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TECHNICAL INFORMATION

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Ageing, Care and Quality of Life

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FROM PERSPECTIVES OF THE ELDERLY: QUALITY OF CARE IN GERMANY

Dorian R. Woods

ABSTRACT

This article reviews state-of-the-art findings on care and quality from published research from 2003-2014 in Germany, specifically from the perspective of the elderly. It is based on a larger project on care and quality in Germany that was funded by the Hans Böckler Foundation. The study provides a much needed overview of current issues on quality and care in light of increased pressure to address care and changes in German social policy. Although quality also encompasses conditions for professional care work and informal carers, this article focuses on the elderly as recipients of care, their perspectives and the ways in which they are involved in their care. Research on care quality from the perspective of the elderly is highlighted in the following themes: 1) the rights of the elderly to quality care 2) elderly perception of satisfaction and quality of outcomes of care, 3) documentation of care as quality control and time, 4) active aging and 5) equality of access. Results show that long-term care rights are more clearly defined and expanded, but enforcement problems are present. Satisfaction with care is traced to good communication with carers, but time for care is scarce. Active aging has become a central focus of care and more research on equal access is needed. The article outlines strengths and weaknesses in German quality care provision as well as learning effects for other countries.

Keywords: Care, Quality, Elderly, Germany

JEL Classification: I310

1. INTRODUCTION

Germany has one of the fastest aging populations in Europe and because of pressing demographic pressures in Germany, the country has moved to innovative measures around care policy. A major care policy measure has come on the heels of increasingly high percentages of the elderly who had fallen into social assistance receipt because they had exhausted their savings for care. The state established a universal long-term care insurance in 1995, one of the first policies of its kind to battle growing poverty as a result of long-term care costs and high care expenditures in social assistance (*Pflege-Versicherungsgesetz*). Insurance measures to cover social risks of elderly and dependent care caused ripple effects in reforming further areas of care policy, such as organized information centers that would help manage different care needs (care management) as well as available services for information dissemination in local areas of need (*Pflegestützpunkte*: For more on *Pflegestützpunkte*, see Höhmann, 2009; Röber/Hämel, 2011). Also, Germany has been in the process of re-assessing education and training for professional care and has considered policy instruments that might help encourage more people to go into the caring profession. Adjustments and change have been continuous and

steady in Germany's long-term care policies, and its regulations in measuring quality have been increasingly updated in recent years.

With these social policy changes in long-term care, research on quality of care has expanded. In the midst of changes and political discussions of policy development, there has been an explosion of research on how to improve quality of long-term care and how to regulate it. However, up until this point there has not been a compilation or an overview of the research on quality. In particular, little is understood how the perspective of the elderly is taken into account within quality evaluations and research – and not much is known about the elderly perspective. Therefore, this article provides an overview of research with a special focus on research from the perspective of the elderly. The paper addresses the following research questions:

- How does German research handle quality of care from the perspective of the elderly?
- How does the literature provide new insight to German welfare state issues around long-term care and class, gender and race?
- How are German research issues relevant for other countries?

Social policy and welfare state research categorizes Germany as a corporatist/conservative welfare state (Esping-Andersen, 1990; Schmid, 2002). This means that class, gender and ethnic social status is preserved in many social policy structures, and policy is steered through social pacts of government, business, unions and large non-profit organizations. German social and government structures are said to preserve the status quo. Specifically, this means that social risk is secured most often through insurance-based social policy. When social policy is insurance-based, individuals pay contributions to a social fund and receive payments based on contributions. Such a system usually upholds social status because those with enough financial means will be able to pay into the system while others with lower-paying, precarious or marginal employment will have paid fewer contributions. These individuals who pay less, receive less pay-outs, for example, in retirement. Social safety nets in conservative welfare states, however, guarantee basic needs when social insurance systems do not adequately cover risks for those less insured. In this way, costs for long-term care for under-privileged had been covered by social assistance for the elderly until 1995 when it became clear that large numbers of people were falling into social assistance because of care costs. In 1995 the long-term care insurance was introduced universally, but it was decided that insurance payments for long-term care would intentionally not cover all the costs of long-term care. Pay-outs are based on levels of a recipient's infirmity but not on the costs of care itself. This means that, true to conservative welfare states, social status is upheld when those in higher social classes can better afford out-of-pocket co-payments for long-term care. Co-payments are still high enough (about 1380 Euro a month for the lowest level of care in 2011) that people with low income and low savings still are in danger of falling into poverty (Pflegestatistik, 2013).

The impact of social status is crucial when examining quality of long-term care from the perspective of the elderly in Germany, and just as important are analyzing how traditional values of gender roles in social policy impacts quality of care. In terms of gender, conservative social policy in western German federal states promote a male-breadwinner family constellation, and many care-taking responsibilities for children and the elderly are performed by stay-at-home or part-time employed mothers. Institutional policies, such as little or only part-time child care services, half-day schooling (as opposed to full-day schooling with lunch), and policies which discourage maternal paid employment are said to be forms of familialization. Here, families are largely burdened by the social costs and risks associated with care responsibilities (Woods, 2006, 2012, 2014). Because the long-term care insurance still relies heavily on private care and co-payments, authors such as Leitner and Auth call it furthering familialization tendencies in Germany (Leitner, 2014, Auth, 2012).

Care is traditionally a private responsibility of the family in Germany and over two thirds of the elderly and dependent care recipients are cared for exclusively at home. Women tend to perform on average more care than men (Pflegestatistik, 2013). This might lead to fewer resources for women's own care as they get older because they have weak ties to paid employment. Private co-payments further encourage at home care when co-payments for institutional care are high. This said, however, little is known about care quality for recipients according to their gender or how gender roles impact quality of care for individuals.

The article examines the perspective of the elderly to better understand social policies and their impact on servicing different groups of the elderly. The following article provides an overview of current research on care quality in Germany with special emphasis on the elderly perspective. The first section explains the context of this article within a larger study on care and quality. This section also outlines the policy context of Germany around long-term care and the political developments in measuring quality of care. The next section analyses the research reports on quality and the ways in which elderly are taken into account in measuring and assessing the quality of elderly care. Five themes are identified and analyzed in the reports: 1) the rights of the elderly to quality care 2) elderly involvement in determining goals and outcomes of care and the elderly perception of satisfaction, 3) documentation of care as quality control and the role of time, 4) active aging and 5) equality in access to quality care. The conclusion summarizes strengths and weaknesses in German quality of care provision according to the research. It also considers learning effects for other countries. Finally, the article reflects on future developments that examine the perspective of the elderly as an integral part of quality measurement.

2. BACKGROUND TO THE STUDY

2.1 Methods and Data

This article is based on a literature review of research on care and quality that covers the perspectives of a) the elderly, b) relatives caring for the elderly, and c) employees in the elderly care sector. The main study, funded by the Hans Böckler Foundation, evaluates 171 articles regarding research on care and quality in Germany. Most of the studies are in the German language but some international studies are in English. Dates of the articles are from 2003–2014, although most studies are from 2010–2014. The rationale for this timeframe is coverage and solid representation of current German research on quality of care. The early 2000s mark a time where political discussions and legislation on quality were gaining ground, such as the beginning of a government commission on the care dependents' rights to care and quality of care as well as the initial passage of a law on care quality and a new nursing law. Some background articles are referenced from earlier dates, mostly for explanation of specific topics or developments on care and/or gender issues in Germany. The articles are gathered from academic journals as well as from journals oriented toward the practitioner. Searches for studies covered university, applied science universities, and research centers as well as homepages of interest groups for the elderly and the public and private umbrella health insurance homepages. Furthermore, the search engine of the German Center for Gerontology "GeroLit" was used with key words of *Qualität* ("quality") and *Pflege* ("care"). The larger study is meant to be a representative study on the issues of care quality, so special care is given to provide a sampling of studies from different academic institutions, funding foundations, journals, and research centers. Some federal and state ministry reports and insurance-funded research are also reviewed. Research on care was performed in settings at hospitals, elderly care institutions, ambulatory care services, and

care performed by relatives, neighbors, or friends in the home. Research on care in private homes was less frequent.

My original report outlines research on quality and care from three perspectives but the advantage of highlighting the literature from the perspective of the elderly independently, as I do in this article, is to underscore how research focuses on the elderly themselves as gauges of quality. The outcomes of their care are the very measure of quality. On the other hand, goals and expectations of the individuals are essential to understand in evaluating outcomes of care and it is difficult to understand in how far the elderly's perspectives are included in their care: It might be easier for measurements of quality to cover quantitative data on institutional capacities of hospital beds or personnel keys than it is for researchers to conduct interviews on individual elderly expectations of "good" care - or ask them to evaluate their own care. Researching informed decisions and wishes of the individual in need of care is a "messy" undertaking for studies, not least because of dependency issues and their need to be on good terms with their carers. There are situations, such as in dementia, which makes it difficult to assess individuals' needs. In addition, general rights to quality of care are not so well known nor the enforcement of these rights well understood. By focusing on the elderly, the study can explore different groups of the elderly and analyze how they can access quality care. This article explores the viewpoints and focus on older people within the larger report- reflecting both on a specific German context but also on possible wider cross-cultural implications of this study.

2.2 Politics and Policy

Improvements in long-term care have taken on a more prominent role in the last decade in the German political agenda. The major political parties placed long-term care reforms explicitly in their election manifestos. After forming the large coalition government, the two major parties (Christian Democratic Union and Social Democratic Party) called for the reform of long-term care in two phases. A draft policy agenda for 2015 includes a raise in four percentage points for care payments to reach about 2,5 million recipients. Care services will be extended to support more of those with dementia, with general handicaps and those with psychological handicaps. Senior citizens' homes will be provided with more qualified personnel, extending from about 24,000 to 45,000 employees. Support will also be provided for those who are caring for dependents at home: An at-home carer will be able to have up to four weeks of reprieve. Their dependent family members will stay at a nursing home or ambulatory care arrangements will be made, so that the caring family member will be able to take a break from caring. If family members are working and caring, they will be able to take leave from work for 10 days with pay, and will have the right to leave work for up to six months without pay. Any kind of flexible employment arrangement, such as reduced hours, will be dependent on approval of the employer. The German government has also planned to set up financial long-term care funds to cover future expenditures and guard against a pending collapse of care insurance because of increasing recipients rolls. Education of long-term care and nursing will be reformed: the current division between these trainings will be abolished. In the future workers will train for a general diploma and then can be more flexible on the labor market to enter either nursing or long-term care. In a second phase of improvements, the government intends to expand the long-term health insurance to cover more care for patients who have psychological needs, such as dementia. To cover costs, the insurance will include a raise in contribution rates that will result in about 6 billion Euros a year.

Before the enactment of the long-term care insurance in 1995 there had been no nationwide regulation of quality in care institutions. Non-for-profit welfare organizations have been historically strong in Germany in providing care services, such as the Catholic organization

Caritas and the Protestant *Diakonie*. They have also played a strong role as advocates of the needy. Before long term-care insurance, care quality was primarily regulated internally within these organizations and their corresponding institutions. The law in 1995, however, outlined specific criteria of care quality and rescinded the welfare organizations' responsibility of its supervision. The management of care quality (setting the principles of care, measurements and quality enforcement) falls now to the umbrella organization representing long-term care insurance, organizations representing state-wide agencies of social assistance, the federal association of municipal associations, and the federal union of national agencies of care institutions. The German Medical Health Insurance Service (*Medizinische Dienst der Krankenkassen- MDK*) was given the authority to oversee services in care institutions and in that way there was a significant institutional change in the responsibilities of monitoring care. Welfare and non-profit organizations kept their role as service providers and as agents or representatives for those in need of services at the political level. However, quality control became the responsibility of insurance agencies. Quality assurance shifted to organizations responsible for overseeing collection of insurance contributions and care service payments – and was no longer in the hands of the service providers.

In the wake of the new long-term care insurance policy, a social pact between researchers, care management, education/training and care management formed on the national level: the National Conference on Quality Assurance in Health Care (*Bundeskonferenz zu Qualitätssicherung im Gesundheitswesen- BUKO*). It promoted an independent institution for the development of quality standards, helping to push legislation on laws for care quality. A law on care quality (*Pflege-Qualitätsversicherungsgesetz*) was consequently passed in 2001. This law standardized care quality with one set of criteria for all ambulatory and institutional care for the first time. It also stipulated that institutions would have to carry out internal management of care quality and produce documentation for external review. The umbrella insurance agency representative, the MDK, received stronger powers of overview and sanction when evaluating care providers, so that they could revoke payment when certain kinds of quality were not met. The measurement of quality, especially personnel ratios and stronger patient rights and protection, was emphasized (Hamdorf, 2009, 11ff). Quality assurance was further expanded in 2008 with the Long-term Care Insurance Development Law (*Pflege-Weiterentwicklungsgesetz*). Here care management was extended through long-term care insurance and the law also established unpaid protected employment leaves for family members who were caring for dependents at home and had to leave employment in acute emergency situations. There was also the incorporation of a grade system for long-term care institutions so that consumers might more easily recognize the quality of a care facility.

