affectionate companion as something you don't need (C1; C2; C9; C10) Reject because the patient may not know what he

		was doing (C2; T8; T15) Unpreparedness to accompany sexuality in the elderly with dementia (C5; T6; T7; T9; T12) Family members rejection/confusion (T1, C6; C9 Surprise and shock (C3; C5; T7) Taboo (C2; C10; T5; T9; T10; T12; T13; T15; T1; T8; T12; T17; T18)
f)	Healthcare professional's reaction to sexuality, intimacy and sexual behavior of the elderly with dementia	Discrete/natural reaction (C11; T1; T2; T4; T7; T10; T11; T12; T13; T16; T17; T19) Not reprimand or prohibit (T1; T5; T8; T10; T11; T16) Cease sexual behavior (T8; C10)
g)	Behavior	Absence of inappropriate sexual behavior (C1; C2; C3; C5; C6; C11; T2; T8; T14) General disinhibition (C2; C4; C7: C8; C9; C11; T1; T3; T5; T7; T11; T19) Involuntary / unconscious (C5; C11; T4; T6; T17; T18) Aggressive behavior (C4; C7; T1; T4; T6; T10; T11; T12) Inappropriate sexual behavior as a result of the disease (C7; C8; C11; T4; T10; T15; T16) Disgust, disgrace or discomfort of the participants facing inappropriate sexual behavior (C6; C9; C10; T12) Behavior determine the extent to which the patient has reasoning and decision-making ability (C5; C6; C11; C12; T4; T6; T7; T8; T12; T18)
h)	Formal care/ institution guidelines	Institution with lack of conditions (T2; T4; T20) Ability of the institution to be attentive and control the situations (C1; C2; C11; T4; T6; T12; T19) Lack of capacity of healthcare professionals to deal with sexuality of the elderly (C5; T1; T4; T10; T11; T12; T13; T15; T18) Make possible the effectivity of both companions and relatives (T1; T3; T7; T15; T20) Marriage as the only way for couples to sleep together (T1; T3; T6; T13) Ability to deal with cases of intimacy and sexuality (C11; C12; T1; T3: T4; T8; T9; T12; T16; T17; T19) Cognitive assessments (C11; T1; T2; T6; T7; T16; T17; T19; T20) Psychological counseling (C1; C2; C5; C6; C7; C9; C11; T3; T20)
i)	Decision-making roles in the area of sexuality, intimacy and sexual behavior in the elderly with dementia	Institution in liaison with the family (C2; C3; C4; C6; C9; T6)

		Institution in liaison with the family and the patient (C11; T11; T16) Institution with decision-making power (C1; C3; C4; C10) Family in liaison with the patient (C7) Family with decision-making power (C2) The patient whenever he is capable/possible (C5; C6; C11; T1; T2; T3; T7; T8; T10; T12; T13; T14; T15; T18; T19; T20)
j)	Future developments in the area of sexuality, intimacy and sexual behavior in the elderly with dementia	More cases of dementia (C1; C6; C7; C9; C11; C12) Preparation for healthcare professionals on the thematic of sexuality in elderly (C1; C9; C12; C11; C12; T4; T7; T9; T13; T15; T18) Change of paradigm due to the change of generations (C5; C6; C11; C12; T19) Need for acceptance of sexuality in elderly homosexuals (C5; T6) Arrange rooms/beds fit for this need (T1; T2; T3; T5; T6; T8) Single rooms for each patient/couple (T1; T6; T12; T17)

Note: C (caregiver) and T (healthcare professional) respectively represent which participant reported a given category while analyzing the results

a) Relationships and social support

According to Hubbard (2012), elderly who have strong support systems and well-developed coping skills may be able to minimize the stresses resulted by the diagnosis. In this study the majority of the family participants expressed that a good relation with the patient is crucial to them to deal with this process. Based on the collated data a deep bond was verified between the caregivers and the patient with dementia. This bond is due to the fact that families feel that they should give support to their family members in this phase of life just as they once received from them. This bond is demonstrated by Ana, when discussing her son, who tries to be always present in the life of his father.

> My son is working, but yesterday he still came here to the institution, when he has spare time he comes running, on weekends and every fortnight he comes and gets us ... he comes to spend Christmas and holidays with us, I feel he loves us. **C3_ Ana 64 years old, wife.**

Although a high percentage of caregivers demonstrated being close to their relatives, the study revealed a situation, that reflected other reality, in which a family caregiver didn´t

have a great relationship with his elderly father. The lack of closeness was attributed to the father's "personality". Despite the lack of bond, as son, Mario feels that it is his 'duty' to continue in his progenitor's life and help in his care, even though his father resents this role reversal.

> Our relationship is distant, and at certain stages of my life, even with certain tension between me and my father, so in a direct way we never did get along well. My father was always a very rigid person, rough, distant, provoked certain conflicts due to certain life situations, but is my duty to help him in this stage. **C11_ Mário, 47 years old, son.**

The study demonstrates that most caregivers visit their families in residential care, with the aim of staying as long as possible with them. Moreover, the study also reveals that the elderly patients do not only have one caregiver, instead there are several relatives and loved ones who try to be actively involved in their care. As Maria says:

> I'm not the only caregiver, who also takes care of my father, there is also my mother, who is very old (eighty years old) and therefore is a great burden for her. I help out the best I can and try to be present as much as possible. **C1_ Maria, 50 years old, daughter.**

With regards to the intimate relationships established by the elderly patient with others, some relatives state they are aware of affectionate relationships however this study reveals it is most often the healthcare providers acknowledged this type of relationships. Although, not all the elderly in residential care have affectionate relationships, there are some patients that actively seek a companion, with whom they want to have an affectionate or sexual commitment. While the study shows there are few who make this demand, the findings based on Ana's professional experience demonstrates, that it does happen.

> Yes, she wants to choose someone, no matter whom. She calls and asks, it is quite funny, because she calls the men. It still happened the other day, called someone and asked him if he was single or married, and he said that he was widowed, and she replied that he interested her, but when she has this type of conversation it doesn´t seem she has any dementia, does she? She says: you interest me because I'm a woman and I want to have a relationship with you, even if it is only for a night or two. When you go to dinner, in the end pass through my room. **T1_Ana, 53 years old, Head Technician.**

The majority of those interviewed affirm that the search for an affectionate partner can be important because it provides companionship for the patient as well as promotes well-being, this is verified by Liliana's perspective, regarding a patient she has under her care:

> She recognizes that it's a person who comes, and knows it's a friend, who gives her a state of well-being, because he is affectionate with her and she, with a male figure has that type of reaction, regardless of who it is, she feels more comfortable and has this kind of investment with a person in order to have return of kindness and affection. **T6_Liliana, 53 years old, Technical Director.**

b) Patient capacities and capabilities

In the context of the above theme, the majority of those participants mentioned the presence of cognitive deficits in their patient/family members, which is positively related to dementia. The predominate factor mentioned by family caregivers and healthcare professionals, is the deterioration of the elderly person's memory, as we can see from Pedro's account below.

> When I go and visit her, she thinks I'm her son. She always asks me how my mother and the boys are, that is, she must think that I am my father, that I´m married to my mother and that my brother and I are my children, which is incorrect, but I agree and say that all is okay. If not, and I disagree it becomes too complicated. She remembers me in the past and not in the present. **C2_Pedro, 23 years old, grandson.**

Another common theme mentioned is referenced to the difficulties of movement due to the aging process, as is showed in Maria's account.

> He is currently admitted to an Intensive Care Unit because he underwent surgery, which left him very fragile, needing care that we could not give him at home. He is not very mobile and spends much of his time in bed; he needs physiotherapy to see if he can recover some mobility. **C1_Maria, 50 years old, daughter**

The analysis also demonstrates most of these patients present some level of dependency, if not in full, partially. Furthermore, all participants confirmed that the patients are taking medication. This is demonstrated in the below account.

> In the onset of the illness he was very disabled, but then with adequate medication, it helped a lot. The doctor who accompanied him was excellent, it was a slow process and he was diagnosed early, so he managed to adjust very well to the

medication. **C7_Daughter, 53 years old, of male patient with Alzheimer and Parkinson disease, 79 years old**

c) Reasons for the institutionalization of the elderly in residential care

Although, most family participants stated the decision to send their loved ones to live in residential care was very difficult decision to make, the findings demonstrated that they believed this decision to be the most viable solution when considering their hectic lifestyles. In addition, family caregivers believed it would be problematic for them to provide the best care for their elderly relatives, because of the complex needs they constantly require.

Although the transition into residential care can be difficult (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016), as it involves the person with dementia leaving their home, friends and familiar environments and also in many cases it means a separation between long-term partners, the health care needs of the elderly should always be a priority. Family caregivers, however, may discover there are care needs or certain behaviors which they find difficult to manage. Furthermore the lack of support may cause negative impact on the caring of other family members and additional health problems of the person with dementia (Alzheimer Europe, 2014). As we can see from Santiago's and Verónica's account, people have to be extra careful when considering taking care of elderly with dementia, because they need special care that not all can provide.

> There were no conditions for him to stay alone during the day. One day the house was flooded due to a running tap which was on whole day. In another situation she lit a fire outside the fireplace, and if I wasn't at home she would most likely have set fire to the house. Sometimes she would leave the house and get lost. He used to go to her old home as if she were still living there. **C5_Santiago, 24 years old, grandson**

> Because her daughters are abroad and I have my work and my brother has his work, and besides, demanding a constant presence at home and the hallucinations she had and the care necessary it required a more specialized treatment, from someone who could accompany her the best way. Moreover, the stimulation that she gets in the Institution allows her to maintain her cognitive, motor and related capacities.... I think she'd be worse off if she was still at home**. C12_Verónica, 25 years old, granddaughter**

In addition to the above reasons, the lack of medication control is also considered as a plausible reason to institutionalize the elderly, because this could aggravate the disease itself. This particular issue concerned doctor's and families alike, since the symptoms would

remain stable or get severe, at the same time as family members could become physically and mentally exhausted taking care of someone with this condition.

> Basically, medication was our biggest problem as well as keeping her busy with stimulating activities. **C6_Marco, 46 years old, son**

> I placed him in an Institution because the doctors already said that I was not capable. Yes, I went down, because I have many health problems too, and I always bled a lot from my nose and I didn't sleep or rest. At home the beds had no metal supports and I was always worried and didn´t sleep, in the weekends when he comes there, I don't sleep at all. I was exhausted. **C3_Ana, 64 years old, wife**

d) Positive perceptions of sexuality, intimacy and sexual behavior in dementia

When discussion aging, healthcare professionals and family caregivers emphasized the need to accept the changes inherent to this stage of live Despite the changes characteristic to this group of people, it's important to take into account the good health of the patient, either physically or mentally and promote their healthcare (Landers et al., 2016).

Strong arguments were presented in this area due to the fact that most of those interviewed recognized sexuality and intimacy as a physiological need. They were considered as a normal and natural process inherent to the human being, as we can see from Santiago and Celeste statements below.

> I believe that to reject this reality is to reject an issue inherent in human physiology ... Without this search, the routine ends up stifling a vital and totally linked need, I think, to psychological, physical, social well-being etc. **C5_Santiago, 24 years old, grandson**

> My grandfather is a widower, but they are people with physiological and affective needs like any other person, and these needs must be met whenever possible, in my opinion. **C10_Celeste, 36 years old, granddaughter**

Isolation and loneliness are commonly exhibited in elderly patients diagnosed with dementia (Higgins, Barker, & Begley, 2004). The need for the elderly to have a companion is considered, by the participants, as a way to prevent isolation and loneliness. As the accounts of Lara, Ana and Rosário demonstrate.

> Regarding sexuality in the elderly with dementia, I do not see it as a problem ... if they feel happy, and if the person is correct with the elderly, if they accompany them in this process I would not avoid anything, is it not? **C7_Lara, 53 years old, daughter**

It is part of life and I think it is a good thing because I feel that the elderly is happier, I have older people there like this and I feel that they are happier and more agile. I feel that there is a lot of happiness, they are content. I think that if the elderly has the cognitive abilities to decide that they should advance we should make that possible. T1**_Ana, 53 years old, Head Technician**

It is obvious that this patient having an affective relationship he is much calmer, participates in the activities and through his facial expression conveys much more joy. **T15_Helena, 41 years old, Head Technician**

Many people with dementia, particularly in the later stages, may become less interested in sexual activity. This, though, may not reduce their need for human affection, touch and warmth. The onset of old age or a cognitive impairment does not erase the need for intimacy and/or relationships (Bamford & Serra, 2011). Data gathered from the interviews, support the fact that sexuality and intimacy is more than the sexual act. This is a chance for the elderly to express and receive love/ affection and closeness, from healthcare professionals, family and even from other elders. This view is positively considered, by the following healthcare professionals and family members:

The term sexuality is not synonymous of sexual intercourse. Sexuality involves much more; it presupposes love, affection, sensuality, fantasy, and necessary feelings in all stages of life. Thus, the sexual life does not die out at the advanced age, it only changes characteristics. The desire for intimacy, affection and love does not end at any age. **T17_Mariana, 40 years old, Psychologist**

He gives me affection, kisses and he is always holding me at home, we always sit in the sofa, and he says to me “my beautiful face”, “my love”, it´s just that. We've always got on really well. **C3_Ana, 64 years old, wife**

The old age stage is experienced and expressed in a different way from the remaining stages. In this stage of life, more importance is given to the exchange of affection, complicity of a look, companionship. There is room to love, to be loved, to feel and desire. **T8_Margarida, 24 years old, Nurse**

Affection with the relatives and the family caregivers is very important for the patient and the family members stimulate them through touch, kisses on the face, even with their presence, and in this regard they do it well. **T14_Renata, 49 years old, Technical Director**

Participants also revealed some positive contributions of sexuality and intimacy, it appears that this field of analysis may be advantageous because it may slow down or delay the patient capabilities, which because of the illness decline over time, as well as contribute to the rejuvenation of some patients. Their behavior and humor may also improve when given

the space for intimacy. Furthermore, it may present itself as a way for the patient to feel active and potentially extend functional capacities

> Sexuality in the elderly is already something of interest, as well as a stimulus to promote some delay in the development of the disease **C6_Marco, 46 years old, son**

> I think sexuality in the elderly should be maintained as a form of expression, and it is a way for the elderly to feel that they are active and that they feel they have not yet lost all abilities. I think it is easier for the elderly to adapt as the years go by and this entails having the sexual side present, because there are often depressions associated with the fact that the elderly no longer have functional/sexual abilities, on a day-to-day basis, in dementia it´s a way for the elderly to be present in reality, they run their whole life, usually having had companions and it tends to be an alert to reality, which is still here, and dementia entails several changes and is a form of coherence and intensification of what he was. **T3_Mara, 36 years old, Nurse**

It also appears that there are healthcare professionals who consider the issue of sexuality as something "funny" in a loving sense, by seeing in the elderly an emotional aspect and peacefulness that otherwise would not be seen or felt.

> They react well, they think it as a natural thing and it turns out to be really funny regarding the age they have, because through some eye's sexuality does not happen in the elderly and the reality we see is completely different.... there is always an employee or another who is more reluctant, but most are already prepared for these things, they even think it funny and even play with these situations. T1**_Ana, 53 years old, Head Technician**

> I always think it is beautiful and sometimes really comical and believe that in general the expressions of affection give a sense of personal appreciation, reduces loneliness and even promotes communication between patients. **T12_Viviana, 48 years old, Sociocultural Animator**

e) Negative Perceptions of sexuality, intimacy and sexual behavior in dementia

The topic of sexuality and intimacy also triggers some behaviors and sensations that are not that positive. Cultural attitudes that prefer productiveness and youth may contribute to the expectation that older people are asexual (Deacon, Minichiello, & Plummer, 2015). Some study participants assumed, since patients no longer have the capacity for an erection or are uninterested in achieving the act, there is a reduction or end to sexual activity from the moment an elderly person is diagnosed. This is demonstrated by the following accounts:

Because he was out of action it practically was all gone. But he was very addicted to it ... I don´t know if he had the ability to have sex. We had none because he slept with me and nothing happened. When he was healthy the moment he came close to me it was instant. In the past he was very addicted. **C3_Ana, 64 years old, wife**

In the elderly with dementia it is quite different, in these cases they want peace and quiet, they want someone to treat them in the correct way, to be accompanied as it should be and in a minimally dignified way. **C11_Mário, 47 years old, son**

While some agree that the patient has the right to express his or her sexuality (within certain parameters), others simply ignore the subject or even feel these manifestations as an affront to their personal principles and moral codes (Devesa et al., 2013). Several participants referred to religion, specifically catholic religion, as having a repressive role in this area. They refer to it as a blocker to sexual manifestation of the patients. They hold to a restricted regime of respect for God and the only thing they've learned was to act according to the rules of the church, all the decisions should be based on a religious thought. As demonstrated by some family members:

I think that the role of the church was decisive for a sexual "castration" in the human being, especially when they become older and the search for new sexual attractions is seen as a sin. **C5_Santiago, 24 years old, grandson**

With regard to sexuality, I do not think it had much influence because she has been a widow for many years, and the fact that she is in the Catholic religion makes her, in some way, live in chastity since my grandfather died **C12_Verónica, 25 years old, granddaughter**

Families are often uncomfortable when asked questions about their loved one's intimacy history (Hellen, 1995). It appears that family and society also manifest an oppressive attitude by disabling sexual behaviors for the patients, since most of them affirm that it can be difficult or awkward to talk about that and sometimes it can be painful for families.

However, I think the big "problem", saying so, is related to one's own family, by not accepting the sexual behaviors of the parent. They find it inappropriate and this can somehow hurt the family's feelings, by feeling that one is replacing someone dear **T16_Vânia, 25 years old, Psychologist**

We started a conversation with my grandfather and mother and it turned out to be quite surprising and awkward because in childhood we never discussed this. It was taboo. **C8_ Eduarda, 34 years old, granddaughter**

It can also be difficult for families and healthcare professionals to think that the patient may not know what he is doing in terms of intimacy and sexual intercourse. For some family caregivers it is easier to accept that sex and intimacy is not essential or even necessary in the patient´s life. As we can see from Pedro's and Marco's account below:

> I think she never thought about it, she became widowed eighteen years ago, I must have been five or six, and as far as I know she has never been with anyone, neither has had that intention. **C2_Pedro, 23 years old, grandson**

> It's something that is repugnant to me and I do not even want to explore it. For example, my mother or other people that I've seen with dementia, it´s very confusing to me. Usually the elderly, despite having "time" will not have time to develop new healthy and affective bonds, considering some exceptions. If we involve the elderly with dementia in these calculations, the filter will be even tighter. **C6_ Marco, 46 years old, son**

Taking into consideration the reactions of shock/surprise and outright rejection by the family/ healthcare professionals we conclude that most of them don't feel comfortable in dealing with this issue. As we can see from Liliana's statement when she gives her opinion regarding other colleagues of work:

> I think they think that is a joke, for them these things are funny and sometimes they are unaware that the fact that they are talking to a person about her own sexuality or some need and they laugh about it, they can be hurting the person in question. I think it's not that much as them not being able to, i think they have more difficulty ... for example when washing an elderly man, apart from the erection, co-workers think they are seeing some malice, they think they are being offended. **T6_Liliana, 53 years old, Technical Director**

The above sentences demonstrate, from the point of view of some caregivers and family members' perspective, that this theme is inappropriate and "taboo". Society often associates sex to young people and ends at advanced ages (Bartlett, 2010). As we can see from the perspective of Mariana about what she thinks of these taboos.