This past decade has seen the establishment of quality assurance on a national level with objective criteria and inlays into quality assurance for private care. As it is now, a grading system for institutional care is made up of 82 evaluation elements. Of these, 64 elements make up the complete grade for institutional care- that is very much like a school grade (averaging 1, 2, 3, 4, 5 and a failing grade of 6). Another separate quality grade sheet is compiled from the rest of the 18 evaluation elements and is gathered from interviews of long-term care recipients themselves. In effect, these subjective evaluation elements are an additional supplementary guide for consumers. All 64 elements of care evaluation for the primary grade have a scale from one to ten which then is averaged to get the final score. Some problems have been recognized in these grading systems: for example, the average grade for an institution might actually mask poor quality in some essential elements of care if less essential elements receive high marks (ZQP, 2012). Care facilities have an annual quality assurance visit. Quality-assurance for long-term care recipients who receive care at home has other criteria than the grading system for institutional care. The insurance agency reviews care every half year with house visits but care that is performed by family members

(which is most of the care at home) does not fall under review (Wiener *et al.*, 2003; Wiener, 2007, 13-14). In general, insurance agencies place less emphasis on quality assurance for care performed at home and in the community than for care performed in institutions (GKV-Spitzenverband, 2004).

3. ELDERLY PERSPECTIVES

An abundant amount of literature has grown as a consequence of the establishment of long-term care insurance and subsequent regulations on care quality, not least research on elderly perspectives of quality. The studies that have focused on the elderly themselves will be presented in the following sections. I found that the German articles which focused on the perspective of the elderly can be grouped into five main categories: 1) the rights of the elderly to quality, 2) the elderly perceptions of satisfaction and outcomes, 3) documentation in care quality and the role of time in care, 4) support for elderly independence and 5) equal access to quality of care. As insurance and regulations of quality become law, actual rights of the elderly have been strengthened. In the first section I examine studies which consider new rights to quality of care as well as the actual exercise of these rights. In the second section, perceptions of satisfaction are more closely examined. Here, researchers are concerned with collecting valid interviews and understanding when and how elderly perspectives are taken into account for measuring quality. The third section examines documentation, questioning especially how perspectives of the elderly are included. Related to documentation are New Public Management strategies. Time has been an important issue for researchers because New Public Management instruments divide care tasks into time units. A high importance is attached to care documentation. Here I review research on quality of care and time, especially with regard to documentation and time that is needed for care relationships. The fourth group of research deals with issues around care that promote independence ("active aging"). Active aging has become a buzzword in policy-making across Europe and staying at home for the longest time possible is a general preference among the elderly. As the population grows older and has tended to stay healthy longer, research has focused on measuring well-being and the best supports for the elderly to stay healthy and be involved in their communities. The final fifth section examines research on care quality and access to quality care across different groups of the elderly. This shows the specificity of individuals as groups of care consumers.

3.1 Rights to care quality

With more of the German population facing care-dependence, there has been a growing interest in formulating rights to quality care. From 2003-2005 two German ministries set up an expert panel to develop guidelines for rights to quality long-term care. The German Ministry for Family, Seniors, Women and Youth along with the then Ministry for Health and Social Security called in many experts. They were to research the situation of those in need of long term care as well as formulate directives for the establishment of laws around care (BMFSFJ and BMG, 2010). The "Round Table on Long-term Care Issues" (*Runder Tisch Pflege*) was made up of about 200 experts from a variety of agencies: from senior citizen's homes, individual German federal states, municipalities, non-profit welfare organizations, private service agencies, nursing home superintendents, long-term care insurance companies, lobbyists for the elderly, researchers, research foundations and charitable foundations. The group established a Charta of Rights for those in need of long-term care (*Charta der Rechte hilfe- und pflegebedürftiger Menschen*) which was completed in the fall of 2005 (Deutsches Zentrum für Altersfragen, 2005a,b,c,d). The Charta outlines rights which should be available

for those in long-term care. It also suggests concrete recommendations to improve care at home and in long-term care institutions, such ways to reduce paperwork and bureaucracy. The Charta defines quality in long-term care as care that concentrates on the personal needs of dependents, supports their health and is carried out by qualified carers (Artikel 4) (BIVA, 2012). Assistance and treatment in long-term care is placed firmly under consumer protection. Some recommendations became later confirmed by law: for example, in federal reform laws in 2006 that provided more protection for nursing home inhabitants (*Wohn- und Betreuungsvertragsgesetz*) as well as a further protection of patient rights in May 2012 (*Patientenrechtegesetz*).

The Charta lists and describes eight codes of rights for the elderly and long-term care dependents. The right to independence and help for active aging is in the first decree. Support should be given to help those to live independently and make decisions about their lives as much as they can. The second degree concentrates on the right of care-dependents for protection against bodily and psychological harm. The third article declares a right of protection to privacy and the fourth article concentrates on the rights of care-dependents for care that is tailored to their needs. This care should be supportive of their health and well-being and performed by qualified personnel. The fifth article declares the right to extensive information about possibilities and services in counseling to find adequate care as well as in the actual care assistance itself. The sixth article spells out rights of dependents to be treated with respect, to be able take part in community life and have social relationships. Article seven stipulates the right to practice one's own religion and be able to live within one's own culture and by one's own moral convictions. The eighth and last article encompasses palliative care and outlines the right to die with dignity (BMFSFJ and BMG, 2010).

Not surprisingly, the establishment of concrete rights to care and rights to care quality has led researchers to investigate whether such rights are enforced. Some actual studies show the arduousness in rights enforcement. A study by the German branch of Transparency International (Stolterfoht and Mariny, 2013) found that it was difficult to enforce patients' rights in long-term care because of the complicated and non-transparent long-term care structures. Because there is a high number of people and agencies who are involved in the financial transactions of long-term care, a clear responsibility for decision-making on the behalf of the care-dependent is unclear. Those who bear the financial costs of long-term care are family members, the long-term care insurance agencies, the health care insurance agencies, social assistance departments, social security/retirement agencies and sometimes also accident insurance agencies. Service providers and the service provider employees also include many people, so that it is challenging to hold anyone accountable, should the rights of a long-term care recipient be violated. The study suggests that rights be more concretely anchored in legislation of care procedures: for example, patients and their family members should have the right to see recommendations that preceded certificates of quality from the German Health Insurance Medical Service, responsible for regulating the quality of long-term care. A federal central registration of documentation as well as on-line information and transparency of documents is recommended. The gray area of the law for medical attendants who act as legal custodians of long-term care recipients is found to be especially problematic. The present unaccountability of custodians in the system makes their acts prone to misuse, according to the study. The misuse of this responsibility is hardly punishable, if such custodians act in the disinterest of patients or even in self-gain. The authors recommend wider dissemination of information and a strengthening of due process in custodial regulation which would help avoid such present problems (Stolterfoht and Mariny, 2013). In another study, Moritz (2013) highlights the German state's lack of protection of the elderly specifically in nursing homes. She compares the rights of individuals set through the German constitution and the data on nursing home practices reported through the quality reports of the MDK.

Transgressions in patients' rights – such as their right to fulfillment and respect, which is also stipulated in German constitutional law - can be observed in the inadequate personnel ratios to patients according to Moritz (2013, 132 ff). The high numbers of decubitus (bedsores) as well as personnel's difficulty in observing pain in patients violate rights in articles protecting bodily integrity and respect.

While there has been more development and research on rights in institutional care, less is known about care at home. Studies on care performed by family members and its quality are few and far between (for an exception, see Bode and Chartrand, 2011). Although quality criteria for measuring care and the fundamentals for quality were spelled out further in the German Law for Adjustments in Long-Term Care in 2012 (*Pflege-Neuausrichtungsgesetz*) in order to determine ambulatory and part-time inpatient services, a discrepancy remains between the instruments to measure quality at home in comparison to instrument of measurement in institutional care. Family care is seldom regulated for its quality and few family members have been sanctioned for bad care (Wiener *et al.*, 2003; Wiener, 2007, 13-14). Visits for monitoring quality also need a framework to insure optimal overviews (Habermann and Biedermann, 2007). Wiener points out that it would be beneficial to compare quality care at home and similar care in institutions: this would be informative because aspects of quality for long-term care at home are not well-known. Most of long-term care recipients prefer to be cared for at home for as long as possible (Pinzón *et al.*, 2010), so that research in this area would cover a vast group of recipients, and knowledge of such care could have a potential wide impact. On the other hand, studying quality of care at home pose formidable research problems because of funding limitations and the hurdles of collecting original data. Because of the low cost benefit of researching and of regulating quality of care in private homes, insurances are more likely to concentrate their research funding on institutional care.

3.2 Satisfaction and quality outcomes

The German research around satisfaction and outcomes of care generally focuses on how to define and measure these indicators. Satisfaction is often from an individual perspective - so research focuses on valid measurements. Research on outcomes in care often follows the approach from Donabedian (1980). This approach recognizes quality in three areas or levels of treatment. The first level of quality rests at the institutional level and this is easily quantifiable. Quality is measured in institutional out-lays, such as personnel and patient ratios, the available medical and care equipment, available therapy services, the qualifications of the personnel or room standards. The next two levels are more determinate on the perspectives of the elderly: A second level of quality is measured in actual processes of care. Here researchers observe the actual day-to-day interactions and services carried out. Measurements of quality focus on the interactions between the elderly and staff in the processes of care that directly involve individuals. A third level of quality incorporates the outcomes of care. The quality of this last area of care is not easily determined because outcomes can only be measured in relation to the initial goals of care. Studies have shown that it is not easily determined how the perspectives of the frail elderly and care dependents are taken into account when setting these care goals.

In a study performed on nursing homes, Gebert and Kneuhler (2003) report that care providers' must have a good knowledge of the care recipient's situation in order to accurately assess the care situation and set care goals. Setting these goals involves good communication skills from the personnel. Personnel must quickly perceive the needs of dependents and efficiently determine reasonable care goals and effective therapy for reaching these goals. Wiener also emphasizes the importance of care providers' ability to communicate with the care recipient and their family members. Even if a care provider is able to accurately assess a care situation, they will not be able to apply any therapies if the patient and their family

members are not informed and adequately prepared for and open to the therapy. Also, the resulting satisfaction of recipients and their family members for the care therapies is determined by the fulfillment of expectations- that is (in turn) dependent on the carer/ care providers' initial and on-going communication. Furthermore, future developments for therapies are difficult to predict and these might further complicate goal re-assessment. He outlines an additional difficulty in determining the quality of outcomes in care because the goals for care can (constantly) change depending on the conditions of the long-term care recipient, the available care instruments and needs of the cared (Wiener 2007). Finally, Wingenfeld (2010, 24) points out that appropriate indicators of quality of care outcomes differ depending on care sectors and forms of care. Criteria of good quality care that might have a large impact on long-term care in nursing homes might not be fitting for ambulant care or relevant for care in a hospital.

Measurements of satisfaction from those suffering from dementia is one of the more contentious areas in research on care-recipients' perceptions (Flaiz and Meiler, 2010; Schaeffer and Wingenfeld, 2008). Recently in 2012, the German Health Insurance Medical Service funded a study on problems of gathering valid evidence on perceptions of well-being and life quality in dementia patients (MDS, 2012, 124). The report suggests that the quality of care in these situations would be evaluated by viewing patient participation in care facility activities as well as through interviews from third parties or family members. In an earlier study, Wiener examines case-management and computer-assisted instruments of assessment to determine effective best-practices in dementia care (Wiener, 2007, 18f.). When it is not easy to receive input from patients themselves, institutional quality is incorporated in measurements of time for care, personal/patient ratios, measurements of independence, etc. (Frey and Heese, 2011). Quality outcomes can also be determined by avoidance of worse case conditions: for example, decubitus, lowering subjective contentedness of care recipients or worsening general health conditions. Other indicators of quality in care outcomes have been measured in time expenditures and resulting costs. Flaiz and Meiler (2010) among others have drawn up indicators for subjective well-being and quality of life from those suffering from dementia. They suggest that input from care personnel especially helps to evaluate well-being. Many of the indicators were based on comparative and verifiable evaluations of physical, mental and social aspects for care recipients. The indicators were developed from questionnaires of long-term care recipients in retirement homes and input from family members.

Studies on elderly perceptions of satisfaction with care are methodologically complicated. According to Neugebauer and Porst (2001), the validity of care recipients' statements on the quality of their care is strongly related to the type of relationship that a care recipient has with his or her care provider. For example, the authors caution that receiving honest opinions from long-term care recipients about their care is often curtailed by their dependence on carer/professional staff members. Those dependent on care providers might fear retaliation if they speak negatively about their care provision. Methodologically, this problem could be eliminated when interviews were conducted after a completion of care and recipients were no longer at an institution of care that was being evaluated. Another method of assessment commonly used if recipients were permanently in long-term care or hospice was to interview family members and other third party observers.

Satisfaction with care often depends on an individual's personal expectations and on factors such as age, health, education and social status (Voges, 2009; Neugebauer and Porst, 2001, 22). Different studies have shown that patients who are younger and well-educated are more likely to openly express criticism about their care. Neugebauer and Porst (2001) attribute this critical stance to younger and well-educated patients' estimations that they have the possibility of changing something in their care. Social status seems to be a factor

in satisfaction with care as well. The authors found that the greater the difference between the social status of a patient and a doctor, the more satisfied the patient was with his or her doctor. Patients of higher classes often had higher expectations about their care while at the same time people from lower social classes often were satisfied with what they saw as the status quo (Neugebauer and Porst, 2001, 22). In a similar vein, Wüthrich-Schneider (1998, 88) found that patient satisfaction was generally lower when patients were treated by younger doctors, or when male patients were treated by female doctors. The authors also caution that other individual factors can play a role in perceptions of satisfaction. Especially the health of those in long-term care play a role in satisfaction: those who are healthier after a successful treatment are more likely to rate their care more highly than when they have had a treatment which has not gone well, for other reasons than the care itself (Voges, 2009).

3.3 Documentation and real time

Long-term care in Germany uses instruments of New Public Management for quality assessment and cost-efficiency controls. New Public Management instruments include documentation of the care process as well as estimation of time allocation for specific care tasks (Reinmann 2011). These instruments are used by service providers to prove care has taken place, validate its quality and efficiency, justify its compensation as well as use it as a means to procure future contracts. Documentation instruments are used to legitimize costs and to reflect an “objective” observation of care quality and the needs or well-being of patients. The elderly are usually not directly involved with documentation of their own care nor are they directly involved in determining how much time care tasks (should) take. However, both documentation and time estimates/allocations for tasks are relevant for the elderly in terms of how accurate these instruments reflect real time and real care. Some studies reflect weaknesses in time calculations and they also find that care documentation posits some possible snags or difficulties itself. The elderly perspective then is “lost in translation” both in care documentation but also in the real need and use of time for care.

Studies from Manzei (2009, 211) and Rotondo (1997, 211) show that instruments that gauge the time expenditures for care personnel are usually not good indicators of the real time that specific care actually takes. Even typical routine time-costly and work-intensive care practices, such as washing and changing bed sheets, moving patients, changing infusions and psychosocial care of patients are difficult to calculate accurately. Manzei reports that relationships are built in every-day routine care work, such as helping patients dress and wash, and it is often in these daily activities where patients take the time to ask questions about their care. And so personnel often are performing psychological care and imparting information to patients within otherwise routine bodily care tasks (Manzei, 2009, 48). This routine care is also important in setting the foundation for how those in need of care comply with care arrangements and how carers impart information about their care to them. The “small” daily routine care acts are symbolic of how both the cared for and the carer agree about general care practices and come to a consensus about it. Goals can be more easily found when normal procedures are imbedded in good communication about care options and the necessity of certain care arrangements.

Studies have not only shown that time for care is difficult to predict in measuring individual care tasks, but a few studies have criticized the (exorbitant) time it takes to document care in New Public Management standard procedures. Researchers such as Buchinger (2012, 131) finds that in some cases documentation of care takes time away for the actual caring tasks. She outlines the expansion of documentation instruments in the non-profit sector that justify service contracts and the study states that available time for actual care might actually be reduced because of the intensive documentation of care. Indeed, federal and state laws have recognized that there are increasingly large amounts of bureaucracy in different

areas of elderly care which should be ameliorated. Although they encourage the reduction of paper work, actual reductions in bureaucracy have not been easily forthcoming.

Pitfalls in documentation are also noted in the literature. Author Möhring-Hesse (2008, 158) reports weaknesses in the documentation process in its ability to reflect actual real care. Möhring-Hesse suggests that supervision and reports from external experts would guarantee better quality controls as internal documentation. The study also questions whether documentation might actually hinder the innovation potential from smaller institutions: when, for example, insurance agencies base their service contracts with care institutions on past documentation of their procedures. Not only are institutions then “marked” for certain procedures in the future but should care facilities have incomplete or limited documentation of their care in the past, they will have a hard time arguing for service changes in the future. This could affect smaller institutions to a larger degree according to Möhring-Hesse because of their limited capacities to document cases and because of their smaller numbers of clients with a potentially narrower type of therapy. Hasseler and Fünfstück (2010) critique another weakness in documentation. They point to faulty documentation that records the process of care but does not address how services meet the specific needs of individual patients. On a different note, Wingenfeld (2010, 23) states that supposed deficiencies in care can often be traced back to incomplete documentation. In this sense, documentation itself poses hurdles to care quality and future care service (for more, see Reinecke, 2010).

3.4 Active aging

The European Commission created policy for “active aging” on several levels and this terminology and these policy directives have also been adopted in the German political arena. Policy for “active aging” supports independence of the elderly in their aging process. Active aging policy also makes it easier for the elderly to partake in diverse societal activities and contexts, so that when possible the elderly can contribute to the economy and society (OECD, 2012; WHO, 2002). Guiding principles for active aging were written up by the Employment Committee and the Social Protection Committee of the EU and instruments evolved, such as the Active Aging Index to assess elderly potential and the European Innovation Partnership on Active and Healthy Aging which brings stakeholders together to synthesize innovative measures. Innovative measures aim to strengthen intergenerational solidarity, extend social ties beyond the family, provide aid to caring families and services of long-term care, create volunteer work which might be attractive for the elderly, promote healthy lifestyles for the elderly, and invest in life-long learning and education (Tesch-Roemer, 2012, Tesch-Römer and Wurm, 2012).

German researchers have concentrated on the frail elderly and the longer spans of time that they remain at home, despite being in need of care (Mnich *et al.*, 2013) as well as generational solidarity (Böll, 2012; Löwenstein and Ogg, 2003). Schneekloth and Wahl (2006) study the available resources in care services that enable the elderly to stay at home longer and report that services need to be coordinated and evaluated more directly on the needs of the elderly (2006, 206ff). The OASIS study (Löwenstein and Ogg, 2003) examines the living situations of the elderly as well as their preferences for state and family interventions in care. They examine how state policy around long-term care influenced family solidarity, and in an international comparison they found that state supports not only insured that more elderly individuals had care, but such services did not affect family involvement negatively. Family members did not reduce their time spent caring for long-term care dependents - indeed, family members expressed that the care was more manageable. Germany was a country that offered fewer state supports and individuals on average wished for an equal balance between state and family care. Specific measures of intervention to support responsible self-determination in the area of nutrition and physical activity was

tested in the Mnich *et al.* (2013) and it was found that health promotion in old age may lead to changes in nutrition behavior but had less influence on physical activity. Activeness, self-reliance and social involvement of the elderly have also been the focus of research in technology developments. These studies usually test new equipment for networking or supporting the information distribution and services (see for example, Freisacher, 2010; TABLU, 2013; BMBF and VDE, 2012; Fraunhofer, 2013).

Studies have concentrated on different social and ethnic backgrounds of the elderly and their community use of care resources (Böll, 2012; Angerer *et al.*, 2010; Heusinger, 2007). In a study on self-help potential from those elderly in need of care, Heusinger (2007) found that the ability to be self-reliant often depends on milieu-specific social strengths and weaknesses. Results show that those elderly in need of care who are from working-class backgrounds have a comparative large practical social network potential in their near vicinity. For those in higher social classes, self-help potential and social networking was much less present than for those from working-class backgrounds. However, there was still a good chance for those in higher classes to receive good quality care, because they had the financial resources to pay for it, they had knowledge of how to access such paid care and they often had experience of finding and using it. This study affirms previous research findings which show that lower classes have less readily access to structural/institutional resources to care but they can rely to a large part on familial obligations to perform care (compare Blinkert and Klie, 2005, 141ff.). The study also shows that those individuals with better financial resources were comparably more comfortable with hiring outside help for care than those individuals with less financial resources.

Self-determination and the active involvement in decision-making around their own care arrangement are topics which have generally had little research attention in Germany. An exception to this rule is Messer (2013) who examines the potential of the “shared decision-making” approach in the German context, where collective decision making processes are supported to find common ground between health professionals and patients. Heusinger (2007) argues that often information is missing for those individuals in lower classes. This group is especially in need of information and (neutral) counseling. In order to insure quality care for those with fewer societal resources, care facilities must take more time to offer such supports. Heusinger’s report also concludes with the observation that often lower social classes are reluctant to express critique about their care, their doctors and carers. Thus, patients and the frail elderly are less likely to investigate options and most likely not be fully informed of their care options. In order to insure its quality, it is especially necessarily in these cases to examine services with impartial scrutiny and make special efforts to inform these groups about care (Engel and Sickendiek, 2005).

3.5 Accessibility

Accessibility to quality in long-term care has been another theme in German research that deals with care quality. Studies have concentrated on care provision mixes and their complex arrangements for different populations. Services affect different groups of long-term care recipients because of social policy structures as well as other state structures, such as employment or cultural contexts. Most studies concentrated on outcomes in care provision or options in care. Overviews of Germany that connect general accessibility of care services and welfare state frameworks are mainly in comparative studies of care regimes (Pfau-Effinger, 2012; Theobald, 2010; Leitner, 2014; Auth, 2012). In this sense, accessibility is connected to employment structures and generosity of services, concentrating to a large degree on gender differences, and less on class or race. Theobald (2011) and Lutz (2011) are exceptional here because of their research of migrant care workers in Germany as well as Schupp (2002) and Schupp and Schäfer (2005), who concentrate on available data of

informal home services in Germany. Less is known about the ethnicity and class perspective of the elderly who need care – nor the quality of this care.

Men and women as groups experience long-term care differently. A study on life-quality from Scholz and Schulz (2010) found that German women spend on average a longer time in long-term care (3.9 years) in comparison to men (2.1 years). A report on care from the Barmer GEK health insurance agency found that women are much more likely to find themselves in long-term institutional care than men. On average, women pay double the costs that men need to pay for care in their life-time (Rothgang *et al.*, 2013). On average, women need to pay about 84.000 Euros for long-term care that includes about 45.000 Euros of out-of-pocket costs. Men, in comparison, have an average cost of about 42.000 Euros, of which 21.000 Euros are out-of-pocket. Women earn, however, in comparison to men far less on average in their life-time: A women's pay ratio is about 77% to every dollar a man earns. Inequality between men and women are multiplied if women's care costs are about double of men's but women earn less income in the first place.

Comparisons of equal access of women and men to care quality are less of an issue in German studies. An exception to this rule can be found in the research from Backes *et al.* (2008; 2011). According to the authors, gender-specific equality problems arise especially in implementation and financing of care services. Insurances pay more long-term costs if the care is performed by a professional care institution- hospital, nursing home, etc. but the contributions of private out-of-pocket expenditures also rise for institutional care. Care recipients have a financial incentive to pick home and ambulatory care first before institutional care. The authors view the German government's explicit policy goals of "ambulatory care" first and foremost over "institutional care" ("ambulant vor stationär") as a form of "re-familialization". In this way, care responsibilities are pushed onto family members which ultimately places care burdens (back) on women as primary care takers (Backes *et al.*, 2011, 81). Home or ambulatory care might be the cheapest kind of care for the care recipient, but it exacts the highest tolls on family members' resources- and so is more likely to burden women who are more likely to care.

The issue of poverty among the frail elderly is complex. The authors Falk *et al.* (2011) studied poverty among the frail elderly and its challenge for professional long-term care staff. Personnel could offer poor people in long-term care more options and power over their ambulatory care and ease handicaps resulting from poverty when they were educated in handling these issues. Another study from Bauer and Büscher (2007) examine inequality in access to care services because of lack of knowledge of people with disadvantaged backgrounds. The authors report large deficits in people's knowledge about available care services nor is it known how they access high qualitative care. The authors stress that more research is needed to understand how professional carers deal with those in care need who are faced with social disadvantage (Bauer and Büscher 2007). (For more on socio-dynamic utilization of services from caregiver's, see Lüdecke *et al.*, 2012). Friedrich Hauss (2008) examines not only the perspective of people with disadvantages but analyses the dynamic of how different disadvantages are summed together in individual situations. He examines constellations of disadvantage, such as poverty, unemployment, sickness and need for care, low educational achievement, the necessity to care for others in a home and single parent status. The author finds that individuals who had more types of disadvantage at once were the most likely to have the longest spells of disadvantage. Especially disadvantages that were located at home and stemming from care issues (such sickness, caring for others in long-term care or being a single mother) caused longer spells of disadvantage than many other kinds of disadvantage.