> The taboos that culture imposes on an individual, directly influences the exercise and the feeling in relation to the experience of sexuality. They often transform the physiological changes of aging itself into a problem, preventing the view that it is a new phase of life that requires re- adaptations. Sex is erroneously associated with youth, as is denied sexuality to the elderly, wrinkled by life. **T17_Mariana, 40 years old, Psychologist**

The fact is that there is a willingness to talk about sexuality and intimacy implanted in generations, but it is a topic that is not being exploited with naturalness and therefore being considered as something offensive, as we can see from Pedro's quote.

> I do not think it's an easy topic to discuss currently, I think it'll probably get easier to discuss over time, but if you find a cure for dementia you might not have to address this topic. **C2_Pedro, 23 years old, Grandson**

f) Healthcare professional's reaction to sexuality, intimacy and sexual behavior of the elderly with dementia

The responses and reactions of professionals, who work in a residential care environment, are varied when the above topic is discussed. Most professionals consider individual's particular situation and acknowledge the importance of acting with naturalness, so that patients do not feel disturbed. This is demonstrated by Sofia's comments below.

> Yes, I deal with it the most natural way, anyway if I did not know how to respond to a certain situation, I always find for a more competent healthcare technician to assist in the answers and when doubts manifest. **T19_Sofia, 37 years old, Head Technician**

The way healthcare professionals react and behave with patients, strongly influence elderly patients and can provide them with an opportunity to live in a healthier and autonomous way (Branco, 2012; Teles, Eugénio, Cardoso, & Figueiredo, 2006). The current study supports this view, as according to Catarina's perspective having training in this area is crucial for helping these vulnerable individuals.

> As much as we have our opinion it is important to take into account the training we've had, and in my case what I was taught was that the elderly are in their right to manifest themselves sexually, for example masturbating, because it is very natural and instinctive, it is a necessity that every human being has and we must allow the manifestation of the act and we must neither judge nor condemn, nor repress, however we must nevertheless remove it from context so that the person is not practicing anything in front of other patients. We should take them to a place where the person could satisfy their needs in a more reserved way. But it is important to give the person that reserved space. It happened once, a patient who had a kind of masturbation ritual, that is, we knew that on a particular day of the week that he liked to be satisfied, and I was angry with a colleague of mine and often brought it to her attention because she would stand at the door in order to prohibit him from doing any kind of activity and I think she should have given him that privacy, he was even very oriented/balanced, he just needed some support so I think the best we could

have done was go for a walk, do other tasks and after some time we could return and see if it was over so we could finish our task with the patient. **T11_Catarina, 28 years old, Health Assistant**

According to Fonseca and Soares (2010), healthcare professionals need to understand how dependent these vulnerable elderly patients with dementia are, and to develop emotional intelligence to deal with these particular issues but they also should improve their special skills to deal with sexuality and intimacy in the elderly. However, there are healthcare professionals who feel incompetent in responding to the needs of the patients in this area. As such, they prefer to find colleagues a little more experienced who can deal with this situation more adequately. There are also some healthcare technicians who prefer to discourage and stop the behavior of the patients as a way of avoiding embarrassing situations. Situations involving personal hygiene can be especially challenging, requiring particular skills to manage correctly, which it was not the case of Margarida as accounted below.

> On that day, a colleague of mine and I went to give a bath to an elderly man with dementia, in the shower. In the middle of the bath the man began to stimulate his sexual organs, initially we tried not to give much importance to his behavior and even tried to distract him, but we were soon embarrassed and not knowing very well what to do. The elderly man persisted in maintaining the behavior, so our attitude was to finish the shower and dress him. In consequence we ceased the sexual behavior he was having. This situation was kept only between the two of us, we did not ask anyone for help. **T8_Margarida, 24 years old, Nurse**

g) Behavior

As the disease progresses, changes in sexual behavior may occur. The most likely change in the sexual behavior of a person with dementia is indifference (or apathy). On the other hand, disturbing or 'inappropriate' and aggressive sexual behaviors are also found in residential care situations. These may vary from loss of inhibition or increased desire due to changes in the brain (Alzheimer's Association, 2014). These behaviors can cause problems in the care of the residents. For example, undressing at the wrong time, exposing themselves, masturbating in public, making what seems like sexual approaches, using obscene or sexually explicit language (Alzheimer Scotland, 2011). Although this can embarrass caregivers, it is vital to remember that dementia affects a person's understanding of social situations and therefore their ability to behave might turn out affected (Alzheimer Scotland, 2011).

Behaviors such as hugging, holding hands or kissing, happen frequently between patients with dementia, the occurrence of explicit sexual behavior (involving touch or attempt to touch the genitals) also happen among some residents and may seem inoffensive to a casual observer (Medeiros, Rosenberg, Baker, & Onyike, 2008). In relation to the default

behavior adopted by patients, there does not appear to be a direct relationship between dementia and inhibitory/ aggressive sexual behavior in this study. Both family caregivers and healthcare professionals refer that there are patients demonstrating passive behavior however there are also patients with varied inhibitory behaviors. As we can see from the varied perspectives below:

> I do not know if these behaviors are common or not in dementia. My father has never had them until now and I do not think he will. If that happened with him in my presence, I'd probably feel awkward at first, but nothing I couldn't overcome. **C1_ Maria, 50 years old, daughter**

> No, she would break dishes and call me names and then started screaming and I would call for my daughter she would say to her "look, here comes a cow" **C4_ 71 years old, husband**

> It was funny to see his complete disinhibition on a subject such as sex, that was completely taboo and from the moment he got sick it became a completely banal subject. He touched his penis and said he could not do anything anymore and we talked about his ex-girlfriends. I had no idea that they could become this inhibited. Even if it is unconscious there are patients who are cognitively debilitated, but physically are well and who have this type of behavior, so in the passages they show their sexual organs, send compliments, ask for a hand in marriage, saying "You are still good for marriage," they touch their penis and say, "this is still capable of something." **C8_Eduarda, 34 years old, granddaughter**

Many healthcare professionals and family caregivers associate the sexual behaviors of the elderly as being involuntary or even unconscious, and in some cases as a result of the pathology. The study also revealed a wide range of reactions the part of the study's participants, some took the issue of sexuality as completely natural, whilst others felt shame, discomfort or even disgust. As validated from the statements below.

> They become more inhibited but not in a critical way, they are less afraid to show their emotions, sexual behaviors, have more capacity for affection, holding hands, touch, of everything, it is a matter of affectionate closeness. **T3_Mara, 36 years old, Nurse**

> I cannot see it as provocative because I think they are involuntary, unconscious. It seems to me that it is beyond their ability to rationalize that which is the pattern of community behavior. I have obviously been harassed and flattered by elderly women at my work but never experienced the exposure of sexual organs. I reacted comprehensively due to the circumstances. **C5_ Santiago, 24 years old, grandson**

I consider it inappropriate and maybe normal for certain pathologies, but I think that the caregiver has a fundamental role in helping to overcome this situation, because in the homes there are a wide range of pathologies**. T15_ Helena, 41 years old, Head Technician**

h) Formal care/ institution guidelines

In general, the residential care environment does not lend itself to discussions about sex and many patients find it difficult and embarrassing to talk to healthcare professionals about sexual issues/matters (Taylor & Gosney, 2011). When analyzing the way each residential care facility works, the collated data clearly showed varied views on what the established values were pertaining to each organization.

Few residential care institutions were proactive in minimizing inherent barriers resulted by sexuality issues. Some were attentive to the needs of the elderly and easily controlled challenging situations, and also offered psychological counselling to better deal the sexuality and intimacy of elderly issues. However, most institutions admitted a lack of conditions and training to deal with these specific situations/thematic. The diverse perspectives are accounted for below:

When couples enter, they can never stay in the same bed, even if they have been married 30/40/50 years I think this separation is violent when they are faced with this, by the time they enter in the Institution. There is no such thing as privacy here; the most we can do is to put the beds together, for them to have more closeness. **T4_Patrícia, 24 years old, Nurse**

Within our possibilities yes, whenever we have a case we try to make sure the patients go to a more reserved space in order not to affect other patients. This is the best we can do for the moment, considering the situations, and making them more comfortable to talk to us about things. **T7_Graça, 59 years old, Sociocultural Animator**

Several of the healthcare professionals expressed anxiety in relation to some of the norms or lack of them in the residential care facilities. In particular; management expectations, attitudes of fellow workers, 'closed' mentalities, as well as lack of management support were frequently mentioned as causes for concern. These were seen by the healthcare professionals as having a direct impact on the way they carried out their duties. As verified in Vera's statement.

Lack of support from management. Lack of open mentality regarding the subject, both from management and employees. It's not considered a priority. Sexuality in the elderly is still taboo in this present time and it's a subject that should

be further explored. There have already been debates, lectures and formal training about this. We try to make this a normal subject to address, but in practice there are still many reluctances. **T10_Vera, 33 years old, Health Assistant**

Most healthcare professionals reported that it is particularly difficult to provide resources that facilitate the active expression of sexuality, mostly because there are no individualized spaces that allow patients to have their privacy. The only thing that institutional ethics may allow is that married couples can sleep in the same room, even though, in separate beds.

Only if they could find a lounge or a room for them to be private, but it does not exist here. We have couples who have already entered as couples and are together in the same room, we also had a couple who had to get married and then went to sleep in the same room, but they got married because the Institution does not allow sleeping together if they were single, if they wanted to be joined, they had to get married. **T1_Ana, 53 years old, Head Technician**

Psychological assessments are usually performed by psychologists in most institutions. As participant Isabel accounts below, these are undertaken in order to assess the capability of the elderly patient with dementia to evaluate which mental faculties they still maintain or have lost.

The periodicity of the evaluations of the patients that are monitored by the sector is every six months, to periodically analyze their cognitive impairment and to determine the extent of the 'damage', if faculties in the life of the elderly are still preserved and those that are not. **T2_Isabel, 28 years old, Psychologist**

The provision of psychological counseling by the residential care institutions was considered very important by healthcare professionals, family caregivers. Many participants expressed feelings of uncertainty about what the correct decisions to take and expressed doubt as to whether or not they always acted in accordance to the best interest of their elderly patients diagnosed with dementia. As noted in the below accounts.

The psychology sector, in informal conversations, frequently deconstructs myths and taboos with patients about the issue in question. It also provides information and/or clarification of doubts that patients may have (contraceptive methods, alerting for sexually transmitted diseases, etc.). Although in the eyes of the elderly person this is still spoken with embarrassment. When situations are frequent and in which the employees no longer know how to deal with the situation (elderly men with dementia), the psychology and nursing sector try and see the best way to approach the situation with the patient, drawing the attention of the elderly to have such behaviors in more appropriate places (ex: bathrooms), but always mentioning that it is a normal situation. **T2_Isabel, psychologist, 28 years old**

Yes, there are many doubts about this disease and this subject. **C1_ Maria, 50 years old, daughter**

No doubt it would be important to have someone to share the story with and learn from it. I have the privilege of being very close to someone who can give it to me. **C6_ Marco, 46 years old, son**

i) Decision-making roles in the area of sexuality, intimacy and sexual behavior in the elderly with dementia

As stated by Spece et al. (2017), a person with dementia may be incompetent in one area and fully capable of reasoning and making decisions in another. The level pf capacity influences of the elderly with dementia can determine the decision-making process. Not being able to decide may result in frustration, anger and fear, especially if the person finds it hard to communicate their needs to others. Older people with dementia feels the need to express their sexuality however, in a residential care environment this can potentially be problematic, especially if this behavior takes inappropriate forms. It then becomes necessary to manage this sexual behavior. This leads to the need of making decisions based on ethical and moral issues, especially when new emotional relationships develop (Heath, 2012). Such circumstances can cause difficulties for healthcare professionals who don't feel prepared to deal with these complex decision-making situations. Ideally, at these times it is better to have someone experienced in dealing with the issue, however, in practice, multiple people with varying knowledge and experience can contribute to the decision-making process.

Decision-making in the context of the elderly with dementia is complex and dynamic. The issue of who should take an active role in decision-making when addressing this subject (Ballard, 1995), has been debated for some time. There is a great divergence in the opinions expressed by the participants of this study, on who should decide what is best for the elderly patient with dementia. Most of those participants affirmed that, as long as, the patient has the capacity to decide, they should continue to have an active role in decision-making. However, when they start to deteriorate, some participant's like Veronica believe no one should decide on behalf of the elderly patients with dementia, since one may decide something that they don't want, and thus one may be disrespecting their wishes. However, some participants like Alice, have a different opinion about the same situation, as accounted below.

One has to be attentive and realize that the elderly must be able to make their decisions and the extent to which these decisions are made conscientiously; here is where the health professionals have to come in to assess that cognitively the patients and their abilities are preserved. Considering the initial state in which my grandmother is still in and her marital status of widowhood I think I would accept if

my grandmother decided herself to find a companion to talk to, hold hands, and get some cuddles. I think she still has the ability to decide in these areas. However, if the dementia was aggravated, and there was no logical speech and given the fact that the patient no longer verbalizes what he/she wants, we should not decide anything on behalf of that person. **C12_ Verónica, 25 years, granddaughter**

I think it should be the Institution and the family, that is to say, the Institution always has a say because the patient is always there and they get to know the person. And regarding the family, as the patients are not in perfect judgment, they do not know what they do, in this case I think that us children should be made aware of those moments**. C9_Alice, 51 years old, daughter**

In discussion around consent, the ability to demonstrate agreement is emphasized as an essential condition for being sexually active if the individual has dementia (Syme et al., 2017; Wilkins, 2015). The same findings are verified in the current study and exemplified in Santiago's and Lara's account.

I think it depends on the degree of dementia of each patient. Being something consented this issue should be regarded as something extraordinary within the different variants of the physiological needs. That is, as long as the patient still has verbal abilities to express himself, I feel that he should, in this case, decide what course to take in his decisions. Because if the opposite happened, from the moment the person is diagnosed with dementia, he would no longer have his own opinion and would be dependent on others. **C5_ Santiago, 24 years old, grandson**

I think right now he does not have great skills to decide what kind of sexual behavior to adopt. It's a complicated situation because he could even make the decision, I could even accept it, but I would have to analyze the situation of the other person, if she would be a good influence on him and so on. **C7_Lara, 53 years old, daughter**

Whilst it is important that patients, whenever they can, retain their decision-making over their sexual behaviors, healthcare professionals and the healthcare institutions consider it is important they can have an active role on the decision when discussing sexuality and intimacy of the elderly with dementia, as demonstrated in the below accounts:

I think that the families should not have decisive power in these situations. We have situations where the relatives do not like it very much, but he still knows what he wants although he already has some indices of dementia, but it doesn´t mean that he obeys with what his daughter tells him, and we also don't mention anything to their family, in these situations. **T1_Ana, 53 years old, Head Technician**

In this case, as the patient does not have family members who accompany his case, the Institution should do it's best to respond to the needs requested by him. **T15_ Helena, 41 years old, Head Technician**

j) Future developments in the area of sexuality, intimacy and sexual behavior in the elderly with dementia

In this last section of the content analysis, information relating to the potential future developments, as expressed by the viewpoints of both healthcare professionals and families were collated. Within this analysis, most of the participants believe that the rise of dementia cases is inevitable, due to stress and our current hectic lifestyles. Verónica affirms that dementia amongst the elderly will increase:

> We live in a society where the pressure of work, the acquisition of material properties, and social pressure make us live a life of extremity, where there is only anxiety, depression, conflicts and for these reasons I think that dementia will increase significantly, and more and more patients are going to be institutionalized with dementia. **C12_ Verónica, 25 years old, granddaughter**

Participants expressed limited knowledge and lack of practical guidance in relation to sexual expression in the elderly with dementia. Consequently, many expressed the view that it would be advantageous to implement training and follow-up actions, which would provide pertinent information and help them to respond and develop the required skills to deal and discuss with these issues. The below accounts expressed by participants, demonstrate the need to explore sexual expression in the elderly with dementia to turn this subject as something natural to be talked about, the importance of developing practical guidelines and training for those caring for them.

> It will be necessary for Institutions to adapt to the realities of our times, as a young person I have ideals and thoughts that my grandmother did not have when she was my age, perhaps what I will need in the future will be different from what my grandmother needs are today. That is why I believe that the issue of sexuality will be increasingly debated and there will be more and more people approaching this subject as a natural thing, allowing for more dialogue in the future and the availability of means and resources that will enable Institutionalized elders to live their sexuality as they see fit. **C12_ Verónica, 25 years old, granddaughter**

> Making Institutions more sensitive to this subject. I think it is good to have people come here to discuss what is normal and what is abnormal and for us to open our minds a little and realize that sexuality is not only that, the sexual act, there is a lot more beyond. **T4_Patrícia, 24 years old, Nurse**

> The Institution's leadership should be more receptive to these situations and not be so prejudiced. **T15_ Helena, 41 years old, Head Technician**

> I just think that there should be training to know how to deal with and be able to respond to these situations, more for the healthcare technical staff who accompany the patients in a more direct way. We shouldn't impose our ideas as we wish, there must be guidelines, from which we can be orientated. We often do not know how to deal with these situations because we have never experienced and never addressed them, especially regarding sexuality. **T7_Graça, 59 years old, Sociocultural Animator**

A change on the current mentality is one of the aspects pointed out by participants that would contribute to a greater harmony inside intuitions and improve openness and naturalness that this subject area demands.

> There will soon be a paradigm shift, a change of generation. There is a generation that is growing older and who have been more distant from the oppressions once lived, arising either from the church or State itself. The conditions of life, the values disclosed, fear interfered a lot in the society´s personal life. Sex is the greatest example of this intervention that conditioned the autonomy of the individual's behavior, so much that it interfered in the most vital part of the human being. **C5_ Santiago, 24 years old, grandson**

As for homosexuality, this particular area lacks a path of acceptance and is currently an issue largely ignored within Portuguese institutions. However, this issue needs to be addressed to ensure this specific group of elderly people are treated equally when dealing with their sexuality and intimacy and do not experience neglect and/or are not discriminated against. A comprehensive study conducted by de Vries, Mason, Quam, and Acquaviva (2009) substantiated that there is a deficit in the legal recognition of non-heterosexuals, thus it requires them to take different actions to ensure their end-of-life wishes will be executed, and potentially also leads to increased fears about late life.