Studies from Kolleck and Angerer *et al.* concentrate on cultural-sensitive care professionals (Kolleck, 2007; Angerer *et al.*, 2010). The studies examined the effects of education and

learned skills in handling cultural differences. Cultural training included language and religious and cultural information, such as cultural understandings of sickness, dealing with bodily issues and knowledge of cultural tabus. The main interest of the study was whether cultural training of professionals made a difference in better fulfilling patients' expectations and if the potential for conflict and/or misunderstandings could be reduced. Both studies found that the number one factor that improved care quality was good communication. They found that conflicts in care were especially in danger of appearing when cultural differences went unheeded. In worst case scenarios, miscommunication could lead to inadequate cooperation of patients in such a way that patients might be even ready to abandon their therapy or care goals. The studies also pointed to a lack of cross-cultural knowledge among professional care staff and the need to fill these gaps. Disseminating cross-cultural knowledge is suggested in curricula for education and training of professionals but also in translation services at care facilities, documentation and coordination between facilities (for more information, see Von Bose, 2012).

4. CONCLUSION AND OUTLOOK

In sum, this article reviews current topics in research on the care of the elderly in Germany from the perspective of the elderly. The reviewed topics fall roughly into five categories: 1) studies on rights of the elderly to care quality, 2) elderly perceptions of satisfaction and quality outcomes, 3) time measurement and care documentation, 4) support for independence in "active aging" and 5) equal access to quality care. These categories make up different facets of how elderly perspectives are included in research on care quality. This article advances the growing debate on quality of care, and also provides an overview to the research being done on quality of care in Germany. Until now, there has been no systematic compilation of German research on care and quality, nor has there been a critical evaluation of this research as a whole. This conclusion summarizes the findings per topic and then outlines the strengths and weaknesses of care provision. Finally, the future research topics on care quality are considered as well as lessons for other countries.

The first group of articles focuses on rights to quality, documents the development of elderly care rights and explores their enforcement. Between the years 2003–2005 the German Ministry for Family, Seniors, Women and Youth and German Ministry of Health and Social Security had set up a roundtable of about 200 experts to discuss and establish a code of rights for high quality care for the frail elderly and disabled. However, both rights outlined here and the representation rights in the constitution are found to be in need of improvement in the financing, provision, service representation, and regulation of care.

A second group of research topics focus on perceptions of satisfaction of the elderly and quality outcomes. Research shows that the opinions of the elderly are often influenced by their identity as well as their relationships to their carers: for example, they might often not tell the truth about negative aspects of care, if they fear retribution. Also age, health, social status, education, and gender make a difference in elderly expectations of care and its quality: for example, elderly of lower social status often do not seek second opinions and question their doctors and carers less. Also, measuring satisfaction can be difficult in cases where the elderly are not cognitively aware, such as in dementia patients. In many cases, the elderly wish to stay at home, but little is known about what kind of care they are receiving.

The third area in current studies focuses on the critical issues of documentation of care and the estimates of time it takes to perform care tasks in comparison to real time for tasks. Research finds that it is difficult to estimate the real time for care – especially, for individual cases. Satisfaction of the elderly with their care often was based on the relationship with their

carer(s), and yet carers often did not have the time necessary to invest in time-intensive care, such as psychological care or imparting information. The documentation of care itself might take time away from the actual caring for the elderly. Documentation itself as an instrument of New Public Management poses problems for care quality in other ways, such as curtailing smaller institutions with limited capacities in services.

The fourth area of research focuses on the ability of the elderly to prolong their independence in active aging. The potential for self-help is measured for different groups of the elderly and studies find that lower-income social classes have a high self-help potential. These individuals are able to rely on family and friends in the community, while elderly from upper classes are more likely to buy care. However, information on care services is especially lacking for poor elderly. Research on technology and its ability to contribute to independence of the elderly is part of a growing body of literature around active aging.

A fifth area of research studies the elderly's equal access to quality care. Much research is still needed in this area. Estimates show that women have more than double the care costs of men when they become older but while there are gender inequalities in costs, not much is known about outcomes in care quality. This is also true for inequalities resulting from social class or ethnic background. Cultural sensitive care and research on how caring can be improved for ethnic minorities is still in its beginning stages. Community access to care and information about available resources is often incomplete; thereby, the imparting of knowledge of available care services is an essential tool for better access to care.

The strengths and weaknesses in German quality care provision from the perspective of the elderly are quite clear. The establishment of universal long-term care insurance has strengthened the rights of the elderly to care. Long-term care insurance has changed the way in which the elderly receive care: As payers into insurance, the elderly receive benefits as a right. The insurance has also helped pave the way into defining and measuring quality of care as well as setting conditions for sanctions, should this quality not be met. Another incredible strength in Germany quality provision is its support for the elderly's preferences to stay at home for care. Active aging has become a policy goal in Germany's elder care and inroads have been made in research to test ways to help support elderly independence. These are all strengths in German provision of care from the perspective of the elderly.

The studies in this report also expose weaknesses in quality of care provision in Germany and some further needs for development. For one, weaknesses in German provision stem from poor enforcement of elderly rights. Another major weakness is the level of long-term care insurance payments. Germany's universal long-term care insurance is meant to soften the financial burdens of care but it does not cover all costs. Co-payments for care costs are high so that social risks are still quite high for poverty. Although informal care is encouraged, it is not well paid: the insurance pays almost two thirds less of costs for informal care compared to similar formal care. Studies seem to agree that satisfaction of the elderly with their care and overall high quality of care can be traced to good communication and good relationships with their carers, but at the same time studies show that time for this care is scarce. The research also exposes some questionable gaps in knowledge about quality care. Equal access to quality of care - especially with respect to gender, ethnicity, and class - are some essential issues that need to be further researched. This report also finds that care quality is researched mainly in hospital settings but institutions such as senior citizens' homes are documented less often. Care at home, which is the most common type of care, is the least researched.

The literature on quality of long-term care does not provide a complete picture of German welfare state issues around class, gender and race. German quality care provision with respect to elderly identities goes to a large degree un-reflected in official statistical data and not many individual studies handle these issues. Germany has tended to follow a

“conservative” welfare state path. There has been a general trend to set guidelines for quality care and to recognize social risks resulting from long-term care, but little is known to what degree some people carry more risk than others. Little is known about gender and care, except that generally, as care recipients, women are more likely to have longer spells of long-term care, and on average their care costs are more than twice as high as men’s. It is known that women are more often cared for in institutional care but women themselves are more likely to care for others in long-term care at home. Women are, on average, less strongly tied to the labor market, which makes them vulnerable for exiting the labor market when family members need long-term care. More research on this issue is needed.

Little is also known about the impact of race and class identity of the elderly and their access to quality care. There have been inroads to cultural sensitive care and studies have been performed on the use of professional care among different social classes, but more studies are needed in these areas. Studies repeatedly emphasize the importance of information for the elderly in lower social classes in order to access quality care. However, time taken for informing patients is often in short supply and little is known about how this affects the elderly. Class and ethnicity are also not covered in long-term care statistics of the government. More studies are needed in this area.

Research shows that Germany has made great strides in defining and institutionalizing quality in long-term care, and social risks around care have been ameliorated but not solved. Tensions remain around the ways in which Germany can provide quality care if the status quo around gender, class and race remains unchanged. Changing deeper problems, such as problems of reconciliation of work and family life, or addressing problems of adapting to an ever-increasing migration population in Germany are necessary. In addition, the status of care - in terms of the low compensation of long-term care personnel and the “feminization” and “migration-alization” of its workforce will need to be addressed. More research in this area might not only improve our understandings of universal access to quality care but also promote more equality and legitimization within care policies.

This overview of German research on quality care is relevant for other countries in several ways. Because Germany was one of the first countries to initiate an independent long-term care insurance and because it has had time to fine-tune and adapt its policy to demographic pressures, many countries examine the long-term insurance instruments for possible “best-practices” in their own countries (see, for example, Campbell *et al.*, 2010 for the US or Glendinning and Moran, 2009 for the UK). Financial outlays in Germany in terms of its per cent of GDP have tended to be less compared to other countries’ long-term insurances (Campbell *et al.*, 2010; Wild, 2010). These costs, however, need to be evaluated with the elderly’s relatively high co-payments necessary for hiring care services. Also, the heavy reliance on informal caring should be understood for its implications both for gender inequality as well as for the elderly being able to choose optimal care. A controversial issue in German long-term care is the insurance’s definition of who needs care. This definition is central because it defines which care tasks will be compensated (KDA, 2002; BMG, 2013). For the most part, only bodily care was considered for compensation up until recently and that had huge consequences for the elderly. Psychological care was not well covered and many dementia patients were severely handicapped because of inadequate insurance payments for necessary care. Lessons, such as these, are valuable for other countries in order to optimize their care coverage.

The perspective of the elderly in German research can especially inspire research in other countries to adapt and optimize the quality of their own long-term care. In turn, Germany would profit from research from other countries. It would be helpful for countries to compare their formal rights of the elderly to other countries. And just as important, there needs to be cross-evaluations of the ways in which institutions are held accountable for monitoring and

reinforcing these rights. Furthermore, countries can gather important information from the challenges that institutions face when including elderly perspectives into measurements of quality: for example, methods of getting valid opinions from the elderly about the quality of their care if they are heavily dependent on their carers. Distinctions in quality of care should be made between institutional services and home care as well as between lengths of time in services (see, for example, São José *et al.*, 2013, 197). Also, all countries face similar hurdles in formulating care goals and measuring outcomes for care dependents. In particular, there are problems in identifying the well-being for dementia patients. Further upcoming issues that will need to be addressed are the living conditions of the elderly, although actual studies on the quality of care here are scarce in Germany, especially in terms of elderly perspectives. All in all, lessons can be learned from Germany if also its welfare state structures are taken into account in such comparisons. Most likely the elderly in conservative welfare states might be more divided in their opinions about the role of the state and private care, because elderly experiences of care will be more varied or segregated according to social status, gender and ethnicity.

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IS PHYSICAL ACTIVITY A GOOD WAY TO IMPROVE QUALITY OF LIFE IN THE ELDER POPULATION?

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ABSTRACT

Background: Although evidence demonstrates that physical activity beneficially influences major chronic illnesses, older adults remain sedentary. Many interventions to increase physical activity intend to reduce disease complications as well as improve quality of life by enhancing physical function in our even more aging society.

Objectives: The purpose of this study was to summarize knowledge on randomized controlled trials studying the effects of physical activity interventions on quality of life in the elder population.

Methods: Randomized controlled trials, systematic reviews or meta-analysis were searched in the Pubmed data base. Search terms: “quality of life”, “intervention” and “physical activity” were used to identify English written articles, with humans older than 65 years.

Results: From the initial screening of 234 titles, only 5 articles met the inclusion criteria and were included in the final analysis.

Conclusions: Physical activity interventions seem to have a slight effect on physical function and in improving quality of life of people aged 65 and over. More intervention studies involving physical activity in older people should include measures of quality of life as primary outcome, as well as a standardization of measures would help to compare results and enlarge the evidence base in this area.

Keywords: Review, Elder, Quality of life

JEL Classification: I31

1. BACKGROUND

The stated evidence of the benefits of physical activity (PA) with advancing age (Ehrman, deJong, & Sanderson, 2010), has induced the development of innumerable research on the effects of PA on health.

Many interventions to increase physical activity intend to reduce disease complications as well as improve quality of life (QOL) by enhancing physical function in our even more aging society.

Quality of Life (QOL) is defined as each one’s subjective evaluation of it’s well-being in the physical, psychological and social domains (WHOQOLGroup, 1994), is a multi-dimensional concept and includes both positive and negative aspects of life (José, 2013). Related to this very broad definition are the Health-Related Quality of Life (HRQL) and the Health-Status (HS) concepts, which are not the same as QOL. HRQF is a narrower concept than QOL since it refers to the physical, psychological and social domains as influenced/

impacted by disease (Moons, 2004), contributing to the subjective evaluation of the well-being. On the other hand, HS although including the same domains as HRQL, is a simple evaluation of the function. Several instruments can measure QOL, but the Sf-36 Health Survey and the WHOQOL - The World Health Organization Quality of Life Assessment, appear to be more frequently used in studies analyzing the relationships between QOL, physical activity and health.

As a consequence of the development of many primary studies on the effects of PA on health and in QOL, there has also been summaries of the existing body of evidence on the beneficial effects of exercise on QOL in later life expressed in narrative reviews (Rejeski, Brawley, & Shumaker, 1996) and meta-analysis (Kelley & Kelley, 2009).

However, as stated by Conn *et al.* (Conn, Hafdahl, & Brown, 2009), many of these literature reviews have focused on the “side effects” that increasing PA has on QOL, focusing on symptoms or health outcomes presumed to be related to QOL, ignoring the fact that PA may improve QOL beyond physical function changes.

2. OBJECTIVES

Few available reviews and meta-analysis evaluated QOL as primary outcome variable or used QOL instruments to measure it directly (Fox, 1999; Puetz, Beasman, & O'Connor, 2006). Regarding the older population many studies have summarized the evidence, however, most studies addressed the frail older adults (Chin, van Uffelen, Riphagen, & van Mechelen, 2008; Chou, Hwang, & Wu, 2012) or older adults samples with specific diseases (Devos-Comby, Cronan, & Roesch, 2006).

Considering the need to provide accurate information to practitioners, the purpose of this study is to summarize research outcomes from randomized controlled trials studying effects of physical activity interventions on quality of life in the older population.

3. METHODS

Search Strategy

Pubmed database, was searched for randomized controlled trials, systematic reviews or meta-analysis between September and October, 2013.

The keywords: “quality of life”, “intervention”, “physical activity” and “exercise”, combined using the boolean operators “AND” and “OR”, were used to identify English written articles published in the last five years.

Previous meta-analysis or systematic reviews summarizing the effects of physical activity intervention programs in the variables of quality of life or in physical activity were included and analyzed to identify eventual articles to be included in the present study. References lists were searched to identify any other potential articles missed in the database search and authors were contacted to request missing data.

3.1 Study Selection

The inclusion criteria of studies were: randomized controlled trials (RCTs) developed in humans older than 65 years, with no specific known disease; intervention programs including physical activity with the main goal enhancing the quality of life and consequently increasing participation in physical activity.

Studies were selected if reported outcome measures including quality of life or health-related quality of life as primary or secondary variable, evaluated directly.

Studies were excluded if they were developed with participants suffering or undergoing treatment for any specific or known disease such as: cancer, osteoarthritis, dementia, Parkinson's disease, COPD, cardiovascular disease, obesity or diabetes, among others. Only the studies performed with patients of depression symptoms or anxiety were included because of its relationship to the main variables in study, however, if the outcomes of the QOL variable was not evaluated directly, studies were excluded. Research evaluating the cost effects of interventions, health economic components (QALYS), disability adjusted life years (DALYS) that reported no relevant data, were also excluded.

3.2 Data Extraction and Quality Assessment

Author, year, aim of the study, sample characteristics, outcome measures, methods, and main conclusions were abstracted from the studies into a summary table by two reviewers.

The methodological quality of the selected studies was assessed by two reviewers using the modified version of an established checklist for systematic reviews on quality of life (Van Son, De Vries, Roukema, & Den Oudsten, 2013) and using the Physiotherapy Evidence Database Scale - PEDro Scale, 0-10 score (de Morton, 2009; Maher, Sherrington, Herbert, Moseley, & Elkins, 2003). Discrepancies between reviewers were resolved by consensus.

Flow chart of the study is presented in Figure 1.

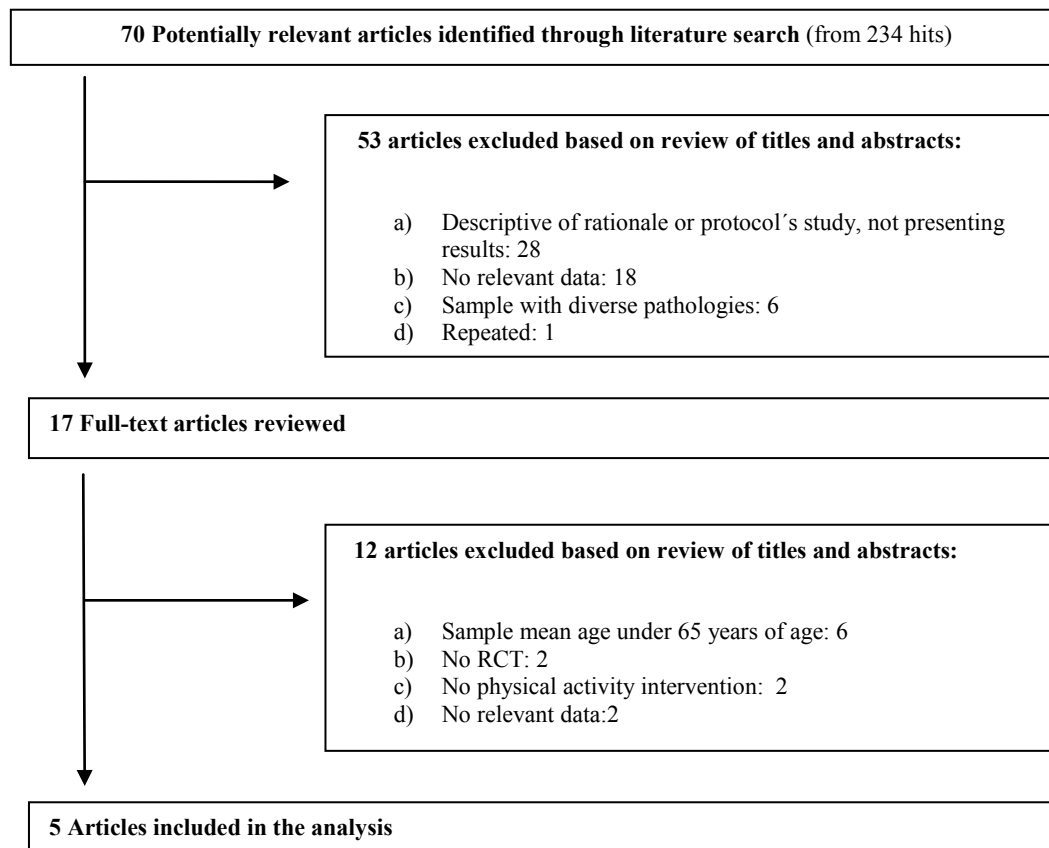


Figure 1 - Study Flow Diagram

4. RESULTS

In the five studies included, sample sizes ranged from 53 to 392, and a total of 958 participants were involved in the trials. Three of the five studies, included only women (Karinkanta et al., 2012; McMurdo et al., 2011; Vestergaard, Kronborg, & Puggaard, 2008),

and one was oriented to inactive or sedentary elders (McMurdo et al., 2011). Others were specifically designed to institutionalized (Vind, Andersen, Pedersen, Joergensen, & Schwarz, 2010) or frail older people (Vestergaard et al., 2008).

The participants were recruited in the community, at home (Karinkanta et al., 2012; McMurdo et al., 2011; Vestergaard et al., 2008), or in institutions (Dechamps et al., 2010; Vind et al., 2010).

The intervention programs, which included a PA component, were characterized by very heterogeneous methods used by researchers. Some, included PA as part of a behavior change intervention (McMurdo et al., 2011), or of a prevention falls program (Karinkanta et al., 2012; Vind et al., 2010), while others implemented a specific training program (Dechamps et al., 2010; Vestergaard et al., 2008). PA was prescribed in sessions ranging from three to four times a week (Dechamps et al., 2010; Karinkanta et al., 2012; Vestergaard et al., 2008), lasting from 26 (Vestergaard et al., 2008) or 30 minutes (Dechamps et al., 2010), to 45 minutes (Karinkanta et al., 2012). Durations of interventions varied from five (Vestergaard et al., 2008) or six months (McMurdo et al., 2011) to 12 months (Dechamps et al., 2010; Karinkanta et al., 2012; Vind et al., 2010).

Only one study reported a weekly goal prescription with no minimum duration or frequency details (McMurdo et al., 2011). One study was not supervised (Vestergaard et al., 2008) and other included a follow-up evaluation after 24 months from baseline (Karinkanta et al., 2012). Some studies included more than one evaluation throughout the study (Dechamps et al., 2010; Karinkanta et al., 2012; McMurdo et al., 2011).

Follow-ups and multiple evaluations may be relevant to address maintenance of behaviors, because effects may take longer to be observed in specific populations such as the older ones. One of the studies with multiple evaluations, observed an increase in PA behavior in the initial three months of trial (McMurdo et al., 2011) which reverted to baseline measures after more three months of a behavior change intervention with inactive older people.

The majority of the RCTs included in this analysis were developed to analyze primarily the QOL effects of a PA intervention program (Dechamps et al., 2010; Karinkanta et al., 2012; Vestergaard et al., 2008; Vind et al., 2010), and only one study evaluated QOL as a secondary outcome (McMurdo et al., 2011).

Only one research measured PA outcomes by means of accelerometry and pedometry (McMurdo et al., 2011) and other applied the Rating of Perceived Exertion - Borg Scale (Vestergaard et al., 2008) for controlling the intensity of the sessions. Other authors did not provide information about the methods for controlling of the intensity of the sessions or informed about other details on the prescription of the PA.

The HRQOL concept was preferred to QOL and was evaluated by different kinds of tools: Euro-Quol (McMurdo et al., 2011), the RAND-36 (Karinkanta et al., 2012), SF- 36 (Vind et al., 2010), and the EQ-5D combined with self-rated health (Vestergaard et al., 2008). One study used the Neuropsychiatric Inventory (NPI) (Dechamps et al., 2010).

All studies aimed at studying the effects of PA in HRQOL. Some studies observed no significant changes in the HRQOL outcomes (McMurdo et al., 2011; Vind et al., 2010), findings that have already been stated in previous reviews with older adults with chronic illnesses by (Conn et al., 2009) and in frail older adults (Chou et al., 2012), and by Kelley meta-analysis (Kelley & Kelley, 2009). On the other hand, others concluded that PA interventions may contribute to slow down the HRQOL decline in elderly persons (Dechamps et al., 2010) and one other verified a maintenance in the HRQOL outcome measures (Vestergaard et al., 2008) at the end of the intervention.

5. DISCUSSION

This review was conducted with the purpose of summarizing the existing RCTs published on the effects PA intervention program in HRQOL in older people (sample mean age above 65 years). However, summarizing the results from the selected studies may be inconclusive considering the diversity of tools used by the researchers to assess outcome measures, the different of ways of reporting results, the differences in PA prescription, and even in the premises upon each one was based.

As subjective as the concept may be, we observed that very few studies included a definition of HRQOL or QOL, or made a distinction between HS and QOL, which may be another factor for discrepancy in results as well as in methodological options observed.

Around six studies aiming at analyzing the effects of PA intervention in QOL were excluded due to mean age of samples be under 60 years of age, which confirms that most intervention studies with older adults have been developed with “lesser” older population, and therefore more primary studies aiming the older population should be encouraged.

Some studies included in this review concluded that PA interventions may contribute to slow down the HRQOL decline in elderly persons (Dechamps et al., 2010), and others observed a maintenance of HRQOL measures (Vestergaard et al., 2008). However, the more positive results came from interventions using specific physical activity (thai-chi and walking), which may limit the extrapolation of the results for other physical activities.

Although the aims of the selected studies were to analyze the effect of PA (or of interventions including PA) on HRQOL, the majority of studies lack a clear cause-effect conclusion. Therefore, a dose-response effect may not be delivered or reported by the investigators or summarized hereby.

The only study using instruments such as the pedometers to measure and control PA variables, showed that these devices ended up to be beneficial only for the maintenance of a low dropout rate, because no improvements were observed in the measured outcomes (McMurdo et al., 2011). For this reason, this study stands out from the rest since is one of the few RCT published using an objective measurement of the PA instead of using self-reported measures. Nonetheless, no improvements were observed in the HRQOL by the use of pedometers, and authors advise that the limitations of their study may be related to the fact that only sedentary women were recruited to participate in the study.

Authors, who reported limited effects of their intervention (Karinkanta et al., 2012), address limitations to the deficient responsiveness of the scale used to evaluate the HRQOL outcome (RAND-36). Since there is no gold standard measure for evaluating QOL, researchers continue to use the one that best suits their aims, which may be too diverse.

6. MAIN CONTRIBUTION OF THIS STUDY

Findings from this review may be limited by the potential bias from the various definitions of QOL and HRQOL, and it was not possible to recommend which type of exercise is most beneficial.

Analysis of the existing literature makes us suggest that future primary studies should address QOL as primary outcome and use specific measures. Also, researchers should define standard ways of reporting results in order to enable comparisons of results and provide summaries of evidence to guide the practice. More studies focusing on the whole dimensions of QOL are needed, and not only those of the physical function.

Finally, answering our research question, we may say that the review performed provided evidence on the positive, but rather weak role of PA interventions in HRQOL in older adults.