> Probably the biggest problem will be in accepting the sexuality of elderly people with dementia, who are homosexual. Although it is not standard, it is a fact that these relationships exist, and Institutions need to respond to all needs, without discrimination. **C5_ Santiago, 24 years old, grandson**

The best practice solutions, from the perspective of healthcare professionals should involve the implementation of patient-specific policies which allows an improvement in the quality of life and the development of self-efficacy. This measure would allow the patient to have freedom to make the decisions that they understand but would also consider the rules of the institution and respect other patients. Liliana suggests potential solutions that could be implemented in order to facilitate the expression of sexuality in general.

I think that if we really preserve the part of sexuality in the elderly, regardless of their age, young or old, with debility or without, there should be single rooms in Institutions, not only for such situations, there are no double rooms, or rather the double rooms would be for the couple, I am not just talking man and woman, I am talking woman and woman, man and man. All Institutions should have these spaces; we should not allow spaces for people who do not know each other, being in the same space to sleep, in a space which should be private and a place where people are more comfortable. **T6_Liliana, 53 years old, Technical Director**

Results from Study 2

The study was subjected to a confidentiality and statistical analysis of the items. This verification tool allows the determination of the probability of the grade failure when considering the random variation of the problem variables. The test used to determine internal consistency was the Cronbach's Alpha test or Cronbach's Index, that determined the lower limit of the internal consistency of the items. Alpha can be interpreted as the average coefficient of all internal consistency estimates that would be obtained if all possible divisions of the scales were made (Maroco & Garcia-Marques, 2013). This limit will correspond to the expected correlation among the scale used and other hypothetical scales of the same topic and with the same number of items used to measure the same characteristic. Cronbach's alpha provides an undervalue of the true reliability of the measure. A high degree of internal consistency is desirable and corresponds to a high value of 'α' (Streiner, 2003).

According to Maroco and Garcia-Marques (2013), an instrument or test is classified as having adequate reliability when 'α' is at least 0.70. However, in some social science research scenarios, an α of 0.60 is considered acceptable as long as the results obtained with this instrument are interpreted with caution and consider the computational context of the index.

Having verified that the reliability analysis of the initial solution of the totality of the items presented a Cronbach alpha of 0.591 considered to be unacceptable, the items **7** [I think my duty as technician / caregiver /, involves more caring for patients than encouraging or facilitating their sexual needs and desires.] and **11** [I see sexual expression as important in people with dementia, but I feel it contradicts or conflicts with my own beliefs or social norms, cultural and religious values.] were deleted, which then generated an alpha of ,70, which it's considered to be acceptable.

The internal consistency of the factors is defined as a variation in the responses that results from surveys, mostly because the answers differ because the wording is confusing and leads to different interpretations, but the polls are varied opinions (Pestana & Gageiro, 2008)m(see table 6 and 7).

Table 6. Reliability Statistics

Cronbach's Alfa	Item N
.70	10

Table 7. Item-total statistics

	Scale average if item is deleted	Scale variance if item is deleted	Corrected total item correlation	Cronbach's alpha if item is deleted
1. The expression of sexuality is important for older people.	10.56	10.027	.577	.657
2. There are positive links between health, well-being and sexual expression for older people.	10.55	9.916	.593	.654
3. Most people as they age become less interested in sex or in sexual expression.	9.40	11.576	.109	**.730***
4. Residents should be able to express their sexual needs in care homes.	10.40	10.169	.491	.669
5. Residents with dementia, compared to residents who have full cognitive capacity, should not be encouraged or facilitated to have sexual relationships.	9.82	10.929	.248	**.709***
6. Care homes should play an active role in allowing residents express their sexuality.	10.27	9.993	.442	.675
7. I think that the Government should produce legislation that would care for the "best interest" in decision-making regarding the sexual expression of users with dementia.	10.10	10.166	.439	.676
8. I value sexual expression in people with dementia, but I don't have enough time in my daily routine to respond to concrete needs that may arise.	9.98	10.629	.296	**.701***
9. For me, sexual expression in people with	10.03	10.194	.359	.691

dementia is important, but I don´t have enough confidence or support to respond to situations of a sexual nature when they arise.				
10. I see sexual expression as important in people with dementia, but I worry about the response of the partners as well as relatives of residents.	10.12	11.087	.231	**.710***

In this analysis, a statistical criterion was used. Items with alpha less than 70 were eliminated, and only those items greater than 70 were analyzed. As we can see from Table 7, only four items were considered, because they were considered to be the most consistent. For a more detailed analysis of the positioning of the majority: of participants, the average of each item was considered. In the analysis it was confirmed that α

- Item 3 (Most people, as they age, become less interested in sex or in sexual expression) with an alfa of ,730 it is verified that the participants place themselves in a moderate level of **disagreement** in this statement. (Mean: 2.84; SD: 0.669);

- Item 5 (Residents with dementia, compared to residents who have full cognitive capacity, should not be encouraged or facilitated to have sexual relationships) with an alfa of ,709 it is verified that the participants place themselves in a moderate level of **agreement** in this statement. (Mean: 2.43; SD: 0.685);

- Item 8 (I value sexual expression in people with dementia, but I don't have enough time in my daily routine to respond to concrete needs that may arise), with an alfa of ,701, it is verified that the participants place themselves in the level of **agreement** in this statement (Mean: 2.27; SD: 0.715);

- Item 10 (I see sexual expression as important in people with dementia, but I worry about the response of the partners as well as relatives of residents) with an alfa of ,710, it is verified that the participants place themselves in the level of **agreement** in this statement (Mean: 2.13; SD: 0.654).

Discussion

Although small in scope, this research provides an important examination and greater understanding of the current views of family members and healthcare professionals regarding sexual expression for people with dementia living in residential care facilities Portugal. The participants' perspectives took into consideration the current reality of the elderly with

dementia with whom they deal. This study had several limitations which created the need for a constant edition of the study's directionality and greater attention of the researcher in order to collect the most adequate and updated literature for the study in question.

Taking into consideration both studies is verified that most of the participants are female. In study 1 the majority of the participants were healthcare professionals, nevertheless in the study 2 most were family caregivers. Throughout this investigation it is perceived that the caregiver's attitude and personal mentality regarding the sexuality, intimacy and sexual behavior in the elderly with dementia played a big role in how they treated and behaved these vulnerable adults.

Findings from the qualitative analyses revealed that more than a half of the families have good relationships with their elderly relatives with dementia. Furthermore, family caregivers made considerable efforts to be actively present in their lives, although they can't visit them every day. Findings also demonstrate that most of the elderly who are diagnosed with some kind of dementia had significant cognitive deficits, especially in the memory domain. Consequently, because of their high level of dependency and lack of medication control, family caregivers chose to institutionalize their family members. Many participants also mentioned that the lack of conditions to be able to provide adequate care at home, thus concluding residential care to be the only viable solution.

More than a half of the elderly on this research had some kind of companion, however it is worth noting that this was predominantly noted by healthcare professionals, rather than family caregivers. However, we often deal with dichotomic views as the participants considered sexuality and intimacy in older people with dementia as something natural and physiological needed, important to promote happiness and quality of life, but in practice this is more challenging so there were some participants reluctant to even address the issue. This is discussed in more detail next.

When the relationship factors were considered, participants established that aging does not imply a stagnation of sexuality, however the way these are manifested may suffer some changes. Although, intimacy and sexuality continue after a diagnosis of dementia, sexual intercourse can be positively replace by love, caresses, affection, proximity, holding hands, communication, fondling, which for them can be sufficiently pleasant at this stage in their life's, this is supported by McAuliffe, Bauer, & Nay´s (2007), study which had similar findings. For some elders, enduring sexually active provides a feeling that they can maintain their role identity and provide something of value to their partners (Davies, Zeiss, Shea, & Tinklenberg, 1998)

When considering the negative perceptions about this thematic, some of participants viewed this topic as very controversial to discuss, others alluded to the fact that sexual activity reduces or even ends up with age. As suggested by Davies, Zeiss, Shea, and

Tinklenberg (1998) cultural taboos, personal beliefs, and inadequate professional training contribute to the lack of existing help that should be given to elders. These suggest that moral and religious ground, strongly influences in the perceived reality of "oppression". These findings are supported by Vandrevala et al. (2017) study, which suggested that ethnicity and religion may influence care home staff's beliefs and views on sexuality or whether the organizational culture can influence staff's views regarding sexuality in dementia.

This investigation also demonstrated that healthcare professionals, tried to be discrete and to behave in the most natural way facing sexual behaviors. As this would give to patients the space that they need to express themselves without the feeling of being censured. However, due to lack of privacy and negative attitudes of the staff this was not always linear. These findings were consistent with Tenenbaum (2007), findings which noted that nursing homes can also physically put barriers in sexual relationships by moving one partner to another floor or to another nursing home or simply by denying patients the use of private space.

Several evocative patterns emerge from the results reported and the current research revealed the importance of developing practical guidelines and training for the elderly with dementia. Furthermore, participants expressed the need to arrange rooms/beds that fit individual sexuality and intimacy needs. These included incorporating both single and rooms for couples (who can share the same bed, which currently is not possible). According to Barker, Herdt, and deVries, (2006), institutions presently providing care to the elderly are powerless to keep up with demand for space due to increased longevity, expansion of morbidity and other factors. The study also acknowledged the issue of the sexuality of elderly who are homosexuals and the necessity to also take their needs into account in order to ensure they are treated without discrimination.

When discussing the expression of sexuality and intimacy, the participants revealed that patients could manifest sexual behaviors through different ways. Few expressed there were elders with inappropriate sexual behaviors (essentially manifested by aggressive behavior, genital exposure and hypersexuality), however many family caregivers and healthcare professionals reveled that there is a general disinhibition on the behavior of the elders since the time they are diagnosed, nevertheless their behavior is frequently tolerated due to their medical condition. Often sexuality in elders with dementia may arise a ISB (Cipriani, Ulivi, Danti, Lucetti, & Nuti, 2016). According to Thom, Grudzinskas, and Saleh, (2017), the incidence of inappropriate sexual behavior among the intellectually disabled is 15–33%; however, the nature tends to be more socially inappropriate than with violent intent. According to participants the behavior of the elderly can determine the capacities he has of reasoning and decision making. As referred by Karlawish (2008), cognitive and functional losses are only part of the spectrum of disability experienced by persons with dementias.

When taking into consideration the standards used by the institutions in dealing with this subject area, findings indicated that most of the healthcare professionals try to have special attention and to deal the best way they can to sexual manifestations. However, many participants expressed a lack of formal training to respond more adequately. Most residential care institutions try to have regular evaluations and cognitive assessments to determine the level of impairment of the elderly residents. For residents with dementia in a nursing home environment, sexual activity can cause a number of ethical impasses for the residents, residents' family members, and staff about what is appropriate behavior (Wilkins, 2015). When we consider acts of sexuality, intimacy and sexual behavior in those with dementia, most of the participants expressed that patient should be given the key choice particularly if they have capacity to express logically what they want. However, from the moment the elderly loses their capacity of expression, a different person is certified to maintain their rights preserved. Furthermore, psychological counselling is a service that some institutions offered to both their residents and healthcare professionals who found it difficult to deal with these issues.

This study found evidence of a lack of skill and training, in some caregivers, to make informed and ethically based decisions which favors the best interest of the patient. In some cases, the management of ISB involve (1) transferring the decision to others who feel more comfortable with the situation or act more naturally, so that the elderly does not feel judged (2) some professionals simple ended dysfunctional behavior, perpetuating prejudices and myths that reduce the individual to an asexual condition.

It is important for healthcare professionals to take in consideration, when setting policy and standards, that sexuality and intimacy are basic human needs and all individuals have equal rights including these vulnerable adults (Hajjar & Kamel, 2003). This will ensure a different level of sensibility of the participants and should create a better care and better quality of life for residents. Taylor & Gosney (2011), proposed recommendations would be preliminary for those institutions who do not have a fix policy in this area. These recommendations include consenting sexual behaviors in private environments and give the time that elders need; being sensitive about the healthcare professional that the elderly choose to care for them; give information about patient's lifestyle choices; deal with one's own preconceptions and subconscious feelings and act according to ethical and moral principles by not giving unrealistic expectations towards the elderly with dementia.

The last theme analyzed were participants perspective of "future developments" with regards to the expression sexuality and intimacy in the elderly with dementia. Most participants believed that dementia will increase both in Portugal and globally. An important factor that was also referred to, is the emergent necessity to increase training of family members and health professionals, in order to better adapt their responses to the specific needs of these patients.

As for the quantitative research, it was verified that the participants also perceived elderly with dementia as people who has sexual interests, regardless of the type of sexual expression they manifest, maintaining their interest in activity and sexual expression. In a study developed by Eloniemi-Sulkava et al. (2002), with married couples verified that dementia did not affect significantly the general atmosphere of the marriage. The result indicated a need among the caregivers to retain identity as a couple, particularly if the patient was in long-term institutional care. A minority of participants agreed that older people become less interested in sex or in sexual expression. This is supported by an Italian research, that advocate that increasing age is associated with a decrease in sex, on that study they examined quality of life and found significantly less interest in sex among the older participants — all 38 centenarians had lost interest in sex but reported greater satisfaction with life than younger people (Buono, Urciuoli, & De Leo, 1998).

As for the encouragement or facilitation to have sexual relationships, most of the participants suggested that residents with dementia, compared to residents who have full cognitive capacity should not be encourage and facilitated to adopt this behavior. Through a comprehensive and respectful informed consent process, the healthcare providers should educate residents, families, and staff about the policies and their importance to residents' health and well-being, providing space to the resident to choose to engage in sexual activities (Spece et al., 2017). All residents should be considered competent to give consent to sexual encounters with their spouse/partners through regular psychological assessments (Mitoku & Shimanouchi, 2014). Consent can be by way of explicit oral or written direction to the facility upon admission; a prior written statement; or, for those without a written statement and unable or unwilling to verbally communicate their wishes, by way of failure to object to sexual advances by their spouse or partner either verbally or physically ("implicit consent") (Spece et al., 2017). The adoption of these behaviors must be done spontaneously and naturally, without the elderly feeling any external pressure and therefore influenced by them.

Despite sexual expression in people with dementia being considered, the majority of the healthcare providers and family caregivers that participated in this research didn't perceive to have enough time in their daily routine to respond to concrete needs that may arise. As verified in Hebert and Schulz (2006), study the participants manifested lack of availability and insufficient time to face doubts of sexual nature. The activities and demands that the profession demands in elderly care with the diagnosis of dementia (cleaning, food, medication ...) may be a factor that will inevitably reduce the time spent dedicated to the care of issues such as dealing with the sexuality and intimacy of the elderly. As it is not considered a basic life necessity, the degree of importance attributed to the subject is devalued and placed in the background. According to Alzheimer Association for many couples, sexual intimacy continues to be a satisfying part of their relationship. As the disease progresses, it's important to take their needs and expectations for intimacy into

consideration, as these changes will affect both the individual with the disease and his or her intimate partner (Alzheimer's Association, 2014).

According to Barusch (2012), care managers are caught up in the physical needs of fragile and vulnerable patients and may find it difficult to devote time and energy to their emotional needs. Many professionals find it hard to talk about intimacy. This issue needs to be addressed if institutions aim to increase quality of life of the elderly with dementia in this specific area.

As for the sexual expression of residents with dementia it is important to consider not only the elderly perspective but also the response of the partners as well as relatives of residents, since it influences the perception about this thematic. Youell (2015),reinforce this idea by referring that the emotional connection between family members makes it more difficult to take best interest's decisions about sex and intimacy. Healthcare professionals, therefore, have an important role as advocates for the patient or resident in their care (Bauer et al., 2014). These findings are supported by Jones & Moyle (2016), who suggest sexuality and intimacy are a way to promote both physical health and psychosocial well-being. Even family members, who are in theory supportive of residents' sexual expression, may find themselves reacting differently when it is their own partner or parent with dementia wanting to have a sexual relationship with another resident, or behaving in a sexually explicit manner.

Due to the limited knowledge, lack of guidelines and training in this area in Portugal, nursing and other staff members may perform poorly in their jobs by responding "using their own tacit judgement, usually based on their own moral code", rather than residents' sexual rights (Rodgers, 2016).

It is hoped the current findings may guide programs of social awareness in society and enable the development of appropriate social care policies in Portugal which will benefit the elderly with dementia providing them with a better quality of life. These would facilitate inclusion, psychological acceptance by others, visibility, and increased openness in discussing the subject, among healthcare professionals and among family members. Regardless of which theory one believes is more correct, it is well recognized that dementia occurs on a continuum of evolving and variable symptoms. Consequently, it's important to evaluate their decision-making capacity, involve them in making decisions about their lives and/or make ethical decisions which contribute to the preservation of capacities.

Limitations

As with other studies, this research also has limitations. The data obtained was from a small sample size, which was selected for convenience, resulting in the lack of representativeness, as such the findings cannot be generalized.

The trend of social desirability may potentially be an issue, since there may have been a tendency to respond in a way which is considered more socially acceptable. In addition, the theme itself may have generated "embarrassment" which may have led to the activation of constraints, beliefs, myths and stereotypes. The researcher found that with some participants this subject was considered a very sensitive issue to discuss. Consequently, due to that the theme was not discussed in a natural way, therefore it was not approached with the desirable profundity has expected. The study sought to mitigate these limitations by adopting a mixed methodological approach, through a reduced questionnaire and a questionnaire of greater depth and more rigorous interpretation.

Conclusion

Portuguese society currently lacks significant knowledge in the responding to the challenges faced when confronted with sexuality in the elderly people, especially the ones with dementia. The research method used allowed the research subject to be explored in a more detailed way, enabling a greater understanding of the perceptions do the participants.

Despite the concern to respond properly to the particularities of this target population, there is lack of institutional guidance, training and time availability. There's a need for more training and education to impart knowledge of elderly sexuality and the skills required to discuss it sensitively. It's important that participants respond to the need of the elderly providing openness and dealing with sexual behaviors in a natural way, supporting the development of quality of life of the seniors (McAuliffe et al., 2007).

Throughout the research it was observed that aging does not imply a stagnation of sexuality, but there may be a decrease of sexual intercourse. However, this research exhibited intimacy as a positive influence in dementia, as people indicated that hand holding, caresses, kissing, affection exchange, physical embraces and flirting can be more positively perceived by these patients. Although sexual expressions expressed by the elderly with dementia may pose risks and consequently require monitoring and redirection. That's why it is also relevant to develop a culture where elderly feel comfortable to express their concerns, acknowledge their emotions without fear of being blamed and ridiculed and support one another in the interests of holistic patient care.

However, it is perceived during this research, which is supported by Di Napoli, Breland and Allen (2013), findings, that the environment of care does not always lend itself to discussions about sex and many patients find it difficult and embarrassing to talk to about sexual problems and ask for any kind of help, which provokes at a more general level a cultural constraint, which inhibits an open and informed discussion.