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ELDERLY'S PHYSICAL-FUNCTIONAL FITNESS AND PERCEIVED FUNCTIONAL CAPACITY AND HEALTH AFTER PARTICIPATION IN A HYDROTHERAPY PROGRAM

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ABSTRACT

Several studies have demonstrated how physical activity in older people benefits their physical fitness, health and well-being. The relation between physical activity and perceived functional capacity and health is yet to be considered. This study is a quantitative research design that investigated the improvement of the physical-functional fitness and the perception of the functional capacity and health of an elderly group participating in a water-based exercise program (hydrotherapy). The data was collected in three different moments of the exercise program through a battery of tests of physical-functional fitness established by Batista and Sardinha (2005) and a questionnaire adapted from SABE project (Lebrão and Duarte, 2003). Twenty-six elderly persons (23 women and 3 men) aged between 60 and 84 years old participated in a 31-week hydrotherapy program (twice a week; 45 minutes by session). Friedman test was used for assessing statistical differences between the physical-functional fitness and the questionnaire responses in each of the three evaluation moments. Results revealed that this program was enough to improve the physical-functional fitness of the elderly, as well as the perception they had about their health and ability to perform activities of daily living.

Keywords: Elderly, Physical-functional Fitness, Perceived Functional Capacity, Perceived Health

JEL Classification: I19, L83

1. INTRODUCTION

In the last decades a new demographic phenomenon seems to have emerged in the developed countries: the aging population (European Commission, 2007). To guarantee life quality of the elderly has become a key issue to the current societies' development. Studies have evidenced that keeping the functional ability, and consequential maintenance of one's autonomy, is a vital factor to the quality of elderlies' life (Allen *et al.*, 2013; Rikli and Jones, 1999), having more impact than the appearance of diseases (Lebrão and Duarte, 2003). Functional capacity correlates with physical fitness and autonomy, being reflected in autonomy for daily and routine activities (Santos, Dantas and Moreira, 2011; Ueno, 1999). In this way, the maintenance of physical fitness through life, and during the longest period of time possible, is important to the health of the elder (Ballard, McFarland, Wallace, Holiday and Roberson, 2004; Barnett, Smith, Lord, Williams and Baumand, 2003; Skelton and

Beyer, 2003). Several studies have demonstrated the crucial effects of physical activity in physical fitness, health and well-being of the elderly at various levels (e.g., Leveille, Guralnik, Ferrucci and Langlois, 1999; Mazzeo *et al.*, 1998). For instance, by reducing the incidence of falls (Rivara, Grossman and Cummings 1997) and the risk of cardiovascular diseases (Berlin and Colditz, 1990). In this field of research, the specific practice of aquatic exercises has also been demonstrated to benefit elderly's life quality (Nakagawa and Rabelo, 2007; Sato, Kaneda, Wakabayashi and Nomura, 2007, 2009). However, to our knowledge little is still known about the effect that the evidenced development of the physical-functional fitness due to a program as such may have in the perception that the elderly have about their functional capability and their health condition.

2. OBJECTIVES

This study purposed to examine the relationship between the improvement of physical-functional fitness and the perception of the functional capacity and health in an elderly group, which performed a program of water-based physical activity. From this general goal, three specific ones emerged: 1) to study the variation of each physical fitness component; 2) to study the variation in perceived functional capability; 3) to study the variation in the perceived health.

3. DATA & METHODS

Twenty-six Portuguese elderly persons participated in this study (23 women and 3 men) aged between 60 and 84 years old. The majority of the participants were between 65-69 years old (corresponding to 46% of the entire sample; i.e., $n=12$) and a minority aged between 80-84 years old. The sampling strategy was a purposive sampling in which all the individuals engaged in the hydrotherapy program were asked to participate of this study. The later were informed about the purposes and details of the research and volunteered to participate. The sampling inclusion/exclusion criterion was the continuation in the program.

Participants engaged in a 31-week water-based exercise program. The sessions of the program lasted 45 minutes each and occurred twice a week. The sessions were constituted by exercises targeting to develop the different physical fitness components (aerobic fitness, strength, flexibility and coordination).

3.1 Data collection

The physical-functional fitness was assessed according to a battery of tests of physical-functional fitness established by Batista and Sardinha (2005) and adapted from de Rikli and Jones (1999, 2001) to the Portuguese population. This battery of tests considered the following parameters: a) aerobic capacity; b) physical mobility - speed, agility and dynamic balance; c) flexibility of the lower limbs; d) flexibility of the upper limbs; e) strength and endurance of the upper limbs; f) strength and endurance of the lower limbs; g) body mass index (BMI, computed as the individual's body mass divided by the square of their height). Were considered the following test items (cf., Batista and Sardinha (2005): *2-Minute Step Test* - Number of full steps completed in 2 minutes, raising each knee; *2.44-meters Up-and-Go* - Number of seconds required to get up from a seated position, walk 2.44 m, turn, and return to seated position; *Chair Sit-and-Reach* - Number of centimetres between the extended hands and fingers and the tip of toe from a sitting position at front of chair and with leg extended; *Back Scratch* - Number of centimetres between extended middle fingers

with one hand reaching over the shoulder and the other up the middle of the back; *Arm Curl* - Number of bicep curls completed in 30 seconds holding a hand weight (2.27 kg for women and 3.63 kg for men); *Chair Stand* - Number of full stands completed in 30 seconds with arms bent across chest.

The perception of the functional capacity and health condition by the elderly was assessed through a questionnaire adapted from SABC project (Lebrão and Duarte, 2003). This questionnaire with closed-ended questions (i.e., including answer choices) allowed analysing the perception that the elderly have of their functional capacities and included: the basic activities of daily living (BADL) (i.e., self-care activities such as eating, bathing, dressing, grooming, etc.); and the instrumental activities of daily living (IADL) (i.e., ability of an individual to have an independent life within the community being, for instance, able to make purchases, handle medications, manage their own finances, etc.). As in Lima-Costa, Firmo and Uchôa (2004)'s study, here we have also included in this questionnaire a final question for health self-evaluation (e.g., *How do you consider your health in overall?*). Data was gathered in three moments: initial or first evaluation (at the beginning of the program); intermediate or second evaluation (three months after the beginning of the program); and final or third evaluation (eight months after the beginning of the program).

3.2 Data analysis

Given that the data was not normally distributed (Kolmogorov-Smirnov $p < 0,05$) we used the Friedman test for assessing statistical differences between the physical-functional fitness and the questionnaire responses in each of the three evaluation moments (Martinez and Ferreira, 2008). Considering that the sample was large, we found appropriate to use the Chi-Square distribution approximation to the Friedman test. Statistical analyses were performed using SPSS 17.0 at the significance level of 5%. Statistical analysis on the responses of the data collected by the questionnaire about the BADL and IADL was performed according to the following categories: *high level of functionality* (i.e., in all the six questions “can” was the chosen answer); *moderate level of functionality* (i.e., 1-2 answers as “achieved with difficulty or help”, meaning they perceived that they could do what was being asked but with a limited extent/conditioned); *low level of functionality* (i.e., 3 or more answers as “can with difficulty or help”).

4. RESULTS

Results obtained are displayed according to the purposes of this study, that is, to assess the putative effects of a water-based exercise program in the: physical-functional fitness of the elderly; their perceived functional capacity; their perceived health.

4.1 Assessing Physical-Functional Fitness

As shown in table 1, the different analysed parameters of physical-functional fitness improved with the program.

Table 1. Statistical parameters of the physical-functional fitness battery of tests applied during of the three evaluation moments

Evaluation tests	1st Evaluation	2nd Evaluation	3rd Evaluation	Friedman Test
2-Minute Step Test				
Mean	60,62 steps	74,31 steps	80,62 steps	$\chi^2_{2,0,95} = 33,838; p < .001$
Median	58,50 steps	74,50 steps	80,00 steps	
Standard deviation	19,50 steps	24,18 steps	23,84 steps	
2.44-meters Up-and-Go				
Mean	6,82 sec	6,15 sec	5,81 sec	$\chi^2_{2,0,95} = 18,608; p < .001$
Median	6,90 sec	6,04 sec	5,89 sec	
Standard deviation	1,34 sec	1,13 sec	0,62 sec	
Chair Sit-and-Reach				
Mean	0,19 cm	3,25 cm	7,96 cm	$\chi^2_{2,0,95} = 30,765; p < .001$
Median	0,75 cm	3,00 cm	7,50 cm	
Standard deviation	7,65 cm	6,39 cm	5,15 cm	
Back Scratch				
Mean	-10,77 cm	-7,92 cm	-7,87 cm	$\chi^2_{2,0,95} = 8,871; p = ,012$
Median	-11,50 cm	-8,00 cm	-7,00 cm	
Standard deviation	9,13 cm	8,47 cm	8,44 cm	
Arm Curl				
Mean	8,73 curls	11,38 curls	15,08 curls	$\chi^2_{2,0,95} = 33,204; p < .001$
Median	9,00 curls	11,00 curls	15,00 curls	
Standard deviation	4,49 curls	4,29 curls	4,64 curls	
Chair Stand				
Mean	10,15 stands	12,65 stands	13,88 stands	$\chi^2_{2,0,95} = 30,372; p < .001$
Median	10,00 stands	12,50 stands	14,00 stands	
Standard deviation	3,37 stands	3,29 stands	3,47 stands	

In what concerns the evaluation of the body mass index, the results showed (see table 2) a decrease in the number of participants with obesity and a small increase of participants with normal weigh.

Table 2. Body mass index in the three evaluation moments

BMI	1st Evaluation	2nd Evaluation	3rd Evaluation
Normal weight	4 (15,4%)	6 (23,1%)	6 (23,1%)
Overweight	13 (50%)	11 (42,3%)	14 (53,8%)
Obesity	6 (23,1%)	6 (23,1%)	3 (11,5%)
Super obesity	3 (11,5%)	3 (11,5%)	3 (11,5%)

4.2 Assessing elderly's perceived functional capacity

The perception of the functional capacity fitness focused on the basic daily living activities and the instrumental daily living activities.

4.2.1 Basic activities of daily living (BADL)

Results presented in table 3 indicate that during the three evaluations the majority of the participants shown a *moderate level of functionality* (between one and two conditioned activities) (1st evaluation: n=9, 34, 6%; 2nd evaluation: n=13, 50%; 3rd evaluation: n=19,

73,1%). On the other side, the number of participants with a *high level* and a *low level of functionality* decreased after the 31 weeks of the water-based exercise program although these differences were not statistically significant (high level: 1st evaluation, n=8, 30,8%; 3rd evaluation n=6, 23, 1%; low level: 1st evaluation, n= 9, 34,9%; 3rd evaluation n=1, 3,8%).

Table 3. Perceived capacity to perform Basic Activities of Daily Living (BDAL) during the three evaluation moments considering all participants

		1st Evaluation	2nd Evaluation	3rd Evaluation	Friedman Test
High	0	8 (30,8%)	9 (34,6%)	6 (23,1%)	$\chi^2_{2,0,95} = 1,877, p = ,391$
Moderate	1-2	9 (34,6%)	13 (50%)	19 (73,1%)	
Low	3 or more	9 (34,6,9%)	4 (15,4%)	1 (3,8%)	

4.2.2 Instrumental Activities of Daily Living (IADL)

In what concerns the Instrumental Activities of Daily Living (table 4), the number of participants with high and moderate levels of functionality increased from the 1st to the 3rd evaluation (moderate n=17, 65,4% to n=20, 76,9%, correspondently; high n=2, 7,7% to n=5, 19,2%, correspondently). In addition, and as also verified for the BADL, the number of participants with a *low level of functionality* decreased during the program (1st evaluation: n=7, 26,9%; 2nd evaluation: n=3, 11,5%; 3rd evaluation: n=1, 3,8%). These results show that the elderly, after 31 weeks of participation in hydrotherapy sessions, significantly improved their perception of their functional capacity fitness when assessed in relation to the Instrumental Activities of Life.

Table 4. Perceived capacity to perform Instrumental Activities of Daily Living (IDAL) during the three evaluation moments considering all participants

		1st Evaluation	2nd Evaluation	3rd Evaluation	Friedman Test
High	0	2 (7,7%)	9 (34,6%)	5 (19,2%)	$\chi^2_{2,0,95} = 7,684, p = ,021$
Moderate	1-2	17 (65,4%)	14 (53,8%)	20 (76,9%)	
Low	3 or more	7 (26,9%)	3 (11,5%)	1 (3,8%)	

4.3 Assessing elderly's perceived health status

When asked about their health status, over 50% of elderly said *reasonable* at the three evaluation moments (1st: n = 15, 57.7%; 2nd evaluation: n = 17, 65.4%; 3rd evaluation n = 14, 53.8%) (see table 5). Elderly people who responded that they had *good health* in the third evaluation doubled compared to the first evaluation performed. Those who recognized their *poor health* in the first evaluation (n = 5) changed their minds on the third moment (n= 0). Overall, in all three evaluations, participants seem to perceive that their health improved with the implementation of the physical activity program.

Table 5. Perceived health during the three evaluation moments considering all participants

	1st Evaluation	2nd Evaluation	3rd Evaluation	Friedman Test
Good	6 (23,1%)	6 (23,1%)	12 (46,2%)	$\chi^2_{2,0,95} = 8,109, p = ,017$
Reasonable	15 (57,7%)	17 (65,4%)	14 (53,8%)	
Poor	5 (19,2%)	3 (11,5%)	0 (0%)	

5. CONCLUSIONS

In general, this study showed that the water-based exercise program (hydrotherapy) that was applied to elderly people during 31 weeks might have lead to an improvement of their physical and functional fitness levels in what concerns most of the parameters analysed. These findings corroborate previous studies showing evidence of physical activity benefits on the following parameters: aerobic capacity (e.g., Gonçalves, 2003; Carvalhais, 2004; Teixeira, 2004); mobility (e.g., Gonçalves, 2003; Teixeira, 2004; Botelho, 2002; Alves, 2001); superior flexibility (e.g., Cavani *et al.*, 2002); lower limb strength (e.g., Batista and Sardinha, 2005); upper limbs strength (e.g., Gonçalves, 2003; Carvalhais, 2004).

The evolution observed over the three evaluation moments in relation to the lower limb flexibility contrast with those observed in studies of Carvalhais (2004) and Padilha (2007) in which no changes were verified in lower limb flexibility after eight months and ten weeks of participation in a program of physical activity and water aerobics, respectively. This can be explained by the fact that the present program did not include specific exercises stimulating this capacity.

Although in this study body composition measures (e.g., percentage of fat mass, lean mass, and water) of the elderly were not considered, nor were controlled variables such as diet and basal metabolism, the trend of decrease in BMI values is consistent with the results obtained by Gonçalves (2003) and Hunter *et al.* (2002).

In what concerns the influence of the program on the perception of the elderly about their functional capacity, both dimensions had improvements but only the perception about the Instrumental Activities of Daily Living (IADL) verified significant changes. Additionally, participants seemed also to perceive that their health improves with the physical activity program. This suggests that the improvement of physical-function fitness levels, and the general improvement of the IADL, may be relevant for the elderly on the overall perception of their health status. The “having a life” category found in the study of José, Barros, Samitca and Teixeira (2013) may be related with the aforementioned relation, in the sense that “*having a life*” considers “the capacity to be independent (although with some restrictions and adjustments) associated to the capacity to sustain some daily routines” (p.197).

In short, this study’s findings suggest that a program of water-based physical activity, held twice a week and lasting 45 minutes by session, during 31 weeks, seems enough to induce changes in the physical-functional fitness of the elderly, as well as in the perception they have about their health and ability to perform activities of daily living.

6. MAIN CONTRIBUTIONS OF THE STUDY

This study reinforced the known relation between physical-functional fitness and the systematic practice of physical activity, in this case a water-based exercise program. The study also revealed that an improvement in physical-functional fitness might have also

induced an improvement in the perception of the capacity to perform daily living activities and of elderly's health condition.

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ARE SOCIAL REPRESENTATIONS OF POSITIVE AGEING REALLY EFFECTIVE? THE AGEING PROCESS THROUGH THE EYES OF ELDERLY

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ABSTRACT

In this paper we focused on the experiences of ageing from the perspective of elderly people. Our main aims were to explore their perceptions and representations about the ageing experience and to analyse if their conceptions are closer to positive social representations of active ageing or to ageist social assumptions. Thirty-five females (mean age of 80 years) and seven males (mean age of 73 years) participated in this study, recruited in a network of institutions run by the city council of Setubal. Data collection was conducted with structured interviews and the obtained transcriptions were submitted to qualitative thematic analysis. With this analytic approach it was possible to identify dominant themes in participants' discourses. Results show that elderly perceive and represent the process of ageing according to a binary perspective, displaying both positive and negative dimensions. Even if the ageing experience is described according to a positive perspective, it is also anchored on ageist social constructions. Thus the positive social representations of ageing expressed through active ageing discourses are still not fully assimilated and integrated on people's self-perceptions and identities.

Keywords: Ageing, Older People, Social Representations, Ageism

JEL Classification: I31

1. INTRODUCTION

Ageing has become a central topic in modern societies, as it is associated to a number of complex challenges that individuals, institutions, politics, science and society in general need to face. In fact, from a global perspective, ageing is understood as a fundamental collective challenge considering the overall reduction in the number of births and the increasing in life expectancy (United Nations, 2001). This socio-demographic pattern is particularly evident in Europe (United Nations, 2007, 2009) and became highly significant in Portugal in the last decades (Canudas-Romo, 2008; Mota-Pinto *et al.*, 2011; Santana, 2000; United Nations, 2009).

Academics and professionals from different disciplines have dedicated much more attention to the rapid growth of the ageing population since the 1990's (Pike, 2013) and ageing emerged as one fundamental concern in the international agenda. In 2002, the World Health Organization presented an approach to successful ageing, which was framed on the

concept of 'active ageing' (WHO, 2002), in order to inform and guide research, practice and policies related to positive ageing (AGE, 2012; European Parliament and the Council of the European Union, 2011; Hutchison, Morrison and Mikhailovich, 2006; Sánchez and Hatton-Yeo, 2012).

After the publication of WHO, international institutions and political agents have emphasized the importance of promoting positive meanings in relation to ageing and discourses are now much more related to ideas of autonomy, activity, health and productivity, than they were before. One recent example of such a narrative is evident through the European Year for Active Ageing and Solidarity between Generations in 2012.

Despite these public and political efforts, the way people experience age and ageing, and their level of well-being, are strictly related to their trajectories of life and to the social, economic and institutional contexts where they participate across their life span (Figueiredo *et al.*, 2007). Knowledge about the ageing experience is still limited (Wachelke and Contarello, 2010). On one hand, because it cannot be restricted to a biological perspective, and on the other hand, there is a lack of consensus on what active or positive ageing actually means (Bowling, 2008; Marques, Batista and Silva, 2012; Sánchez and Hatton-Yeo, 2012).

Much of the early literature on ageing and old age was supported on a biomedical model, which underlined the general notion of decline, illness and disease. For instance, in terms of physical health there is a kind of a 'medical myth' that ageing is a synonymous of disease (Sidell, 1995) and older people view illness and old age as strongly linked (Fee, Cronin, Simmons and Choudry, 1999; Sidell, 1995). A recent cross-cultural study suggests that this biologically based perception is culturally shared and less disposed to cultural variation whilst motivational priorities and societal roles are much more dependent on contextual dimensions (Lockenhoff *et al.*, 2009).

The persistence of the biomedical paradigm and the existence of cultural contrasting dimensions strongly reinforce the assumption that the views of ageing held within a given culture are a form of shared cultural representation (Tam, 2014). Indeed, ageing is an object of social construction, culturally rooted, and therefore it can be transformed and adapted through knowledge (Ferreira *et al.*, 2010; Santos *et al.*, 2013). For instance, in relation to health, research has shown that socially shared representations of health exist, and are constructed and transformed in everyday communication (Flick, 2002). Hence, one central question is whether or not the discourses of active ageing impact on, and change, older adults ageing perceptions. Guided by the approach of social representations, in this paper we addressed the experiences of ageing from the point of view of older adults themselves. It is relevant to understand how the experience of ageing is conceptualized from the perspective of the ageing population and how lay knowledge is related to social definitions, individual conditions, beliefs, norms, values and social roles that are culturally embedded.

Research on the topic of ageing needs to acknowledge if older adults perceive themselves and their developmental experiences according to the multidimensionality which is expressed through the discourses of active ageing and well-being or if socially shared negative images of ageing still persist on their self-conceptions. Hence, with this study we aimed to contribute to a deeper knowledge on the impact of active ageing policies and discourses on older people's lives and identities.

1.1 Active ageing framed by WHO and the European Union

The first decade of 2000 was marked by the growing political concern and intervention of international institutions on the topic of ageing and intergenerational solidarity. WHO framework for active ageing was published in 2002 and its main rationale is anchored on the following assumption: "*the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age. [...] Maintaining autonomy and independence as one*

grows older is the key goal for both individuals and policy makers" (p. 12). In this proposal emphasis is placed on health, participation and security of ageing populations. Additionally, remaining autonomous and independent as long as possible is central to the achievement of active ageing goals. Autonomy refers to the perceived ability of individuals to control and decide in relation to their own lives, based on their preferences, values and beliefs. And independence is much more related to the individual capacity to undertake an independent way of life in community. Therefore, in WHO framework older adults are key agents for active ageing programs and full participation in activities of community life is encouraged.

In 2010, with the preparation of the 2012 European Year for Active Ageing and Solidarity between Generations, the Council of the European Union presented a new conceptual proposal for active ageing, where: *Active ageing means creating opportunities for staying longer on the labour market, for contributing to society through unpaid work in the community as volunteers or passing on their skills to younger people, and in their extended families, and for living autonomously and in dignity for much and as long as possible* (p. 5). In this perspective, the concept of active ageing was expanded to include the idea of productivity. Productive ageing is thus linked to the contributions that older adults give or can give to society (Sánchez and Hatton-Yeo, 2012).

In conclusion, both approaches stress the importance of older populations' independence, autonomy and contributions to society but according to different terms. The former is much more related to ideas of participation, self-dignity and self-fulfilment while the later highlights economic and work related aspects. And still, one central question remains: how effective are these discourses about agency, activity and productivity in older people's self-conceptions, identities and ageing experiences?

1.2 Ageing and Social Representations

The concept of social representation is of particular interest for research focusing on the social construction of social knowledge (Flick, 2002). From a broad perspective social representations form comprehensive and persistent *models* about social reality, which are based on specific images, beliefs and symbolic behaviours (Moscovici, 1998). Consequently, they represent 'versions' of reality that are socially shared and have a double function: to orient people's action and communication in different contexts of daily life (Moscovici, 1976). People use categories of meaning that circulate in their social environments and culture to think, talk about or relate with phenomena of social life such as ageing.

Social representations are created and transformed in social interaction and communication, forming a set of propositions, reactions and evaluations that circulate through public opinion. Moscovici (1976) has called it the 'collective choir', where people are included in a voluntary or involuntary way. Nevertheless, this voice of opinion is not homogenous and its form of organization will vary according to social classes, cultures and groups. This is why different codes or 'universes of opinion' co-exist in public space and there is a vast diversity of meanings associated to objects of social life. Different groups can create representations with different contents, structure and coherence, depending on their access to information, values, ideologies and forms of communication, to give some examples.

Thus, social representations can be compared to *theories*, which organize a set of ideas that permit to classify people, describe their characteristics, explain their feelings and behaviours, and so on (Moscovici, 2000). And these aspects are contextualized in a straightforward relation with specific groups and particular historical and political circumstances.

There is a mutual influence between social representations and the construction of social identities: social representations are present in identity processes and these, in turn, are involved in the creation, maintenance and use of representations (Breakwell, 1993). As members of specific groups, people create their self-definitions and definitions of others

according to a close relation between representational and identity dimensions and these are significant elements in symbolism and concrete social interactions (Jovchelovitch, 1995).

Approaching the study of ageing through the framework of social representations is relevant and justified in the sense that meanings which are socially attributed to this particular phenomenon are present and take shape in social organization and interaction. The current forms of social thought that circulate in modern societies have direct implications on self-classifications of older adults, on how they relate with others, and on how societies include or marginalize them (Freixas, Luque and Reina, 2012; Pike, 2013; Reed *et al.*, 2003).

Literature review suggests the existence of communalities in social representations about ageing (Wachelke and Contarello, 2010), even if there are some specific dimensions related to age (Wachelke, 2009) and cultural contexts (Liu *et al.*, 2003). In fact, several studies show that those representations are rooted in two major themes: gains and losses in biological and psychological domains (Ferreira *et al.*, 2010; Pike, 2013). The positive field of representation combines a set of meanings that are associated to this specific stage of life: experience, accumulated competencies and knowledge, maturity, tranquillity and wisdom (Gil and Santos, 2012; Santos *et al.*, 2013; Sousa and Cerqueira, 2005; Wachelke, 2009). This appreciated representation of ageing gains is also related to the possibility of undertaking valued activities, such as taking care of the home place and grandchildren (Ferreira *et al.*, 2010), keeping close to the family, social relationships, social belonging, being personally autonomous and having some capacity to work (Santos *et al.*, 2013; São José *et al.*, 2013).