Specific training to deal with the sexual expression of these patients would also facilitate the decision-making processes, namely in deciding whether sexual interactions are allowed, what kind of sexual behaviors would be accepted, with whom these interactions may

occur, where they may occur and the timing and procedures if the intervention of the healthcare technicians is necessary.

In conclusion, qualitative results demonstrate that there is indeed presence of sexuality, intimacy and sexual behavior in elderly people with dementia, despite the cognitive deficits (Ex: "*It is part of life and I think it is a good thing because I feel that the elderly is happier... I think that if the elderly has the cognitive abilities to decide that they should advance we should make that possible*."). A high percentage of the participants referred that sexuality is a result of a physiological need and should be faced as natural/normal as possible. Sexuality is considered as an important manifestation of love, affectivity and proximity, rather than exclusive presence of sexual intercourse (Ex: "*The term sexuality is not synonymous of sexual intercourse. Sexuality involves much more; it presupposes love, affection, sensuality, fantasy, and necessary feelings in all stages of life. Thus, the sexual life does not die out at the advanced age, it only changes characteristics…*). In this study, the social mentality and education given to date is considered as an influential factor in the rooting of existing taboos about the subject of sexuality in the third age, specifically in dementia. (Ex: "*The taboos that culture imposes on an individual, directly influences the exercise and the feeling in relation to the experience of sexuality… Sex is erroneously associated with youth...*").

Regarding the health care professionals' performance, these refer to being attentive to the needs of the elderly regarding sexual behaviors, trying to deal in the most natural and discreet way to the sexual manifestations of their users (Ex: "*I deal with it the most natural way, anyway if I did not know how to respond to a certain situation, I always find for a more competent healthcare technician)*. However, it is perceived a limitation of training and institutional orientations when the elderly present manifestations as inappropriate sexual behaviors. (Ex: "*I just think that there should be training to know how to deal with and be able to respond to these situations… We shouldn't impose our ideas as we wish, there must be guidelines, from which we can be orientated…*"). Despite being a low number of elderly people who adopt these behaviors, the participants perceived a general disinhibition of these patients, as a result of the diagnosis presented (Ex: "*It was funny to see his complete disinhibition on a subject such as sex, that was completely taboo and from the moment he got sick it became a completely banal subject. … I had no idea that they could become this inhibited…").*

Through these behaviors it is possible for the participants to determine the degree of cognitive impairment and decision-making capacity of the elderly. Given this, it is possible to determine if the elderly is able to make decisions about their intimacy and sexual behaviors that they want to adopt, wherever possible the participants consider it essential that the elderly be the only one to have an active role in their decisions (Ex: "*…I think she still has the ability to decide in these areas. However, if the dementia was aggravated, and there was no logical speech … we should not decide anything on behalf of that person."***)**

In study 2 the main results concluded that: a high percentage of participants disagree with the inference that as people age, they become less interested in sex and sexual expression, then agree that elderly people with dementia must have the freedom to express themselves sexually and intimately in a natural and spontaneous way. However, there is a lack of time that the caregivers dedicate to respond to the inherent problems of sexuality and intimacy and express concern in the responses of the partners as well as the family in relation to the theme research.

The findings of this research are directly relevant to the development of healthcare and public policies within Portugal, these will enable the development of a care environment that supports the individual sexual needs of older patients with dementia. As Spece, Hilton, & Younggren, (2017) findings suggested long-term care facilities need to carefully survey their ideals, attitudes, and beliefs about the sexuality of older people with dementia residents, while considering to manage the rules stipulated for the institution.

The current research's objective was to assess the perceptions of healthcare professionals and family caregivers about sexuality, intimacy and sexual behaviors of elderly with dementia, however the sample size was of small, thus future research should be made including bigger samples, in order to increase the representativeness of the results developed through methodologically well-designed researches. It is also important to continue doing research on this topic and disseminate this information among professionals and caregivers who deal with older people with dementia, so that they may better understand how to meet the specific needs of this population. Although some progress has been made in the literature on the study of sexuality in the third age, much remains to be explored and analyzed when we approach the subject of sexuality and dementia.

More than understanding the current views and the managing process that participants adopt is important to deconstruct beliefs and myths in the area of sexuality and intimacy in older people with dementia. If we want to develop dignified aging we should always consider the sexual dimension of the human being, because one does not exist fully without the presence of the other.

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Chapter 3- Overall Discussion

The 2nd cycle in Clinical and Health Psychology of the University of Beira Interior is structured according to the EuroPsy regulation and intends to prepare the student for an autonomous professional practice as a psychologist. The general objective of practicing as a psychology professional and it is supposed to accomplish with this research is to develop and apply psychological principles, valid information, models and methods according to an ethical and scientific way and to indorse three major aspects: development, well-being and efficacy of individuals, groups, organizations and society (EFPA, 2015).

Considering the objectives proposed by the dissertation curricular unit we came to the concretization of this investigation, that proposed constant research and demand. During the process we come along with a variety of developed competences, and allowed to pass through several steps like defining the subject of the dissertation, literature review of the variables, defining objectives and hypotheses; groundwork on the method, procedures and instruments for data collection; comparison and discussion of the results. In accordance with the requirements of a scientific work, all the steps for the research and practice took into consideration deontological and ethical obligations.

About the conclusions and main inferences to take about the major topic analyzed: "Sexuality, intimacy and sexual behavior of elderly people with dementia in residential care: the perspective of healthcare professionals and family caregivers in Portugal." We can present 6 main results taken from the qualitative study and other 4 taken from the quantitative research. Qualitative results demonstrate that: (1) participants identified presence of sexuality, intimacy and sexual behavior in elderly people with dementia, that result of a physiological need and should be faced as natural/normal as possible; (2) Sexuality is mostly considered as an important manifestation of love, affectivity and proximity, rather than exclusive presence of sexual intercourse; (3) Participants hypothesized that the social beliefs influence on mentality and education given to date and that has an influential factor in the rooting of existing taboos about the subject of sexuality in the third age, specifically in dementia; (4) Participants regarding to the health care professionals' performance, refer to be attentive and try to deal in the most natural and discreet way to the to the needs of the elderly concerning sexual behaviors; (5) It is perceived a general limitation on training and institutional orientations barriers, especially if the elderly manifests inappropriate sexual behaviors and (6) Decision-making is determined by the elderly if he reunites the ability and capacity to manifests what his wishes are.

As for the quantitative research it is concluded that:(1) high percentage of participants disagree with the inference that as people age, they become less interested in

sex and on sexual expression (2) considering they must have the freedom to express themselves sexually and intimately in a natural and spontaneous way. However, there is felt a (3) lack of time that the caregivers dedicate to respond to the situations of sexuality and intimacy (4) expressing concerns in the responses of the partners as well as the family caregivers to the sexual expressions.

The study research mostly reinforced the importance of education in sexual health in all phases of life; even in those who have a pathology such as dementia. This research proposes that more humanized and conscious approaches should be implemented, allowing professionals to recognize that many of the difficulties that older people face are sustained by institutional measures (e.g., the nursing home industry, shortcomings in the training of health professionals and caregivers, the fashion industry, and the media) (Landers et al., 2016). This information may empower people to be more actively controlled over the quality of their lives in old age through political awareness, government legislation, and personal autonomy and regulation.

Many older people enjoy an active sex life, although they are likely to experience problems, mostly due to health problems. Overall, the setting of care does not offer itself to discussions about sex, this can cause frustration feelings in senior. That's why sexual activity in dementia patients is an emerging area of study and it is hoped that this study will have implications in the future actions of both the healthcare technicians, as well as the family caregivers of elderly people with dementia. It is necessary to increase the understanding of this area using a more credible and well-founded tools, that allow a realistic understanding of the phenomena and thus a more adequate intervention.

This research as also the intention to develop health policies in order to improve public services to improve the global needs. It is also important to influence social policies in order to promote inclusion and general wellbeing especially in the area of health. Currently there are barriers to gaining further understanding, as many people consider it a taboo subject and are unwilling to discuss it, choosing to deny its importance to the elderly and believing that they are asexual beings.

Regarding the performance of the psychologist, it is important the application of periodic cognitive evaluations, in order to determine the capacity of the elderly, which has a direct influence on the decision making that they adopt. It's also important to provide a multidisciplinary team, that can be attentive to the preservation of the human rights, that may be easy violated due to the condition of the elderly. It is equally important for the psychologist to intervene in order to demystify taboos and prejudices making possible the creation of home residences that are concerned with the needs of its residents. In addition to this, it allows a targeted follow-up to the area of sexuality, allowing emotional ventilation spaces, which in other circumstances can be suppressed as a topic of discussion and conversation.

It opens new areas for future research, enabling new ways of working with the elderly, using methodologies that respect their limitations and circumstances. This will enable the development of specialized training which is currently lacking in Portuguese institutions. Future research is also required in order to turn this information more visible and consequently more valid to society. This could also motivate scientific community/ colleagues to find solutions for the barriers that are faced in institutions that obstruct sexual health in later life; and by providing effective intervention programs that are designed to maximize the capacity of sexuality expression. The ultimate achievement is to provide to elderls with dementia the resources to live a better and happier life, always considering the ethical questions that may be evolved and the preservation of rights.

Despite the growing literature felt in the area of sexuality in old age this study presents itself as a pioneering study in Portugal by investigating the perspectives of healthcare professionals and family caregivers about sexuality and intimacy in elderly with dementia. This study is aimed to conduce the develop of readers' awareness on the theme studied and should turn actions fairer and more sensitive to the needs of the elderly.

In reference to all the above, it is important to perceive how sexuality can be manifested in this specific group and to realize that is present throughout the stages of the person's life, even if they do not manifest themselves through sexual relations, they manifest through affection, closeness and love. To deny this existence is to deny the essence of the individual, is to deny that the human being is not a person of relationships. In doing a more in-depth analysis of the thematic, we realize that the path on building a society ready to accept the needs of elderly with dementia is still long. However, this study intends to be a small step towards the achievement of that goal.

Annexs

Annex 1: Theoretical Annex

1. Aging of the Human Being

The aging population in Portugal represents one of the main demographic and social phenomena of Portuguese society (de Sousa, 2013), due to the improvement and dissemination of pharmaceutical, medical and health benefits and therefore the development in social, economic, cultural and political conditions (Silva, 2003). It is also an emerging topic of research and influence/concern in the physical and mental health of people.

The population in Portugal has aged in the last few decades (Evangelista, 2013), with significant increases in those aged over 85 (Soeiro, 2010). As with other developed and industrialized countries, the demographic population in Portugal's has changed due to lower birth rates and significant increase in life expectancy (Sobral & Paúl, 2015). Studies indicate, we will continue to see a rise in this aging process phenomenon; on one hand it is projected that by 2050 the percentage of elderly in Portugal will duplicate to 38.9 % (INE, 2012 cit. in Mendes, 2015) and on the other hand, studies also indicate that people over 65 have at least one chronic illness and several simultaneous problems. The greater vulnerability of this age group allows them to be affected more frequently (Silva, 2017).

Aging has been defined as a process that is progressive and dynamic, resulting in several adjustments in morphological, physiological and psychological ways, which may result in a gradual loss of the person's ability to adapt to their surroundings (Moreira, 2012). Consequently, the terms 'active aging' have emerged as a paradigm to respond to individual and collective trials that arise from this particular population (Veloso, 2015). According to Bárrios and Fernandes (2014), the active aging process intends to optimize, as much as possible, the opportunities for health and to develop quality of life during the process of aging, hence it's considered an important research area in the present study.

As for the aging process itself and according to Silva (2017),it can be related to a set of biological, psychological and social vicissitudes that develops throughout life, so it becomes difficult to establish a date from which people can be considered as 'old'. When considering human beings and their development we must consider several factors associated to personal characteristics, life history, social class, health care access, values given by the family structure and society in general (Lourenço, 2014).

In each individual, it's perceived that in physical, behavioral and social occur changes that mature at different rates and speeds (Tierney & Nelson, 2009). Aging is a natural phenomenon that is part of the life cycle and is influenced by intrinsic factors (inherent to the individual) and extrinsic factors (inherent to the environment) (Lourenço, 2014). Extrinsic factors include: life history, values within the family structure, society in general, education, admittance to supportive services such as health care, adapted housing, work chances

adapted to the needs and capacities of the elderly, all influencing the elderly track of life and their life histories. These factors can contribute positively or negatively to elders: on one hand it can help the elderly to develop skills and competences, however it can also contribute making the elderly frail, generating situations of latent or severe conflict, which may result in early senility, and consequently the termination of the physical and social life (Teixeira, 2015).

The aging population has been one of the most discussed topics in recent years, being even considered as a reality of the century in which we live (Tristão, 2012). Major progress is being made in order for the elderly live a longer life with social, political, economic, health conditions that result in a quality improvement. This changes may result in new realizations and in a new redefinition of the aging process (Massi, Santos, Berberian, & Ziesemer, 2016).

Due to the increase in longevity and consequently the aging of the population, there are many challenges that individuals, communities and society over-all face. There is an amplified priority to understand this phenomenon and generate new comprehensive social policies to meet the needs of the aged population. Due to the aging of the population, other changes are occurring, especially in families structures, that have limited the ability to accompany and care for older generations, resulting in a restructuration of all the social organization and intergenerational relations (Lourenço, 2014).

The aging process is commonly seen as a threat to the sustainability of health and pensions systems. However, over time a lot of work was done to dismantle this myth and to promote the thought that older people continue to play an active role in society and can contribute to their development (Schwanen, Hardill, & Lucas, 2012). Successful aging, encompasses the maintenance of a good physical and mental state, continued involvement in social activities and relationships (Alvarenga, Kiyan, Bitencourt, & Wanderley, 2009). According to Pinto (2012), active aging emerges as a new paradigm, responding to multiple individual and collective challenges that arise from the aging process, its referred to as a multidimensional vision that integrates the various domains of individuals' personal and social life.

In the modern gerontology the path to successful aging is to provide to each individual the necessary resources to elderly to fulfill their personal expression of aging (Lourenço, 2014). One of that is providing quality of life (maintenance of autonomy, hobbies, social interactions and promotion of well-being) in later life, considering the problems, losses, and negatives events that older adults may experience (Rubinstein & De Medeiros, 2015; Tristão, 2012).

2. Aging and Dementia

Health can determine the amount of the opportunities that arise from extra years of life. If there is good health, the ability to do the things that matter to elderly people will be slightly different from the perspective of a younger person (Beard et al., 2016). It's important to recognize that the process of aging has led to an increase in the prevalence of chronic degenerative diseases, and old age is often accompanied by poor health and illness. Dementia is one of the pathologies with an onset that occurs mostly late in life (Silva, 2017), which causes decreases in physical or mental capacity and has major implications for older people and for society (Roelofs, Luijkx, & Embregts, 2017). The lifestyle that an individual adopts through their lifecycle, as well as the progressive deterioration of the organism and the personal fragilities, makes the elderly more susceptible to the disease (Cruz, Loureiro, Silva, & Fernandes, 2010).

Predictions about mortality indicate a marked increase in the number of cases with dementia, whereby dementia is considered one of the most frequent mental health problems in the elderly, having a great impact on the Portuguese population (Sobral & Paúl, 2015). This number is projected to increase to more than 131 million worldwide by 2050, as populations ages (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016) and in systematic review developed by Gonçalves-Pereira, dementia prevalence rates for people 60 years of age or older ranged from 5-7% and in 2010, it was estimated that the world population included 35.6 million people with dementia, and these figures would double every 20 years (Gonçalves – Pereira et al., 2016).

As for the concept itself, dementia is a health condition that have a significant impact on people, families and society in general and although associated with different somatic conditions, dementia always includes memory loss, and eventually a decline of all cognitive and physical functions (Evangelista, 2013). Alzheimer's disease (AD) is the most prevalent degenerative condition (Gaugler, James, Johnson, Scholz, & Weuve, 2013; Jessen et al., 2014), accounting for 50 to 70% of dementia cases globally (Santana et al., 2015).

According to Alzheimer Portugal, the most recent epidemiological data showed that the elderly with dementia is expected to continue to increase, as it is estimated that over 64% of people with dementia in Portugal are older than 80 years (Santana et al., 2015) and the number of people with dementia worldwide has risen 22% in the last three years and could triple by 2050 (Alzheimer Portugal, 2017 cit. in Silva, 2017).

Based on the latest DSM criteria (APA, 2013), dementia is classified as a major neurocognitive disorder, since it confines both cognitive function and performing everyday activities. Dementia is by definition a change in competences, deteriorating the individual's

mental capacity (Nunes, 2016). Furthermore, according to Maloney and Lahiri (2016), dementia is considered as a set of brain disorders that result in behavioral and cognitive deficits, in memory, communication and language, focus and attention, reasoning and judgment, and visual perception. This specific condition is caused by brain damage, even without perturbation in the level of conscience. The severity of the cognitive deficit in dementia interferes in the normal familiar, social and occupational functionality of the person (Portellano, 2005).

The deterioration of cognitive and functional abilities associated to aging and neurodegenerative dementia does not occur the same way for all elderly, neither follows a fixed pattern, especially because the ability to confront and solve the challenges of their daily life differs from person to person (Sobral & Paúl, 2015).

Has it's been documented, dementia has no cure and symptoms progress as the disease evolves. As for the treatment, the main purpose is to delay the progression of the illness, which can result in a meaningful increase of time to spent with the elderly (Peters et al., 2015), letting people with dementia rise the opportunity to make important decisions such on economic, legal and health matters, while they still have capacities (Prince et al., 2016). A diagnose at an early stage of the disease may also allow the person to profit from medical interventions, that helps to slow the evolution of the disease and contribute to the preservation of their quality of life for a longer period of time (Nunes, 2016). Furthermore, early diagnosis is also important so that caregivers can prepare themselves and others to deal with the condition progression or to come to terms with the diagnosis (Alzheimer Europe, 2014).

As referred before, the working population, essentially family caregivers, hardly have the time to reconcile work with family life and keeping a healthy lifestyle. So, in order to provide the best care to the elderly, family members often find institutionalization as the solution to provide them a life with dignity (Silva, 2017), and a move into an Residential Care Facilities (RCF) can ease the burden of the family (Hajjar & Kamel, 2003; Roelofs et al., 2017).

Lourenço (2014), suggests that families have a notable commitment to help and care for relatives, however, it is perceived that they may fail to assume this same role when a diagnose of dementia arises. Due to changes in the family structure felt over time, family caregivers experience poorer physical and mental health which may lead to depression and caregiver burden (Wasilewski, Stinson, & Cameron, 2017) with women leaving their role as caretaker of the house and entering the labor market, therefore they now have less time to care for their sick elderly relative (Brodsky, Resnizki, & Citron, 2011; Brown, Smith, & Kromm, 2012).

Lourenço (2014), affirms that over the years old-age institutions have received increasing numbers of dependent or semi-dependent elderly people, however, it's been verified that they have failed to adapt to their needs, which resulted into an unfavorable view of society from nursing homes. This erratic view led to most of the families to perceive institutionalization as the last alternative to be taken.

Although institutionalization may be the last resource for many families to guarantee the continuity of the elderly's life with some quality and dignity, for most of families this may be necessary. In reality, parents may lose their say in the haggling process when they have dementia and/or become extremely fragile (Barczyk & Kredler, 2018). When families feel like there is less cognitive ability in their family member, incapability in decision-making, loneliness, isolation and illness, affective, social and economic changes or when they are absent or live far, for professional and social reasons, institutionalization may seem the best solution for their relative's care (Fernandes, 2014).

According to Lourenço (2014), the preservation and development of individual capacities is perceived by families as a priority for the well-being of the elderly and in order to avoid frustration and disappointing interactions. The elderly can perceive the institutionalization in two ways: in one hand the process of institutionalization may arise feelings of loss which can affect their personality and led to a new reconfiguration, since they change their usual context and deal/ meet different kind of individuals. On the other hand elderly may perceive this life change as an improvement on the wellbeing, social interactions and including feel more intense levels of happiness (Cordeiro, Paulino, Bessa, Borges, & Leite, 2015). In dementia, other factors may be perceived, as the loss of intimacy, lack of privacy, autonomy, responsibility for personal decisions, intellectual stimulation and spiritual deprivation may lead to a loss of security and personal values (Lourenço, 2014; Syme et al., 2017) .

In a study developed by Wilkinson and colleagues (2012 cit. in Beatriz, Freitas, Maria, Torquato, & Agra, 2016), elderly revealed that families who maintained continuous contact and if they receive frequent visits from friends and family members it created a pleasant sensation of preoccupation and care for the elderly, resulting in the preservation of satisfaction, protection and sensation of being remembered. These results provided the elderly with protection without being a major change in their autonomy.

The constant development of artistic, recreational and sensorial activities within the institution, preserve cognition capacities, as well as the feeling of being useful, revealing emotions such as: well-being, improvement of self-esteem, companionship, satisfaction, support, freedom, joy. These types of activities also favor social interaction with other elderly people, and show the importance for the development of positive emotional behavior (Santana, 2011). The way the elderly are welcomed and cared in an institution benefits the

adaptation phase of the elderly with dementia, making them feel safe and protected (Freitas & Scheicher, 2010).

3. Common changes in aging (with dementia)

Wrinkles, gray hair, arthritis, sagging and a multitude of other physical conditions indicating age-related changes verified in elders. Furthermore, older adults are more susceptible to age-related diseases resulting from physical, psychological and social factors (Goldsmith, 2014; Mroczek, Kurpas, Gronowska, Kotwas, & Karakiewicz, 2013). In general, people are hesitant to accept or appreciate the changes that occur with age. However, aging is a natural and inevitable process that requires multiples adaptations and changes in the behaviors, as new situations and experiences arise (Gradim, Sousa, & Lobo, 2007).

Aging carries with it a series of physiological, morphological and functional changes. The signs of aging become visible and involve the biological, psychological and social elements (Silva, 2017). In the elderly, limitations due to, organic and physiological degenerations, can diminish an individual's ability to maintain an active and healthy life, causing increased limitations. Although these changes are natural, their progression and manifestation depends on the hereditary/personality characteristic of each person, and essentially the way which individuals live (Gindri et al., 2012). As referred by Hwang, Cummings, Sixsmith, and Sixsmith (2011), the interaction between the person and his or her surrounding environments, changes the person's competence level and their nearby environments are considered dynamically related. The less capable/able an individual, the greater the impact that the environmental setting has. By decreasing environmental barriers, the constructed environment enhances an individual's overall functional competence.

According to Fechine and Trompieri (2012), the biological system most devoted to aging is the Central Nervous System, responsible for sensations, movements, psychic functions (life relations) and internal biological purposes (vegetative life). The pace of learning becomes slower in an older person and a simpler approach leads to a reduction in learning the elements of a task. In the case of dementia, a number of changes take place in the brain which affect the person's memory, mood and behavior (Alzheimer's Australia, 2007).

There are many types and symptoms of dementia that impact differently on individuals, even when those individuals are affected by the same illness (Alzheimer's Australia, 2007). Normal aging brings physical changes in both men and women. In the research conducted by Ferreira, Fernandes, Alves and Dantas (2015), older men were found to have more difficulty in adapting to the limitations of aging, such of those of a sexual nature, such as; impotence, lack of desire, effects of medications under sexual function,

physical pain and limitations. These changes sometimes affect the ability to have and enjoy sex (Alzheimer's Association, 2014).

Current research consistently suggests that increasing age its's not associated with a decrease in sex interest, however older persons sometimes accept the idea of "age means asexual" regardless of functional capacity or interest (Ballard, 1995; Dominguez & Barbagallo, 2016; Vandrevala, Chrysanthaki, & Ogundipe, 2017). Although, we can also associate the incidence of sexual dysfunction and a possible decreased of sexual desires in this age group, which can be related to the increased rate of health problems, rather than old age per se (Kalra, Pinto, & Subramanyam, 2011). In a report of the English Longitudinal Study on Ageing (ELSA) analyzed that maintaining a healthy sex life in older age could be instrumental and can also improve cognitive function. However, changes brought on by age can often make a person's sex life more difficult, which is verified in a Italian study, that looked at the quality of life and found significantly less interest in sex among the older participants—all 38 centenarians had lost interest in sex but reported greater satisfaction with life than younger people (Buono, Urciuoli, & De Leo, 1998).

With a condition such as dementia, changes in the behavior of friends and loved ones can change because of the limitations perceived. Such changes are very common, but they can generate stress on families and caregivers. Because of the alteration in cognition and possible personality changes even the elderly can be objectified and devalued losing their identity (Alzheimer's Australia, 2007). Isolation and loneliness are commonly exhibited in elderly patients diagnosed with dementia (Higgins, Barker, & Begley, 2004). The need for the elderly to have a companion is considered as a way to prevent isolation and loneliness. These findings are supported by Jones and Moyle (2016), who suggest sexuality and intimacy are a way to promote both physical health and psychosocial well-being (Jones & Moyle, 2016).

Queiroz and colleagues (2015), suggest that every individual is unique as well as their history, current circumstances and relationships, and that we should focused on the individual strengths and not on the difficulties they experience, this will allow elderly to adjust to their limitations and adapt better to their new reality.

4. Concept of Sexuality, Intimacy and Sexual Behavior

Sexuality has existed since the beginning of civilization. The concept of sexuality has been studied in the scientific field since the nineteen centuries (Kontula, 2009). Sexuality and intimacy concepts are complex, they include biological, social, psychological, spiritual, ethical and cultural dimensions that evolve over a person's lifespan, including in those who are elderly. It is considered a natural part of being human and can enhance well-being

(Kontula, 2009; UNESCO, 2018). This notion is extensively defined by several principles such as: culture (Devesa, Cruz, & Simões, 2013), religion, education. Sexuality may be the source for happiness and satisfaction and is the principle motivation for the formations of couples, however it may cause frustration and suffering in cases of sexual dysfunction (Kontula, 2009).

Although we have come a long way constructing a more open society and have better-quality information on the subject of sexuality (Simpson, Brown Wilson, Brown, Dickinson, & Horne, 2017), it is clear, as indicated by Kontula (2009),that further research is necessary to be made.

Over the course of history, the definitions and conceptions of sexuality have varied (Benbow & Beeston, 2012). According to the World Health Organization, sexuality is conceptualized as a central characteristic of being human throughout life encompasses. From this concept arise notions such as sex, gender identities, gender roles, sexual orientation, eroticism, desire, intimacy and reproduction (World Health Organization, 2006). Sexuality is practiced and expressed through thoughts, fantasies, wishes, beliefs, attitudes, values, behaviors, practices, roles, relationships and therefore influences physical and mental health (UNESCO, 2018). Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors (Spece, Hilton, & Younggren, 2017). Sexuality and sexual relations are essential to procreation and to generate sexual health, though most sexual activity may not directly be connected to reproduction and is of relevance throughout a person's lifespan, so sexual health is considered to be a broader concept (World Health Organization, 2010).

Physical changes that occur over the years, although normal and natural, can, as referred before, affect behavior, sexual response and aspects of sexuality in aging (Gradim et al., 2007). These modifications are a vital part ~~of~~ of human beings and is understood as a basic human need, this englobes the desire for contact, intimacy, emotional expression, pleasure, love and care (Pontes, 2011; Queiroz et al., 2015)

According to WHO (2001), sexuality is considered as an energy that can arise changing points in life, mobilizing and incentivizing to find love, touch, tenderness and intimacy; integrates the way people feel, move and touch. Sexuality is a multidimensional construct that incorporates more than just penetrative sex (McAuliffe, Bauer, & Nay, 2007). Sexuality is not linear has many other elements, it can mean different things to different people. It encompasses the need to convey love and tenderness as well as physical desire (Bauer, McAuliffe, & Nay, 2007).

According to Nay, in the perspective of older people sexuality is perceived as looking nice; spending time with the opposite sex; intercourse with a long-time partner; and relieving one's frustrations with a sex worker. Sexuality can also be expressed in the act of getting dressed up and feeling spoiled; looking one's best; enjoying sexually stimulating material;

talking ‘dirty’; cuddling with a partner in bed; kissing and masturbating. Sexuality exclude any form of abuse of human rights, the same as the conditions that delay the positive expression of sexuality in older people (Nay, 2004 cit. in McAuliffe et al., 2007).

In the context of nursing home settings sexuality is perceived, most of the time, as taking the form of affection, romance, companionship, personal preparing, touch, and the need to feel attractive and masculine or feminine (Lightbody, 1993; Mulligan & Palguta, 1991). In other words, any activity that means the sensation of feeling loved and respected (Mazaheri, Eriksson, Nasrabadi, Sunvisson, & Heikkilä, 2014)

Intimacy is distinct as it englobes giving and receiving affection (Kuhn, 2002). Costa (2005), refers to intimacy as a structure that supports the relationship and love. It’s the basis element of a relationship between peers, however, the definition of intimacy should consider the temporal dimension. Sousa (2013), suggests that intimacy, contemplates the capacity of transparency and openness to the other, accompanied by the acceptance. Essentially, within an intimacy context, an individual is able to share their most common aspects of their personality, sharing personal data, their imperfections, making them known who they really are to the other, without fears of judgments or rejection.

Intimacy is also relevant to the psychosocial development of adults; intimacy plays a developmental role in identity construction, through the consensual authentication of personal worth generating feelings as being understood and accepted as they are in a relationship (Timmerman, 2009).

As for the elderly perspective the same occur despite some differences. The principle characteristic’s that are appreciated are being valued; giving and receiving affection; sharing pleasant experiences of socialization; as well as the feeling of belonging to something. Intimacy support the cognitive, physical and psychosocial abilities of residents with dementia, which includes: sense of well-being, normality, ego strength, self-confidence and self-esteem, dignity, assistance of social skills,; reminiscing of enjoyed experiences, rituals and traditions; opportunities to give and receive affirming touch, using touch as a link to genuineness (Hellen, 1995).

As for the human sexual behavior it is considered as an activity that induces sexual arousal. There are two aspects of human sexual behavior: the response pattern of reproduction which is part of each individual’s genetic inheritance; and the degree of restraint of society in the expression of this sexuality. There are however, many sexual health problems which may arise, manifested in a non-normative way for the culture where the individual is inserted (Kontula, 2009), such as inappropriate sexual behaviors (ISB) (Cipriani, Ulivi, Danti, Lucetti, & Nuti, 2016; Kamel & Hajjar, 2003).

According to Guay (2008), and Wilkins (2015), dysfunctional or inappropriate sexual behavior include increased libido and can be defined as behaviors that are inappropriate,

disruptive, which can include sexual explicit comments and language, excessive hugging/ kissing, preoccupation with sex or having sexual acts (touching, masturbation in public, grabbing of the genitals and/or breasts of other residents or staff) and implied sexual acts (sexual hallucinations, delusions of infidelity, attempting to seduce other residents or staff, chasing other residents for sexual purposes, requests for unnecessary care, exposing one's genitals in public, and undressing in public). Some behaviors may be inappropriate only because they are performed publicly, if they were made in the privacy of the room, it would be perceived differently. Higgins and collegues (2004), suggest that inappropriate sexual behavior is not particularly common in people with dementia, however it is perceived a general disinhibition.

Sexual health is fundamental to the physical and emotional health and well-being of individuals, couples and families, and to the society and economic in general, in order to develop communities and countries. Sexual health, incorporates the rights of all persons to have the information and chance to follow a safe and careful sexual life (World Health Organization, 2010).

Intimacy, sexuality and sexual behaviors are subjects that the majority of healthcare professionals who provide care for the elderly with cognitive deficit, predominately try to avoid. Although some agree that the patient has the right to express his or her sexuality (within certain parameters), others may simply ignore the subject or even feel embarrassed to talk about it (Devesa et al., 2013).

5. Stereotypes and Myths on Aging

Ageism is the most common type of stereotype made and used to denote discrimination on the basis of age bias, and it designates the social processes of marginalization and the construction of judgmental stereotypes, especially in relation to the elderly population (Marques, 2011; Nunes, 2009), this kind of stereotype triggers discriminatory practices and favors the isolation of the elderly (Torres, 2016). Discrimination against the elderly is a form of intolerance that limits opportunities and favors unsatisfactory treatment (Carreira, 2011). Thus, aging may face a number of problems involving social discrimination, usually expressed in behaviors and attitudes present in everyday interactions with elderly individuals, who are constantly challenged to prevail social patterns that tend to value the symbols of youth (Filho et al., 2010). Ageism can also prevail when older adults fall in love, this may have especially calamitous consequences for those living in residential care facilities (Barusch, 2012).

The concept of stereotype or representations, assumes a preponderant, as both reflect the attitudes, prejudices and images, used to describe specific social groups, namely the elderly and aging. Social representations are very important in order to understand the behavior adopted for a society, because the way we act can often influence how other react with us (Neves, 2012). Attitudes toward the elderly are different across cultures (Fernandes et al., 2017), and the majority of perceptions regarding the elderly are mostly positive (Torres, 2016), however there is a commonly discussed thematic, that faces many socio-cultural prejudices, constructed from legacies of the civilization, which maintain norms and rigid dogmas of behavior, discriminating the elderly (Araújo, 2015).

In a youth-oriented culture, the concept of sexuality is often attributed to the young, healthy, and attractive, and the myth that the elderly are asexual beings predominates (Hajjar & Kamel, 2003). The literature shows that mostly women, are influenced by both social values and health status (Fernandes et al., 2017).

As a result, from these negative views, it's more difficult for older people to express their sexuality and to discuss their sexual needs and desires. The stereotypes and myths together with later life sexuality determine an equivalence that are often negative, described as lacking sexual interest. These views of later life sexuality may affect the attitudes of the caregivers/staff who look after the aged when responding to their sexual expression (Chen, Jones, & Osborne, 2017).

Despite the evolution in the conception and practice of sexuality nowadays, there is still a preconception by health professionals, by the elderly and by society in general (Pinheiro & Couto, 2013). Although sexuality can mean different things to different people, the stereotype of the older person being a human without sexual feelings, desires, or ability, should no longer be acceptable, especially those who are dealing daily with elderly. The attitudes and practices of healthcare professionals should be carefully considered (Bauer et al., 2007).

According to Luz, Machado, & Felipe (2015), the way sexuality is experienced has a strong effect on how elders internalize feelings. Thus, when it is prevented or disabled, the elderly person experiences the loss interest, especially in the sexual desire, romanticism and the possibility of being recognized by others. Many older people act in accordance with the rules of society, which understands sexuality in old age based on moralistic and prejudiced concepts. In Bauer's perspective the assumption that is made by society is that sexuality is unimportant, or irrelevant, to older people. These attitudes, crystalized and are fixed in the belief that ageing is a negative event, marked by deterioration, and is something to be feared, rejected and not talked about (Bauer et al., 2007).

If we consider aging gay men and lesbians many other challenges are verified, that includes limited access to gay-friendly healthcare, feelings of invisibility and hostilities with

ageism within gay and lesbian community environments, often leading to a rejection of nursing home visitation rights for partners, loneliness and social isolation, internalized homophobia, and accelerated aging (Herdt & De Vries, 2004).

When considering sexual intercourse, we often think about younger people or adults and rarely do we consider older people. However sexually transmitted diseases (HIV) can be transmitted in all ages. Older people usually don't think about this when they create new relationships and are sexually active. More sensibilization should be made in order for elderly practice safe sex (Bamford & Serra, 2011).

There is an irrational rejection of the whole thing related to old age. In general the elderly are perceived as ill, depressed, incapable, weak in initiative, inflexible, resilient to change, unmotivated and disinterested, ideas that quickly become myths and preconceptions concerning the elderly (Fonseca, 2012). Such attitudes can assume different behaviors such as stereotypes concerning beliefs about older people that sees aging as a phase of homogeneous development; prejudices related to feelings towards older people, and discrimination that incorporates acts and affective behaviors (Marques, 2011).

6. Sexuality and Intimacy in Older People

According to Alencar, Paula and Marques (2016), sexuality is a theme that needs to be incorportated on the present of human health of the elderly, whether in campaigns, educational actions or routine consultation. The exercise of sexuality in elderly needs to be understood as a positive experience, from the point of view of both the elderly (as long as they consent and desire it), as well as the health professional. Although there is a growing body of knowledge regarding the impact of dementia on sexuality, many questions remain to be answered (Davies, Zeiss, Shea, & Tinklenberg, 1998), such as nature and cause of sexual behaviors in institutions, about the roles nursing staff, physicians, and administrators in identifying individual's needs, while safeguarding both the residents and the staff from the consequences that may arise (Szasz, 1983).

Sexuality is a basic human need that begins at birth and continues throughout life. The sexual needs of the elderly are similar to those of the young, but with variations in frequency, intensity, and manner of expression. Regardless of age, every individual has a need for love, intimacy, and companionship (Hajjar & Kamel, 2003). In order to discover emotional changes in the elderly, a variety of methods should be applied, such as caring, listening, positive feedback, acceptance, and experience sharing (Zhou et al., 2012).

Contrary to societal beliefs, sexual and intimate behaviors are exhibited by older adults in nursing home settings, and by those that have dementia-related diseases (Syme et

al., 2017). Several studies concluded that whilst the frequency of sexual intercourse tends to decrease with age, the level of interest and the necessity to engage in sexuality and intimacy remains (Kalra et al., 2011; Miller, Sehgal, & Dziegielewski, 2011) and older adults continue to engage and be interested in being sexual and intimate (Bastos et al., 2006; R. Fernandes et al., 2017; Hajjar & Kamel, 2003; Syme & Cohn, 2016). This is also supported by Benbow & Beeston's (2012) study, which found that as adults, elderly people with dementia also feel the need to express their sexuality. Nevertheless, Nogueira et al. (2013) suggest intimacy and sexual activity in those with dementia are negatively influenced by the level of care that the illness demands.

Sexuality is considered an important constituent of quality of life and can be vital to the maintenance of healthy interpersonal relationships, self-concept and a sense of integrity (Birnie-Porter & Hunt, 2015). Beyond this, sexual identity is easily linked to one's sense of self-worth and, if denied, can have consequences as damaging effects not only on sex itself, but also on one's self-image, social relationships and mental health (Bauer et al., 2007).

The idealization of sexuality by the elderly, specifically woman, occurs through expressions of understanding, romanticism, dialogue, complicity, intimacy (Bastos et al., 2006; Fernandes et al., 2017). According to Hegland and Fleming (2009, cit. in Spece et al., 2017) sex may be considered as a statement of continued participation with life, a source of emotional sustenance, and a validation of self-worth. This may not even result in orgasms, it can be simply caresses and gentle touching (Spece et al., 2017).

According to Brito (2014), friendly relationships between couples, regardless of their age, are important to an enjoyable emotional life, based on mutual respect and cordiality, where love prevails. On the other hand, it is worth revealing that often the emotional failure and consequently the less enabling sexual practices are related to the cultivation of conflicts.

As for couples, in particular those of advanced years, since it is a period in which there is a greater probability of becoming ill due to chronic degenerative diseases, demanding the use of medication when the partner becomes ill or becomes impotent, can result in the end of sexual expression (McAuliffe et al., 2007). According to Fernandes and collaborators (2017), it is not only biological aging but also physical, mental and psychological health that should be considered when elderly maintain aspect of sexuality and intimacy.

The process of andropause and the use of drugs to overcome erection problems such as erectile dysfunction is common in elderly who want to preserve an active sexual life. Nevertheless, men are the gender that struggle the most with this issue, it is thus difficult to admit the need to use artificial drugs to accomplish what they have always gotten naturally (Tsatali & Tsolaki, 2014). Furthermore, as the desire, the need for sex and orgasm in men decrease with age, the use of this medication is not always effective, however in many cases it can help overcome this issue. Consequently, with aging, men will need more time to reach

orgasm; they will need a longer interval between one ejaculation and another and the ejaculated volume will be lower (Gradim et al., 2007).

Doll (2013), noted that older adults engage in sexual and intimate actions across different living settings, including dependent care settings. Institutionalization may lead to a decrease in autonomy and loss of identity, which can result into the interference of the expression of the sexuality of the elderly. Sometimes manifestations of sexuality in old age can easily be perceived as a behavioral problem and not as a natural expression of a basic human need for love and intimacy, and because of that, residential care homes are considered to play a central role in care, in order to demystify these beliefs. In that perspective, it is conceivable that intimacy and sexuality cannot be experienced in the same way people were used to when living (together) in their own home (Roelofs et al., 2017). According to Venturini (2017), in this context, understanding how the nursing team perceives the sexuality of institutionalized elderly population assumes relevance, since it can be influencing the care actions of elderly in this dimension.

7. Sexuality, Intimacy and Sexual behavior in Elderly with Dementia

By developing and understanding concepts like sexuality and intimacy, inherent terms such as active aging arises, which is an important matter to be carefully analyzed. As dementia is a complex disease, it important to promote and develop "active aging", by optimizing opportunities for health, participating to improve the quality of life of the elderly, enabling them to develop their potential for good physical, social and mental health as much as they can, and partake according to their needs, desires and capacity (Tristão, 2012). Therefore, current research developed by Chen and collaborators (2017), indicates that sexual relations and intimacy remain important to older people and can improve their overall quality of life, and consequently promote active aging.

For older people with dementia, sexuality implies a continued involvement with life (Bauer et al., 2014), a source of emotional support and an validation of self-worth and self-esteem (Mahieu & Gastmans, 2012). Likewise, sexuality and intimacy have the potential to contribute to the quality of life in the systems evolved, health, and well-being, of people with dementia, their family and caregivers (Jones & Moyle, 2016).

During the process of assessment of elderly with dementia, family members and technician should consider the different levels of neurocognitive impairment. Consequently, people need to consider how to care about individual specifies and to adequate assess to their behavior towards them (Schulz & Mann, 2016).

Dementia may affect sexual feelings; however, it can result as elderly who doesn't have health conditions such as changes in behavior or the desire for the expression of affection. Gentle cuddling and holding may be mutually satisfying and will let technicians and family members know if the person is able or inclined to engage in further intimacy. Nevertheless some elderly people do not respond in the same way as before or may seem to lose interest (Alzheimer's Association, 2014). For some couples, sexual intimacy continues to be a satisfying part of their relationship. As the disease progresses, it's important to take the needs and expectations for intimacy into deliberation, as these changes will affect both the elderly with dementia as his or her intimate partner and family members. The person with dementia may make excessive demands for sex or behave in a way that makes others feel uncomfortable. Furthermore, couples may feel guilty about needing or wanting to sleep separately (World Health Organization, 1994).

Sexual activity in elderly couples, in which one partner has dementia, is still poorly studied (Nogueira et al., 2013). Some partners may feel concerned about sexual propositions from a spouse who no longer knows their name or sometimes does not recognize who they are (Frankowski & Clark, 2009; Litz, Zeiss, & Davies, 1990). Furthermore, memory problems and declines in decision making capacity can interfere with intimacy, for example, when a couple member has frequent sexual propositions from partners who do not reminisce an episode of sexual intercourse that happened earlier in the evening (Davies et al., 1998).

As for the capacity to consent, caregiver's spouses express concerns that the patients with dementia may not have the capacity to have sexual manifestations, and are concerned about violating the privacy right of their loved ones (Bartlett, 2010). The beginning of the illness does not erase sexuality, but rather changes the way in which love is given and received (Kusi, 2017). For some patients, remaining sexually active provides one of the few residual behaviors in which they feel they can care their role individuality and provide value to their partners (Davies et al., 1998; Kalra et al., 2011).

In addition, in a study developed by Dourado, Finamore, Barroso, Santos and Laks, (2010), male husbands describe feelings of guilt about having sex without the explicit consent or understanding of the wife, since the progression of the disease, awareness of the deficits and the decision-making capacity decline. The joint impasse felt of sexual activity in dementia relates to the conflict between the protection of patients and spouses/family members and maintaining sexual needs for the couples or elderly with dementia (Szwabo, 2003).

For people with dementia, the loss of intimacy on multiple levels occurs for a number of reasons, such as the impact of the disease on their self-concept, anger, disappointment with themselves and their situation, and in the majority of the cases discontent at their spouse for their inability to handle the changes in them (Harris, 2009).

Many studies have emphasized the importance of orienting elderly to the physical changes inherent to the aging process and also of the specific modifications naturally felt in the stages of dementia, so that there is no influence or in order to have a smaller impact into the quality of sexual life of the elderly. It is also important to clarify that having a sexual life and sexuality in old age is something natural, and it is necessary and essential to prepare for coping with these changes throughout life (Santos & Faustino, 2017). However, when the disease manifests itself in advanced stages, some elderly may increase their interest in sex and physical closeness; however, they may not be able to judge, what appropriate sexual behavior is (Rheaume & Mitty, 2008). Those with severe dementia may not recognize their spouse or partner, but they may still desire sexual contact. Most of the times it can be confusing and difficult to know how to handle this situation, that's why formation is vital in this multifaceted process (Alzheimer Scotland, 2011; Ballard, 1995).

Over the years it is felt that there is a greater approximation and openness about subject such as intimacy of the elderly, with feelings based on love and companionship, taking the experience of sexuality new potentials for adaptations and reinventions. The fact is that, contrary to what has been proclaimed for so long, the ability to live fully sexuality is not lost with the age or disease, it only modifies (Brito, 2014). It is evident that the human desire for intimacy endures even through the cognitive decline of dementia. Nowadays, the religious community recognizes that people cannot live without love but until these new conceptions, sexuality had negative and demoniacal symbology. That is, they accepted the sexual act as something integrated in the marriage but only as an act of procreation and reproduction of human beings and not as something associated with affective manifestations of people who love each other, making the manifestation of sexuality in elderly as something harder to accept (de Sousa, 2013). In addition, many older women continue to think that they must remain faithful to their husbands, even after becoming widowed (Palacios-Ceña et al., 2016). However, changes are happening and there are new developments in this area.

8. Inappropriate sexual behavior in elderly with dementia

As symptoms of people with dementia, they may experience fluctuations in reasoning and decision and the expression of the sexuality may result in behaviors that are challenging to manage, such as inappropriate sexual behavior (ISB) (Cipriani et al., 2016). According to Mental Health First Aid Australia (2015), environment can influence ISB behavior, for example going out in public or having visitors at times of the day when the problem behavior is more likely to occur, or having a different persons helping with showering.

Improper sexual behavior may differ according to the type of dementia suffered. It appears to be one of two types: intimacy-seeking and disinhibited, that differ in their

association with dementia type, dementia severity and, possibly, other simultaneous behavioral disorder (Medeiros, Rosenberg, Baker, & Onyike, 2008). Despite the different perspectives from different authors, inappropriate sexual behaviors are not infrequent among cognitively impaired elderly. Burns, Jacoby, & Levy (1990) study showed, 7% of 178 nursing home residents with dementia of the Alzheimer's type exhibited sexually disinhibited behavior. It is important to understand, however, that their sexual needs are real and modify constantly as the disease progress. Memory loss and impaired judgment may lead the nursing home resident with dementia to seek sexual activity with other residents or staff members (Chen et al., 2017).

ISB is often seen as a part of the symptom of interactive and psychiatric conflicts associated with dementia, which can often be disruptive and stressful for both patient and their caregivers (Johnson et al., 2006 cit. in Vandrevala et al., 2017). An estimated 80% of elderly with dementia at some point of the disease show behavioral complications such as aggression, agitation, disruptive vocalizations, etc. (Ozkan, Wilkins, Muralee, & Tampi, 2008). Therefore 'inappropriateness' may derive from the disapproving attitudes and judgments of observers (clinicians, nurses and other staff, family, other residents) rather than the actions, and may reflect the lack of privacy inherent in residential care environments (Medeiros et al., 2008).

In several cases, elders adopt behaviors such as hyper sexuality and abnormal sexual behaviors because they go beyond the disruption of neural systems. Human beings have a psychological need for intimacy and can be enhanced by the lack of physical closeness (touching and intimacy) in the trained healthcare professional's environment. Intercourse can reduce loneliness, fear, anxiety, and boredom. The loss of memory of the recent events can be minimized when there is frequent sexual activity, because the patient quickly forgets prior activity (Guay, 2008).

These findings, are considered important elements to address when considering the planning and management of dementia care in residential facilities, especially considering the differential diagnosis of dementia and to provide formation to professionals. Many ethical dilemmas often arise when harmonizing safety versus freedom issues for patients in an advance stage of the disease, who become inept of with regard to moral or legal restrictions (Cipriani et al., 2016).

According to Litz and colleagues (1990), and Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, (1999), some people suggest that men with dementia are more likely than women to exhibit inappropriate sexual behaviors. This can often result in feelings of anxiety, embarrassment, or nervousness in caregivers, and the result can be the disruption in continuity of care for the patient at home, leading them to be institutionalized in places which are perceived to be more capable of manage these kind of issues (Holmes, Reingold, &

Teresi, 1997). Many orthodox notions construct older men as predatory and older women as submissive, weak and sexually disinterested (Simpson, Horne, et al., 2017).

9. The perspective of family caregivers to sexuality in dementia

In Portugal, it is within the family unit that the elderly predominately finds support, affection and resources to overcome the obstacles they are facing with their diagnoses. The role of the family is to help the elderly to live, not only longer, but better and to ensure the person is integrated into the family and community system (Lourenço, 2014). Although family still offer the greatest support to their elders, many of their responsibilities have progressively passed into the state domain.

Over the years there has been a measured evolution of social responses that prepare families for the changing situations, these include: home support, day and night centers, social centers and temporary or permanent homes (Ellard, Thorogood, Underwood, Seale, & Taylor, 2014). However, challenges are many times faced, such as residential homes having long waiting lists and their services become unproductive in responding to requests and they need to keep depending on family to a large extent or in hospital services, which in verified in the study developed by Amaro, in that one of the elderly had to wait three months on the hospital to have a spot in the residential home, because he couldn't came back to his house due to his health condition (Amaro, 2013). According to Lourenço, there other issues, such as: changes in the family structure, the deterioration of housing conditions, health problems, the loss of self-governance, the lack of a sustenance system that simplifies the social and family integration of the elderly, lack of economic possessions, among others. These matters question the viability of maintaining the elderly at home. Some older people and family members often accept that institutionalization is the only viable response to ensure a satisfactory condition of life (Lourenço, 2014).

Lichtenberg and Strzepek developed in the year of 1990, a three-step model that facilitates assess on individual's capacity to consent to sexual intimacy in nursing home settings. This practical model could be helpful to caregivers/married couples who fear they own attitudes as they may be taking advantage of their spouse. This model evaluates the patient's consciousness of the relationship (for example: if the patient initiate sex with the caregiver; if patient recognizes the spouse and if the patient states the degree of intimacy that he or she feels most comfortable with). However, it is necessary to determine what is the patient's capacity to avoid exploitation (for example: if the patient's has consistent behaviors such as beliefs and values and if the patient is capable of declining sexual invites). The final step evaluates the patient's awareness of potential dangers (for example: if the

patient realize that relationships may be time-limited or if is aware of what medical problems/risks his or her partner brings to a sexual meeting) (Davies et al., 1998).

Family members may find difficulties in agree with the concepts of autonomy and personhood of the sexual expression of the elderly with dementia. An adult family member is often the one who makes the decision to place a relative in a nursing home, commonly known as a tutor, and to be present in the choices that are necessary to take with is family member (Kamel & Hajjar, 2003). It is often verified a role reversal in family members, whereby paternal attitudes toward their parents occurs, and afterward they interpret sexuality in their elderly parent as they would be a teenager in a sexual condition, the same may occur in the spouses relation (Harris, 2009). In reality, relatives may lose their say in the haggling process when they have dementia and/or become very debilitated (Barczyk & Kredler, 2018).

According to Breland (2014 cit. in Spece et al., 2017) adults-children that assume a parental position of their parents are almost forced to assume during the transition of a parent to nursing home care that they need to make choices for the parent, during the period of the parent's placement, including choices about the parent's sexuality. Despite of some facilities encourage and facilitate open communication about sexual activity among elderly residents and their families, there are more conservative facilities (Benbow & Beeston, 2012), which may influence negatively the family members in discouraging and monitoring the sexual activity of their parents, especially the ones with dementia. As families perceive their role of monitoring and controlling the residents' sexual activities, most of the time they try to protect the resident from potential harm, diminishing the risk of residents' sexual abuse (Spece et al., 2017).

As for couple's difficulties, some caregivers have concerns and difficulty in determining whether or not their spouse can consent to sexual activity. In the context of sexuality, participation in decision-making involves the negotiation of different and often, conflicting positions held by manager, family and colleagues (Vandrevala et al., 2017). Caregivers may feel forced to make all the choices which could affect them as a couple when there is a bad knowledge about the subject (Barczyk & Kredler, 2018).

According to Scultz (2016), in the early stages of the disease, caregivers generally struggle with the transition process, as they perceive their family members a person that it's ill and will need specific care. Caregivers carry the burden of a constant unexpected loss that changes marital relationships at the same time many of them are dealing with the increasing demands of their own aging. This process can generate anger, frustration and fear. For example, an elderly man who has a partial dependency on his spouse to accomplish certain tasks of basic needs can finds himself in unfamiliar circumstances. This can lead to modifications on the relationship and many years of role expectations changes, in a way that this person may miss his marriage partner but on the other side learn new roles and new skills to compensate the lost function (Ballard, 1995).

Most of the relationships face innumerous modifications over time, however dementia can brings has been referred increased physical and emotional dependency between partners however it can have impact on the relationship, by reinforce this connections and fortify solid feelings for each other (Alzheimer Scotland, 2011).

The biggest dilemma is between protecting the elderly with dementia whilst maintaining his sexual needs. In some relationships, the partner who is the caregiver often try to deal with the guilty while they still wish to have sexual relationships, however the actual condition of the person with dementia may turn the hole process of sexual expression, like being submissive and impassive (Alzheimer Scotland, 2011). In these conditions, partners may start to feel constant need to have intercourse with their partner is an exploitation of the relationship, which may compromise the human rights of the elderly with dementia (Bulla & Kaefer, 2003).

According to Santos & Faustino (2017), when we discuss gender difficulties differences it is substantiated that older women who are caregivers of their spouses don't usually obtain any help, while men maintain their role as husbands, however they search for more help and usually receive it for caring for the wife with dementia.

Patients most of the time have difficulty in recognizing the various cognitive and functional deficits, therefore, couples can disagree on the reasons for disruption or sexual dissatisfaction. The patient's view seems to be influenced by cognitive impairment, as past sexual activity can be erroneously reported as being in the present. (Dourado, Finamore, Barroso, Santos, & Laks, 2010) This may result in spouses reporting feelings of taking advantage of someone who no longer has reasoning and decision-making capacities (Hayes, Boylstein, & Zimmerman, 2009)

10. The perspective of healthcare professionals about sexuality in dementia

Sexuality as an intrinsic dimension to human life and is very present in the institutional environment, besides, professionals are regularly confronted with these aspects in their actions (Venturini, Beuter, & Backes, 2018). Although sexuality should be more recognized as a main aspect that accompanies admission into the institutional setting, health professionals do not always feel comfortable addressing this issue (Venturini et al., 2018).

In a study developed by Venturini et al. (2018), the healthcare professionals reported difficulties that may be related to many challenges made by these professionals in identifying and dealing with situations related to sexuality, especially those that are homoaffective. The

difficulties are associated with professional categories and pre-judgments related to the kind of expressions. Identifying embarrassments related to sexuality, incorporates personal and professional factors and consequently their attitudes.

There is signalized that each professional's principles and culture aspects reflect and determine the performance and the perspective of those who are involved directly to the theme. The presence of cognitive disabilities can result, has reference before, a change on the elderly behavior, that can reveals embarrassments and certain attitudes can be difficult to manage however natural in the universe of sexuality and in the institutional context (Venturini, 2017). Thus, recognizing the occurrence of sexuality in RCF's has repercussions outside the intersection of a basic human need but also on the organizational and structural aspects. It is perceived that health professionals do not yet have the habit during this kind of manifestations of questioning aspects related to the sexuality of the elderly, having an ignoring attitude that doesn't allows them to develop (Garrett, 2014).

Assuming the elderly growing population, manifested as a significant proportion of users of the health system, it's important that health professionals adopt a different posture and propose questions of the sexual life of these individuals, so that they can receive a better guidance to improve their work position and most importantly to provide a better quality of life to the elderly people with dementia, based on better understanding of their needs (Bastos et al., 2006).

Human sexuality and particularly sexuality in the elderly with this health condition requires more attention by healthcare professionals (Kalra et al., 2011). Because of the constant exigences of the pathology, care managers often find difficult to dedicate the necessary time and energy to the emotional needs of elderly with dementia and to talk about intimacy and sexuality (Lightbody, 1993). Despite the high number of changes occurring in the process of aging and dementia, healthcare professionals and family caregivers play a key role in providing openness and facing this subject, and most important contributing to the improvement of their quality of life (McAuliffe et al., 2007). Unfortunately, there is a lack of explicit legal guidance, which informs this professionals on how to respond to sexual and intimate expression in a way that both supports and protects nursing home residents and staff (Lindsay, 2010).

According to Vandrevala and collaborators (2017), older individuals are commonly viewed as asexual people, who lost their interest in sex and their capacity for sexual behavior, and nursing staff are not exceptions in this rationality, continuing to preserve this stereotypes, as they find it difficult or inappropriate to consent to the formation of sexual relationships for residents with dementia (Hajjar & Kamel, 2003), some even deliberate it is relatively unprofessional to enquire clients about love, adopting sarcasms as a form to maintain distance from the lived experiences of clients (Barusch, 2012). Consequently, this results in a lack of responses to the needs of the elderly, that are frequently ignored by those

caring for the elderly. In order to change this reality is important to discontinue communication difficulties and improve as possible the decision-making capacity of the elderly, making more realistic their desire and protect residents in order to maintain their dignity as much as they possibly can. As Tarzia and colleagues referred (2012 cit. in Nay, Garratt, & Fetherstonhaugh, 2016, p.338):

> *"Seeking to 'protect' individuals with dementia by not allowing them to express their sexual needs, thereby stifling their autonomy and personhood, is a far greater failure of duty of care."*

Dichotomic perspectives are verified in researches, while some indicates that staff view later life sexual expression as inappropriate behavior, as problems rather than as expressions of a need for love and intimacy, that should be discouraged in residential aged care homes (Kuhn, 2002) others support sexuality and intimacy in later life considering it as a human need (Tenenbaum, 2007). However, both of them should be carefully analyzed, because of the impact that they may cause.

Lack of geriatric sexual education among nursing home staff and family members often results mostly on a negative attitude toward sexual behaviors expressed by residents (Syme & Cohn, 2016). In a survey of a skilled nursing facility, conducted by Szasz (1983), it was found that one-quarter of residents were labeled, by staff, to have behavioral problems because of inappropriate sexual behaviors. These behaviors included using sexually explicit language, inappropriate sexual acts like exposing genitalia or inappropriately touching a staff member, and implied sexual behavior, such as reading pornographic material or making requests for unnecessary condom changes. However, some behaviors between staff and residents, such as hugging or kissing on the cheek, were identified as acceptable and healthy.

The majority of staff caring for the elderly, supports later life sexuality education and training for both caregivers and residents, because it is felt has a lacuna in the offered services (Benbow & Beeston, 2012; Chen et al., 2017; Dogan, Demir, Eker, & Karim, 2008; McAuliffe et al., 2007). Sexual education is frequently considered as a subject with lack of importance in aged-care organizations, and often reflects in limited training programs available(Di Napoli, Breland, & Allen, 2013). Taylor and Gosney (2011), study found that more training is needed for those who work with older people so that they can better understand sexuality in seniors and can develop the required skills to deal and discuss these issues sensitively. If these resources were implemented a major improvement would be made in staff attitudes and broadmindedness towards late life sexuality and the expression of sexuality by people with dementia (Jones & Moyle, 2016).

These processes would even possibly facilitate areas such as decision-making processes, specifically in deciding whether sexual interactions are allowed, what type of sexual behavior would be recognized, with who people should interact and if specialized

intervention would be necessary (Devesa et al., 2013). Healthcare providers would be more thoughtful, attentive and actualized, subject to periodic assessments in order to discuss their intervention procedures, allowing the best assistance to patients with dementia (Jeske, 2017).

The major objective of healthcare professionals is to promote well-being, comfort, self-care and identity, viewed as essential to combat against the pejorative society and restrictions of the patient's freedom, living in RCF's. By talking and caring about this subject, reality may lead to new reconfiguration of identity and, consequently, to a process of adaptation of their own identity. To combat taboos, professionals in this area should be sensitive to these matters and continuously help dementia patients to adapt to this reality the best way they can by providing distinction, quality care that aims to change paradigms, diminishing and enhancing the relationship of the user with the institution that welcomes them, in this last stage of their life (Lourenço, 2014).

It is important for a staff member who is helping a demented nursing home resident with actions of everyday, to completely explain their actions and to notify the resident in advance of what is predictable. In addition, delusion and hallucination, frequently come across in residents with dementia and may trigger inappropriate sexual behaviors. These experiences may also result in a demented resident making a false allegation of sexual abuse, and thus may cause a falsely accused staff member to be discharged (Haddad & Benbow, 1993).

As referred before, care staff displayed relatively inadequate knowledge of later life sexuality and the literature suggests that those who have higher qualifications were more likely to have better knowledge about the thematic (Higgins, 2010). However, this raises an import concern, given that the majority of staff in the long-term health-care industry are people with vocational training in aged care, though most of them are not sufficient qualify to response to resident expression of sexuality. Due to this lack of training and empathetic, healthcare technicians can in theory perceive certain behaviors as problematic and not as an expression of a basic human need for love and intimacy (Venturini, 2017).

Alzheimer's Australia (2010), highlights that guidance and strategies about the approach that should be adopted when there are issues of later life sexuality, education and training for care staff, there is also a development of a background that considers the privacy privileges, the cognitive capacity for consent, autonomy and preservation of identity.

However, when an elderly asks for help on dealing with questions about intimacy and sexual behaviors, home care providers should not hold a passive position, or show absolute disapproval, or even making fun of the behavior of the elderly, even if it is disinhibited or inappropriate sexual behavior and cause embarrassing moments. Professionals should react with patience and tenderness directing the person to a private place. It's always a promising

idea dislocate the elderly in order to modify the environment which will reduce more activation for this behavior (Mental Health First Aid Australia, 2015).

According to Garrett (2014), there are a few considerations that healthcare professionals should take into account, like talking openly to older people about their sexual needs, as long as professionals are ready to promote discussions and informed enough to express what is common and uncommon in the ageing process; it's important to have an active-listener attitude, as these will influence relations and regulate positive openness of the elderly; healthcare providers should also be aware and sensitive to this topic, especially because it helps improve interactions and allow intimate reflections; offers moments of doubts which should be stated lightly and in confidence.

As for the ethical and legal debates, especially in the case of residents with dementia, this thematic can cause significant concern among professionals, due to the difficulty of discriminating the agreement of the expressions. One solution that may be adopted is to develop informed, and policies centered on the residential function, which will provide guidelines to those involved in making these difficult decisions, that will have or search knowledge (Syme et al., 2017). Policy rules as also be considered according to the different degrees of decline, and according to the type of dementia, sexual behaviors as needs may differ. Among the issues raised, the ones that address impact on sexuality are the one's person is suffering from dementia, the charisma of the institution in deciding the occurrence or absence of coercion and whether these expressions reflect a continuo of authentic expressed by the resident over time (Venturini, 2017).

Demonstrations of affection amongst residents obligates a special attention from the staff and residents, especially when expressions of intimacy are legitimized as being part of a relationship Homosexual expressions are often pathologized, sinful, and socially dishonored with heteronormativity predominant, despite this also motivating to innumerable repressions. Upon the dilemmas encountered on a daily basis, it becomes necessary to consider a myriad of legal, ethical, and institutional requirements, in addition to the residents' needs (Venturini et al., 2018)

11. Barriers and guideline to the expression of sexuality and intimacy

According to caregivers that deal with elders with dementia, a number of barriers are blocking older people from expressing their sexuality, and many of these are influenced by the health professionals and services of care, they can therefore have an important role in implementing stratagems to help overcome these barriers (McAuliffe et al., 2007). However

when we mention barriers in nursing homes, we have to talk about a central of sexual expression, that includes lack of privacy, lack of an enthusiastic and able partner, mental illness, physical boundaries, attitudes of staff, attitudes of family members, adverse effects of medications, feelings of being unattractive, erectile dysfunction in men and dyspareunia in women (Hajjar & Kamel, 2003). In RCF's we can identify also barriers such as: Lack of staff education (McAuliffe et al., 2007) and a lack of assistance with medical or physical issues (Bauer et al., 2013).

When professionals seek to deal with these barriers as much as they can or manage sexual behavior of patients, both the person and the situation must be considered carefully. All decisions should be based on careful and rational reasoning, screening the needs of the individual as well as the surroundings. If a resident assumes a sexual act or need assistance in an immoral act, is an fundamentally grave matter, independent of the settings and personal culpability of the performer (Seng, 2017).

To safeguard older people to receive the professional care they deserve, the institutional context must reflect not only on the barriers but also validate that they are being directly addressed (McAuliffe et al., 2007). As Spece et al.(2017), affirm there are some guidelines that should be implemented to protect the residents rights of sexuality and intimacy. The policies includes issues related to: capability; taking consent through clear verbal or inscribed directives; requirement of assessments made by a professional in the area that uses a valid evaluation approach to determine the resident's competency; residents right to rescind permission regardless of their capability (intimacy expressions may end if the resident becomes incompetent of control); residents should be instructed about detailed instructions if they become inept (in order to notify a replacement decision-maker to care for his rights); if the resident lacks the capacity to refer orally or physically or if communicates a wish to cancel consent, the facility shall ensure the resident's privacy and rights; if the resident might be suffering harm, a substitute or qualified healthcare provider can request the spouse/partner to validate the resident has not verbally or physically refused intimacy; if there is confirmation, a qualified employee should bring the matter to court only if it's necessary to determine the resident's best interests to cease intimacy. Best benefits should be determined by considering the resident's past representations and personality knowledge, considering critical and practical interests, their physical and emotional well- being, as for the institution they should determine best interests using the same criteria.

In order to develop the best care and an open environment for the elderly with dementia we should consider: encourage residents to develop friendships and cautious interactions; promote privacy and opportunities for residents to spend time; encourage elders to feel good with themselves and preserve their sexual identity and promote safe secured for safe sex (Bamford & Serra, 2011).

12. Role of decision-making in sexuality, intimacy and sexual behavior in dementia

A prevalent question that it' been made is: who should be responsible for making the decisions when the subject is sexuality and intimacy in those who have limitations? Despite the possible choices that are presented in literature, in dementia care the consent it's directly related with the elderly capacity. When considering the role of decision-making, it is always necessary to adopt an idiosyncratic position and to analyze the degree of the cognitive impairment that the patient displays and the degree of disease progression of the patient, in order to avoid complications that can be unsafe for the patient, such as abuse (e.g. physical and verbal aggression or sexually inappropriate behavior), that it's not the most common thing to happen however it can happen if people don't notify (Alzheimer Europe, 2014).

A conjoint of privacy rights have to be considered, especially those who are related to the loss of these privileges, misunderstanding over consent issues and concerns about sexual abuse. There are several factors that may negatively add the difficulty of dealing with sexuality in home care facilities: (i) sexual orientation, who might face discrimination when institutionalized; (ii) the right of independency in accepting a relationship among people with dementia; and (iii) policy and stratagems for contemporary care have not yet been completely established (Chen et al., 2017).

According to Di Napoli and collegues (2013), one of the possible ways to deal with the incomes of managing residents who express sexual behavior, and based on the actions of healthcare providers is: to use direct intercession, call the family caregivers, or request a staff meeting in the institution. Therefore, nursing home staff, believed that residents: (a) should have a regular neuropsychological assessment to evaluate their current cognitive function; (b) should be aware of who is initiating sexual contact; (c) behaviors should be consistent with the beliefs that are persistently exposed; (d) should be able to determine the level of sexual intimacy they would be comfortable with; (e) must realize that the relationship may be time-limited; (f) need to think about how they would deal if the relationship ends; and (g) should not engage in sexual activity if they believe that the other person is their spouse even if it's not.

Although people with dementia recognize their need of support, they retain a desire to remain central in the decision-making process (Dillon et al., 2013). The study presented by Mitoku and Shimanouchi (2014), reveals that approximately one-third of older adults with dementia are capable of making decisions when they need physical assistance and care and when they are in an initial and moderated phase of the illness. However, the reality is that the majority of this patients will progressively decline over time, and it is essential to ensure that their preferences are reflected in care at the first place. Furthermore, around 80% of the

older adults with dementia were capable of communicating in the study developed by this author. The findings highlight the effort that is need to be made to become closer to people with dementia and to listen to their perspectives in person-centered care, in order to provide an heterogenous quality of life (Mitoku & Shimanouchi, 2014).

Findings also revealed the difficulties in decision making principally if patients are very incapacitated. Having a flexible method can simplify the expansion of policies and measures which capture the elderly's voice and protect them against harm and support safe sexual expression for individuals living in nursing homes (Syme et al., 2017).

Not being able to decide may result in many feelings, such as frustration, anger and fear, especially if the person finds it hard to verbalize their needs. For this reason, there is a great divergence in the opinions expressed by both the healthcare professionals and the family caregivers, on who should decide what is best for the elderly patient with dementia. The issue of who should take an active role in decision-making when addressing this subject, has been debated for some time and it depends on many factors as referred before (Ballard, 1995)

When increased levels of disability occur, most of the friendships that existed since then may start to vanish, and the number of social interactions became less every day, because of the diminished of competences of socialization (Sherman, de Vries, & Lansford, 2000). However, according to Seng (2017), the human desire for social contact, intimacy, undergoes despite the cognitive decline of dementia. As Rowntree & Zufferey´s (2015) affirms, there is no question that people's sexual desire and activity can continue well into later life. Although some changes that occur (inherent to the aging process) may affect the sexual function, no one should disintegrate the natural instincts of the elderly, and as possible they must be preserved as developed in the study of Kalra and colleagues (2011). That's why a lot of considerations must be considered when we direct the power of decision to a person rather than the patient.

Although older people with dementia feel the need to express their sexuality, many can manifest inappropriate sexual behaviors which in a residential care environment can potentially be problematic, especially if it causes problems with other patients. It then becomes necessary to manage this sexual behavior, by making decisions based on ethical and moral order, especially when new emotional relationships develop (Heath, 2012). For the professionals who don't feel prepared to deal with these situations, it is better to search someone experienced on dealing with these aspects. However, if there is no one who has this capacity, the healthcare technician must take into account what benefits the patient, and whenever they can't decide in his place, what is best at the same time as avoiding any risk of victimization (Devesa et al., 2013; D. Higgins, 2010).

The majority of the population supports sexual expression of individuals with dementia that occurs in a nursing home setting. Their approach on the decision-making process is considered similar to the method they may adopt with elders with limited capacity. In order to support intimacy and safety they adopt models on practices for sexual consent assessment (Wilkins, 2015). Considering this, facility administrators should be constantly exploring indicators for healthcare providers who deal with elders, such as a loving, caring rapport, explaining the importance of intimacy needs, and the impact of ageism along with intellectual capacity, risk and safety (Syme et al., 2017).

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Annex 2: Evidentiary of Submission

Sexuality and Disability

Sexuality, Intimacy and Sexual Behavior of elderly people with Dementia in Residential Care: The Perspective of Healthcare Professionals and Family Caregivers in Portugal

--Manuscript Draft--

Manuscript Number:	SEDI-D-18-00041
Full Title:	Sexuality, Intimacy and Sexual Behavior of elderly people with Dementia in Residential Care: The Perspective of Healthcare Professionals and Family Caregivers in Portugal
Article Type:	Original Article
Keywords:	aging; dementia; sexuality, intimacy, sexual behavior; healthcare professionals; families; institutionalization.
Corresponding Author:	Henrique Pereira Universidade da Beira Interior Covilhã, PORTUGAL
Corresponding Author Secondary Information:	
Corresponding Author's Institution:	Universidade da Beira Interior
Corresponding Author's Secondary Institution:	
First Author:	Sarah Pinho
First Author Secondary Information:	
Order of Authors:	Sarah Pinho
	Henrique Pereira
Order of Authors Secondary Information:	
Funding Information:	
Abstract:	Abstract Aims and Objectives: The purpose of this study is twofold: (1) to explore and understand the perspectives of healthcare professionals and family caregivers towards the sexuality, intimacy and sexual behavior in the aged with dementia; (2) explore how they respond and manage the sexual needs of residents with dementia in a residential care context and the roles that they may adopt. Background: The growing phenomena of the aging population and the projected increase in dementia cases is and will continue to have an impact on society, affecting not only the elderly individual diagnosed with dementia, but also their caregivers and loved ones. At present, little information is available on the perceptions of these caregivers in this particular area and how they can help these vulnerable individuals maintain a good quality of life, despite facing these particular physical and mental challenges. Current research shows dementia may lead to a variety of sexual problems/barriers. The dementia sufferer may lose interest in sexual activities, or alternatively, may express unsuitable sexual behavior, causing frustration to their partner and themselves, which potentially affects their quality of life. Design: The methodology used is based on a mixed method approach. Using both qualitative and quantitative research tools. Methods: The primary data collection methods used were semi-structured interviews and an online closed ended questionnaire. The research was conducted in Portugal, using two separate studies. In Study 1, face-to-face in-depth interviews were conducted with a total of 32 participants. In Study 2, the participants consisted of 69 healthcare professionals and 40 family caregivers, responding exclusively to the online questionnaire. Data was analyzed using thematic analysis to help identify repeated patterns of meaning in the dataset. Results: In the thematically analyzed data, three main results were identified,

	namely: the existence of a large number of people who identify this issue as something difficult to be approached and talked about (taboo); the lack of existing information / training, especially in the healthcare technicians of dementia care units and the lack of guidelines in the institutions for the most adequate and uniform performance of institutions. **Keywords: aging, dementia, sexuality, intimacy, sexual behavior, healthcare professionals, family caregivers, residential care.**

Annex 3: Consent Declaration

Declaração de Consentimento

Data: ___/___/___

Eu, Sarah Angélica Almeida Simões Pinho, aluna do Mestrado em Psicologia Clínica e da Saúde da Universidade da Beira Interior (UBI) da Covilhã, pretendo aplicar-lhe um inquérito por questionário e um inquérito por entrevista para a concretização da minha dissertação com a temática – "Sexualidade, Intimidade e comportamentos sexuais na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional."

Neste sentido solicito o seu consentimento para fazer parte deste trabalho de investigação. Mais informo que os dados recolhidos serão tratados e divulgados com caráter de anonimato. O inquérito por entrevista será em formato áudio com a possibilidade de registo de notas.

Eu, Sarah Angélica Almeida Simões Pinho, portadora do cartão de cidadão nº 14074319, declaro que me comprometo ao devido sigilo perante os dados recolhidos através dos inquéritos por entrevista e questionário junto da instituição _____. Tal como me comprometo a eliminar as gravações se assim o entenderem.

A Aluna

_____

(Sarah Pinho)

Declaro participar de livre vontade no trabalho de investigação sobre a temática "Sexualidade, Intimidade e comportamentos sexuais na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional.". Mais declaro ter recebido a informação prévia e esclarecedora acerca dos procedimentos a serem assumidos pela estudante na aplicação dos inquéritos por entrevista e por questionário.

Solicito que as gravações _____ eliminadas no fim do trabalho.

Annex 4: Online Questionnaire Survey

Sexualidade, Intimidade e Comportamento Sexual na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional

A presente investigação, inserida no âmbito da Dissertação do Mestrado de Psicologia Clínica e da Saúde da Universidade da Beira Interior (UBI) da Covilhã, tem como objetivo recolher informação acerca da Sexualidade, Intimidade e Comportamentos Sexuais na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional.

Este inquérito está dirigido apenas a pessoas com 18 ou mais anos de idade.

Desde já muito obrigado pela sua colaboração!

...
Universidade da Beira Interior - Portugal
Departamento de Psicologia e Educação
E-mail:

Ao participar, está ciente dos objetivos desta investigação e aceita disponibilizar as suas respostas unicamente para tratamento estatístico. Garantimos que os seus dados apenas serão utilizados para este fim, de modo a contribuir para a publicação de artigos científicos, dissertações ou trabalhos académicos e, desde modo, contribuir ativamente no avanço do conhecimento científico nesta área. Ao participar, estará a adquirir mais conhecimentos sobre si próprio/a, acrescentando riqueza à sua experiência pessoal, não havendo qualquer risco para a sua integridade física ou emocional.

A sua participação é extremamente importante para a nossa investigação.

*Obrigatório

1. **Declaração de consentimento informado** *
   "Declaro que aceito participar nesta investigação. Confirmo fazê-lo livre de quaisquer pressões ou receios. Assumo, assim, também, que me foram dadas as informações suficientes e os esclarecimentos necessários para a minha decisão." Por favor, confirme:
   Marcar apenas uma oval.
   - ◯ Sim, aceito.
   - ◯ Não, não aceito.

2. **Este questionário diz respeito à sua opinião acerca da pessoa com demência. Indique a natureza da sua relação com o mesmo.** *
   Marcar apenas uma oval.
   - ◯ Técnico (Enfermeiro(a);Psicólogo(a); Animador(a); Auxiliar; Assistente Social...)
   - ◯ Cuidador e/ou Familiar (Esposa; Marido; Filha(o); Neta(o); Sobrinha(o); Genro; Nora...)

3. **Natureza da instituição na qual a pessoa com demência se insere:** *
   Marcar apenas uma oval.
   - ◯ Pessoa colectiva de direito privado e de utilidade pública administrativa
   - ◯ Associação de Solidariedade Social
   - ◯ Fundação de Solidariedade Social
   - ◯ Santa Casa da Misericórdia
   - ◯ Privada
   - ◯ Pública
   - ◯ Outro: _____

Para continuar o inquérito seleccione "Seguinte"

Sexualidade, Intimidade e Comportamento Sexual na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional

Parte 1 - Dados Sócio-demográficos

Primeiro, gostaríamos de saber algumas informações sobre si...

4. **Que idade tem?** *

5. **O seu género?** *
Marcar apenas uma oval.

- ◯ Feminino
- ◯ Masculino
- ◯ Outro: _____

6. **O seu estado marital atual?** *
(indique o que melhor descreve o seu estado atual)
Marcar apenas uma oval.

- ◯ Casado(a)
- ◯ Solteiro(a)
- ◯ Divorciado(a) ou Separado(a)
- ◯ Viúvo(a)
- ◯ Unido(a) de Facto
- ◯ Tenho um namoro/compromisso afetivo
- ◯ Outro: _____

7. **Tem filhos?** *
Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

8. **Se sim, quantos?**

9. **Qual é o seu local de residência?** *

Marcar apenas uma oval.

- ◯ Uma pequena cidade
- ◯ Uma grande cidade
- ◯ Um pequeno meio rural
- ◯ Um grande meio rural

10. **Qual é o seu nível de escolaridade?** *

Marcar apenas uma oval.

- ◯ Até 9 anos de escolaridade
- ◯ Até 12 anos de escolaridade
- ◯ Formação Universitária (Licenciatura/Bacharelato)
- ◯ Formação Universitária (Mestrado/ Doutoramento)
- ◯ Outro: _____

11. **Se é casado(a), quais as habilitações literárias do seu cônjuge?**

Marcar apenas uma oval.

- ◯ Até 9 anos de escolaridade
- ◯ Até 12 anos de escolaridade
- ◯ Formação Universitária (Licenciatura/Bacharelato)
- ◯ Formação Universitária (Mestrado/ Doutoramento)
- ◯ Outro: _____

---

12. **Qual é o seu estatuto socioeconómico?** *

Marcar apenas uma oval.

- ◯ Baixo
- ◯ Baixo-médio
- ◯ Médio
- ◯ Médio-alto
- ◯ Alto

13. **Qual o seu estatuto profissional?** *

Marcar apenas uma oval.

- ◯ Empregado(a) a tempo inteiro
- ◯ Empregado(a) a tempo parcial
- ◯ Desempregado(a)
- ◯ Reforma Antecipada
- ◯ Reforma Não Antecipada
- ◯ Pensão de Invalidez
- ◯ Doméstico(a)
- ◯ Estudante
- ◯ Trabalhador(a)- Estudante

14. **Como se identifica relativamente à sua orientação sexual?** *

Marcar apenas uma oval.

- ◯ Heterossexual
- ◯ Bissexual
- ◯ Homossexual (gay ou lésbica)
- ◯ Assexual

Se seleccionou "Cuidador" na Secção 1 do questionário continue a responder, caso contrário avance para a próxima secção

15. **Qual o grau de parentesco que tem com o doente?**

Marcar apenas uma oval.

- ◯ Sou filho(a)
- ◯ Sou marido/esposa
- ◯ Sou sobrinha(o)
- ◯ Sou irmã(o)
- ◯ Sou genro/nora
- ◯ Sou companheiro/ companheira
- ◯ Sou neto/neta
- ◯ Outro: _____

16. **Há quanto tempo já cuidava do doente antes de este entrar na instituição?**

_____

_____

Agora dê-nos alguma informação sobre uma pessoa com demência que acompanha frequentemente

17. **Que idade tem?** *

_____

18. **O seu género?** *

Marcar apenas uma oval.

- ◯ Feminino
- ◯ Masculino
- ◯ Outro: _____

19. **O seu estado marital atual?** *
(indique o que melhor descreve o seu estado atual)
Marcar apenas uma oval.

- ◯ Casado(a)
- ◯ Solteiro(a)
- ◯ Divorciado(a) ou Separado(a)
- ◯ Viúvo(a)
- ◯ Unido(a) de Facto
- ◯ Tenho um namoro/compromisso afetivo
- ◯ Outro: _____

20. **Qual é o seu nível de escolaridade?** *
Marcar apenas uma oval.

- ◯ Até 9 anos de escolaridade
- ◯ Até 12 anos de escolaridade
- ◯ Formação Universitária (Licenciatura/Bacharelato)
- ◯ Formação Universitária (Mestrado/ Doutoramento)
- ◯ Outro: _____

21. **Qual é o seu estatuto socioeconómico?** *
Marcar apenas uma oval.

- ◯ Baixo
- ◯ Baixo-médio
- ◯ Médio
- ◯ Médio-alto
- ◯ Alto

22. **Qual o tipo de demência desta pessoa? (anote todos os que se aplicam)** *
Marque todas que se aplicam.

- ☐ Doença de Huntington
- ☐ Demência com Corpos de Lewy
- ☐ Doença de Alzheimer
- ☐ Demência Parkinson
- ☐ Doença de Pick
- ☐ Demência Vascular
- ☐ Demência Fronto-Temporal
- ☐ Demência na doença de Creutzfeldt- Jakob
- ☐ Demência na doença pelo vírus da imunodeficiência humana (HIV)
- ☐ Outro: _____

23. **Há quanto tempo está o paciente institucionalizado?** *
Marcar apenas uma oval.

- ◯ Menos de 1 ano
- ◯ Entre 1 a 2 anos
- ◯ Entre 2 a 3 anos
- ◯ Entre 3 a 5 anos
- ◯ Mais de 5 anos

24. **Há quanto tempo foi diagnosticado com a doença?** *

_____

25. **O utente está a tomar medicação?** *
Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

26. **Se sim, qual?**

_____

27. **Indique-nos as capacidades da pessoa em relação às atividades de vida diária:** *
Marcar apenas uma oval por linha.

	Sem ajuda	Com alguma ajuda	É incapaz de o fazer sozinho
É capaz de comer...	◯	◯	◯
Pode vestir-se e despir-se sozinho/a	◯	◯	◯
Pode cuidar da sua aparência, por exemplo, pentear-se e (para homens) barbear-se...	◯	◯	◯
Pode andar...	◯	◯	◯
Pode levantar-se e deitar-se na cama...	◯	◯	◯
Pode tomar banho ou duche...	◯	◯	◯
É capaz de tomar os seus medicamentos...	◯	◯	◯

Sexualidade, Intimidade e comportamentos sexuais na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional.

Analise os itens abaixo e anote se concorda fortemente, concorda, discorda, discorda fortemente, com cada uma das seguintes questões.
Sugerimos que responda a estas questões individualmente.
Lembre-se que não existem respostas certas ou erradas.

28. *

Marcar apenas uma oval por linha.

	Concordo fortemente	Concordo	Discordo	Discordo Fortemente
A expressão da sexualidade é importante para os idosos.				
Existem ligações positivas entre a saúde, o bem-estar e a expressão sexual nas pessoas idosas.				
A maioria das pessoas que vão envelhecendo tornam-se menos interessadas em sexo ou na expressão sexual.				
Os utentes dos lares/instituições deveriam poder expressar as suas necessidades sexuais.				
Os residentes com demência, comparados com residentes que têm capacidade cognitiva plena, não deveriam ser encorajados a terem relações sexuais.				
No que me diz respeito, os lares deveriam desempenhar um papel ativo, permitindo a expressão da sexualidade dos seus residentes.				
Acho que o meu dever, como técnico/a cuidador/a, envolve mais o cuidar dos utentes do que encorajar ou facilitar as suas necessidades e desejos sexuais.				
Acho que o Estado deveria produzir legislação que zelasse pelo "melhor interesse" na tomada de decisão em relação à expressão sexual dos utentes com demência.				
Valorizo a expressão sexual em pessoas com demência, mas não tenho tempo suficiente na minha rotina diária para responder a necessidades concretas que possam surgir.				
Para mim, a expressão sexual em pessoas com demência é importante, mas não tenho confiança ou apoio suficiente para responder a situações de natureza sexual, quando surjam.				
Vejo como importante a expressão sexual em pessoas com demência, mas sinto que contradiz ou entra em conflito com a minha própria crença ou normas sociais, culturais e religiosas ou valores.				
Vejo como importante a expressão sexual em pessoas com demência, mas preocupo-me com a resposta dos/as parceiros/as ou familiares dos utentes.				

29. **Deixe um comentário**

E é tudo! Muito obrigado pela sua colaboração

Para enviar as suas respostas, carregue no botão "Enviar"

Annex 5: Semi-structured interview for health care providers

Guião de Entrevista- **Técnico**

Boa tarde, o meu nome é Sarah Pinho, encontro-me neste momento a fazer um estudo no âmbito da Dissertação do Mestrado de Psicologia Clínica e da Saúde UBI na Covilhã, e pretendo recolher informação acerca da temática: "Sexualidade, Intimidade e Comportamentos sexuais na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional."

Desde já agradeço a sua contribuição

Lembre-se que este questionário deve ter sempre por base um utente com diagnóstico de demência que acompanha frequentemente e que de certa forma você considere relevante para o estudo:

1. Que tipo de função é que exerce na instituição, mais concretamente que tipo de ligação tem com os idosos?
2. Que tipo de demência é que o utente apresenta e quais as necessidades especiais (Ex: medicação a tomar, nível de autonomia do utente, atendimento psicológico/psiquiátrico) que este requer?
3. Qual a severidade em termos de desempenho cognitivo do utente com demência? Há quanto tempo é que o utente foi submetido a um rastreio cognitivo/ avaliação cognitiva?
4. Considera os idosos com demência capazes de decidir que comportamentos sexuais adotar num relacionamento? Desenvolva.
5. Que relações é que paciente estabelece com os outros utentes (ex. se é agressivo com os outros; se é amistoso, se cria conflitos facilmente)?
6. Considera que o comportamento do utente mudou com o diagnóstico da demência?
7. Tem conhecimento de algum tipo de relacionamento afetivo por parte do idoso com demência?
8. O que pensa acerca da sexualidade nos idosos?
9. Se considerarmos a intimidade como algo ligado aos sentimentos de afeto entre parceiros num relacionamento, pensa que esta deveria de estar presente em pacientes com demência? Porquê?

10. Considera os comportamentos sexuais dos idosos inapropriados (nomeadamente exibição dos órgãos genitais em público, atitudes provocatórias) comuns na demência? Em que medida?

11. Tendo em conta o possível sintoma de comportamento sexual inapropriado de um idoso com demência o que sentiu? A quem recorreu para o ajudar? Desenvolva. (envergonhada, chateada, atrapalhada, insegura)

12. Sente-se capaz de, face a uma situação de expressão sexual, acompanhar os casos de idosos com demência respondendo às suas necessidades?

13. Considera que o afeto e a intimidade contribuem de forma global para o bem-estar dos residentes idosos com demência?

14. De que maneira é que as suas atitudes/valores pessoais acerca da sexualidade em geral e da sexualidade na pessoa com demência em particular interferem na sua visão acerca deste assunto?

15. Acha que as pessoas com diagnóstico de demência têm direito sexual/intimidade? Se sim, como? Acha que devem haver espaços específicos reservados para esse efeito na instituição?

16. Que barreiras encontra para lidar com uma situação deste tipo?

17. Sente que a instituição onde trabalha está preparada para organizar condições de vida que são compatíveis com o desenvolvimento de relações/necessidades sexuais de idosos com demências?

18. Comente a frase “Atividade sexual em estabelecimentos de cuidado continuado vai contra as regras da instituição”.

19. Já algum idoso lhe confidenciou ter uma vida sexual ativa? O que sentiu? Como lidou com a situação?

20. Tem mais alguma coisa a dizer sobre o assunto? Gostava de adicionar mais alguma informação?

Annex 6: Semi-structured interview for family caregivers

Guião de Entrevista_ **Cuidador/Familiar**

Boa tarde, o meu nome é Sarah Pinho, encontro-me neste momento a fazer um estudo no âmbito da Dissertação do Mestrado de Psicologia Clínica e da Saúde da (UBI) na Covilhã, e pretendo recolher informação acerca da temática: "Sexualidade, Intimidade e Comportamentos sexuais na demência/velhice: a visão dos técnicos e cuidadores em contexto institucional."

Lembre-se que este questionário deve ter sempre por base um utente com diagnóstico de demência que acompanha frequentemente e que de certa forma você considere relevante para o estudo:

1. Qual o tipo de relação que tem com o utente com demência? Próxima, afastada?
2. Qual é o seu grau de parentesco com o utente?
3. É o único cuidador da pessoa com demência? Se não, quem mais? Que cuidados especiais sente que este deve ter (nomeadamente medicação que este tenha que tomar)?
4. Com que frequência visita o utente institucionalizado?
5. Porque motivo decidiram institucionalizar o familiar?
6. O que pensa acerca da sexualidade nos idosos?
7. Há quanto tempo a pessoa sofre com a doença? Que impacto é que este diagnóstico tem sobre o utente e a família e ao nível da sexualidade e intimidade do utente?
8. Como reagiria se o utente com demência encontrasse um parceiro na instituição?
9. Considera os comportamentos sexuais inapropriados (que não respeitam as convenções sociais) são comuns na demência? Como se sentiria com um possível acontecimento destes? (envergonhada, chateada, atrapalhada, insegura)

10. Como cuidador como se sente quando ocorre tipo de comportamento por parte do seu familiar? Considera que psicoeducação seria necessário nestes casos?

11. Quem acha que deveria de tomar as decisões quando é colocado em causa o comportamento sexual do idoso com demência? Desenvolva.

12. Como familiar sente que deveria ter um papel ativo na tomada de decisão dos comportamentos sexuais do utente? Porquê?

13. Sente necessidade de receber apoio/conselhos para lidar com algumas dúvidas que poderá ter acerca desta temática? Desenvolva.

14. No caso da esposa/companheira… como é que perceciona a forma como a demência influenciou no seu casamento, na sua relação com o utente e consequentemente na intimidade que tem com o seu parceiro?

15. Como encara o futuro com a demência em geral e comportamentos sexuais e intimidade em específico?

16. Tem alguma coisa para acrescentar? O quê?

Annex 7: Questions used for the quantitative research.

Test yourself – a quick quiz

Look at the questions below and note down if you ***agree strongly***, ***agree***, ***disagree***, ***disagree strongly***, ***do not know*** or have ***no opinion***, on the following questions.

We suggest you respond to these questions individually and then open up and discuss some of the answers in a group environment. Remember there are no right or wrong answers.

1. Do you think the expression of sexuality is important for older people?

   ☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

2. Do you believe there are positive links between health, wellbeing and sexual expression for older people?

   ☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

3. Would you agree with the statement that most people as they age become less interested in sex or sexual expression?

   ☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

4. Do you think residents should be allowed to express their sexual needs in care homes?

   ☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

5. Do you feel residents with dementia, compared to a resident who has full cognitive capacity, should not be encouraged or facilitated to have a sexual relationship?

   ☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

6. As far as you are concerned, should care homes play a role in allowing residents to express their sexuality?

   ☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

7. Do you feel your role as a care worker is more about looking after the residents than encouraging or facilitating their sexual needs or desires?

☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

8. Do you feel confident in applying the Mental Capacity Act and 'best-interest' decision-making as it relates to sexual expression for residents?

☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

9. Do you see sexual expression as important for people with dementia, but lack the time in your day-to-day working routine to respond?

☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

10. Do you see sexual expression as important for people with dementia, but lack the confidence or support in responding to situations of a sexual nature when they arise?

☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

11. Do you see sexual expression as important for people with dementia, but feel it contradicts or conflicts with your own social, cultural or religious beliefs, values or norms?

☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

12. Do you see sexual expression as important for people with dementia, but are worried about the response of the partners or relatives of residents?

☐ st.agree ☐ agree ☐ disagree ☐ st.disagree ☐ do not know ☐ no opinion

It is hoped that by exploring your responses as individuals and as a group you will learn more about yourself as care professionals and be able to identify areas in which you may need more support or training.