On the negative field, losses associated to ageing are at the centre of the representation: incapacity, depending from others, general vulnerability and illness, lower agility and physical limitations, discomfort, being close to death, and difficulty to manage daily life independently (Ferreira *et al.*, 2010; Gil and Santos, 2012; Santos *et al.*, 2013; Sousa and Cerqueira, 2005; Uchôa, 2003; Wachelke, 2009).

The emergence of these attributes and negative aspects in the representation of ageing are not independent from socio-economic conditions, level of social inclusion, available socio-familiar supporting resources (Guerra and Caldas, 2010), and also from individuals' perceptions and representations of active ageing (Bowling, 2008).

According to these findings negative attitudes and representations towards old age seem to be linked to the assumption that there is an age related decline in older adults' mental and physical functioning. However, there is lack of evidence supporting a straightforward connection between increasing age and declining health and capability (Abrams, Vaclair and Swift, 2011). Ageism is a relevant and helpful concept to acknowledge this propensity to a kind of gerontophobia (Bunzel, 1972) that takes place both at the social and individual levels.

1.3 The expression of Ageism in the representations of old age

Ageism can be described as negative attitudes towards individuals or groups simply because of their age (Greenberg, Shimel and Martens, 2002). Like all attitudes, ageism can be expressed according to stereotypes (cognitive expression), prejudice (affective expression) and discrimination (behavioural expression) (Lima, 2000). For older people, prejudice and discrimination are commonly associated to subtle ways of expression, according to benevolent or patronizing stereotypes of higher warmth and lower competence. Research from the field of Social Psychology has shown that this form of 'benevolent' or paternalistic prejudice is related to feelings of pity, which follows from a double pattern of stereotyping – being 'friendly' but incompetent (Abrams, Eilola and Swift, 2009; Cuddy, Norton and Fiske, 2005; Ray, Sharp and Abrams, 2006). The exposure to subtle forms of discrimination may have a negative impact on older people's age identification, self-esteem and identity.

To some extent, age is in the eye of the beholder and people also apply ageist stereotypes to themselves, sometimes without having the awareness that they are doing so (Levy and Banaji, 2002). Socially and psychologically the use of age categorization can be highly problematic because it may cause people to restrict their own activities and roles based on ageist assumptions (Abrams, Vauclair and Swift, 2011).

Because Europe is a very diverse region, people in some countries may show more favourable or unfavourable attitudes towards age, or more positive or negative experiences with age. In fact, recent findings from the European Social Survey 2008-09 (ESS) suggest that ageism differs across cultures and is related to cultural, social and political dimensions. Nevertheless, there is a common pattern among the 28 countries that participated in the fourth round of ESS, Age Attitudes and Experiences of Ageing, showing that ageism is seen as a serious problem across Europe.

Moreover, age discrimination is the most experienced form of discrimination, when compared to sex and race or ethnic background, mainly among young people and with subtle forms of expression. Plus, people aged over 70 are more likely to be seen as stereotypically warm (or friendly) than competent (Abrams *et al.*, 2011). In the Portuguese case however the experiences of discrimination tend to increase with age. That is to say, ageism is more frequent towards older people. Additionally, in accordance with other European countries, Portuguese people perceive elderly as a threat to economy, and social contact with individuals from this age group is low (Lima *et al.*, 2010).

These results enlighten the potential consequences of age-based perceptions and attitudes on how people relate with ageing processes, treat older adults and also on how these see themselves (Abrams, Vauclair and Swift, 2011). Hence, an important determinant of the difficulties associated with ageing is truly the problem of ageism.

1.4 Our research

Literature and findings from ESS offer an important insight on how representations of age and other relevant socio-demographic dimensions might be connected to people's attitudes and experiences. Even if there is a political and institutional effort to underline the positive dimensions of ageing, through the discourse of active ageing, ageist attitudes seem to be rooted in cultural values and negative social representations associated to old age. One highly significant consequence of this psychosocial phenomenon is the fact that people internalize these negative assumptions in their conceptions about ageing and in their own identities. In this paper we addressed the experiences of ageing from the perspective of older adults themselves. Our main aims were: 1) to explore their perceptions and representations about the experience of ageing; and 2) to analyse if their own conceptions show the internalization of positive social representations of active ageing or the prevalence of ageist social assumptions.

2. METHODS

2.1 Participants

Forty-two older adults participated in this study on a voluntarily basis: thirty-five females (mean age of 80 years, range 57-90 years) and seven males (mean age of 73 years, range 42-91). The sampling strategy adopted for this study was one of convenience and participants were recruited from a network of institutions run by the city council of Setubal - *Rede EnvelheSeres*. This network includes different types of institutions, namely: day-care centres (DCC – 27 participants), residential homes (RH – 6 participants) and mixed institutions that function both as residential homes and day centres (RH/DCC – 9 participants).

This study was integrated in an inter-disciplinary teaching and learning activity, organized and conducted by teachers and students from the School of Health of Polytechnic Institute of Setubal (ESS-IPS). The main goals of this activity were to promote the understanding of specific features and needs of older people regarding their own ageing process, and to contribute to the development of effective communication competences of students with this specific population.

Each participant signed the respective informed consent before the activity. People with communication problems, severe motor impairments or significant cognitive deficits were excluded from the study.

Demographic characterization of participants is presented in Table 1.

Table 1: Distribution of participants by sex, mean and age range

Sex	N	Age	
		Mean	Range
M	7	73	42-91
F	35	80	57-95
Total	42	79	42-95

The distribution of participants according to the type of institution is presented in Table 2.

Table 2: Distribution of participants according to type of institution

Institution	N
DCC	27
RH	6
RH/DCC	9
Total	42

2.2 Procedures

Data collection was conducted with structured interviews, which focused on the perceptions and representations about the experience of ageing. Multi-professional groups of three/four students (Nursing, Physiotherapy, Speech and Language Therapy) conducted the interviews with each participant. Students had previous preparation with the aims of the interview and the questions to be used. Roles were assigned prior to the interview situation – main interviewer, secondary interviewer, observer and note keeper. The forty-two groups of interview were divided into different rooms in order to minimize external disturbances.

All interviews were conducted and fully transcribed into Portuguese. The authors of this paper were responsible for the translation process into English.

2.3 Analytical methodology

The corpus of interviews was submitted to qualitative thematic analysis (Braun and Clarke, 2006). This analytical approach highlights both the communalities and differences in discourses expressed by participants on dominant themes (Breakwell, 2008) without quantifying the incidence of key words (Flick, 2006). Through coding procedures and analysis of semantic patterns in data it was possible to identify central themes emerging from the discourses of participants. Such a procedure was fully checked and reviewed by four members of the research team in order to guarantee the quality of analysis.

3. RESULTS

Literature on social representations of ageing experience suggests a consistent thematic pattern based on two main dimensions, positive and negative, primarily related to biological and psychological issues (Wachelke and Contarello, 2010).

The themes highlighted by our analysis are also anchored in a binary perspective – potentials and constraints of ageing, however our subjects went beyond the biological and psychological point of view, addressing the significance of meanings in different dimensions of the human personhood and experience.

Regarding the theme of ageing potentials, we identified five subthemes: (1) autonomy; (2) activity and leisure; (3) acceptance of ageing; (4) family relationships and network of social support; (5) experience, learning and knowledge.

3.1 Autonomy

Autonomy is essential to healthy ageing and quality of life and has often been associated with the concept of independence. The ability to carry out activities independently is one of the positive aspects that participants associate with ageing, unlike some social discourses, which underline elderly's dependence or incapacity.

Some of our participants live and make their decisions by themselves, without requiring the intervention of family, friends or health professionals:

"Although I am tired, I keep doing my normal life";

"I manage my daily activities by myself and in an independent way";

"Ageing did not change my autonomy, I manage my money".

Autonomy is also valued and developed according to a proactive attitude and is reflected in a sense of worth and wellness:

"I am an independent person because I want to";

"I am active and autonomous and I really enjoy it";

"I feel good in my everyday life; I live alone, I take my medication and clean my house".

3.2 Activity and leisure

Results show that autonomy is identified, partly, as a consequence of participation on leisure activities. Participants expressed that staying involved in meaningful activities contributes for their well-being and health:

"I am very active and happy";

"I am good at painting, still do some restoration jobs and paint";

"I feel very useful because I still do sewing";

"I like to keep my house pretty and always buy fresh flowers and talk to them every morning".

At this stage of life, some of them referred the importance of having more time and freedom for projects and dreams that they were not able to perform before, such as gardening, travelling and dancing:

"I have more time for myself";

"Now I have a vegetable garden, it's like a therapy";

"Since I retired I made a few trips";

"I have time to do what I like, going out, playing, going to dance";

"I have more freedom and time to do things".

3.3 Acceptance of ageing

Acceptance of ageing corresponds to the third subtheme. This perspective is reinforced by ideas that accentuate ageing as a "natural" process, which must be accepted, despite the possible occurrence of diseases:

"It has been a natural process; it is a phase like many others";

*"I see it naturally and with peace, living one day at time";
"It's been a good experience, a good phase of my life";
"I feel good with myself and with getting older";
"Illness is not a problem; the process of ageing is a positive aspect".*

Acceptance of ageing also involves learning and finding strategies that permit adaptation to different changes/transitions at physical, psychological and social levels:

*"It's a natural process with which one has to learn to cope and live with";
"I am getting aged with joy, with good acceptance of the process and great motivation to live".*

3.4 Family relationships and network of social support

During old age, mainly because of increased vulnerability, informal (family/friends/neighbors) and formal support networks (social and health institutions) become crucial. Participants stress the importance of being close to and supported by their relatives, with whom they can share quality and joyful moments:

*"My brother takes me for walks on weekends, on festive days";
"My family supports me a lot";
"I see my grandchildren very often, they like me very much".*

Being included in a network of social support – comprised of friends and neighbors – seems to contribute positively to the acceptance of the ageing process and to the enrichment of older adults' lives:

*"I like to be with friends, I am happier";
"I have many friends, friends that are as gold; they help me at my worst days and do not let me stop";
"I keep in touch with a friend for 50 years";
"I get along well with the neighbors".*

Formal support networks, such as day centers and residential homes, are also a key resource for health and safety. All participants are included in a formal network of social support, with different institutions from the municipality of Setubal, which allows them to undertake different leisure activities and being socially connected:

*"I love being in day care, it's a support";
"I like being in a residential home because I have the company of my colleagues and it's a way to get distracted";
"The experience at the residential home has helped a lot".*

3.5 Experience, learning and knowledge

In the words of participants, old age also emerges as a stage of life with advantages arising from the experience, learning and knowledge which they accumulated during their lives. Previous experiences help to perceive life in a different way and to develop new interests and connections, particularly with younger people:

*"[Ageing] Brings new experiences and learning with others, especially with young people";
"Being older is very positive; it allows you more life experiences, age allow us to be like encyclopedias";
"[Ageing gives] All the experiences that I gained across life".*

For some, age has permitted psychological growth and change, wisdom and helped them to improve personal skills and social relationships:

*"Now I have more patience and calmness";
"Old age has brought me an improvement in judgment";
"I began to understand and see people as they are, I realized that we need to speak and understand people to like them";
"I find it easier to relate with other people".*

Regarding the theme of ageing constraints, we identified four subthemes: (1) physical limitations and disease; (2) dependence; (3) financial constraints and (4) loss and loneliness.

3.6 Physical limitations and disease

Even if ageing is not a synonym of disease, participants have underlined the association between ageing, illness and physical losses and stressed its impact in their quality of life:

“My old age is a sign of illness and I have some of it”;

“Ageing has not been very good because of health problems”;

“With ageing it seems that we lack everything: vision, hearing, difficulty in walking”;

“After my stroke the experience of ageing has begun, more diseases appeared and I became less active”.

3.7 Dependence

The feeling of being old is often related with an increasing awareness of no longer being able to do things in the same way as before. Some of the participants report their dependence on others and the need to leave their homes:

“I am dependent for many things, I no longer can live in my house”;

“It is hard to depend on others; because I have health problems, it is not possible to be alone”;

“I depend on my son. I cannot be alone so he had to move to my house”.

Dependence is mainly physical and it constrains individuals' capacity and competence for undertaking the routines of daily life and even to enjoy free time:

“I feel physical difficulties and became dependent for the activities of daily living”;

“I cannot travel, I have pain in the joints, lack of balance, lack of strength and lost my autonomy”.

3.8 Financial constraints

Financial constraints reflect a relevant negative aspect of old age and unveil another form of dependence from others. Participants stress their difficulties to manage different sources of expenses, namely with medication and costs related to residential homes, since their pensions are low:

“I have big financial constraints because I don't work anymore and live from my pension”;

“I have financial problems; they took away my exemption from illness and now I have to pay the medical appointments and exams for full price”;

“It has been one of my brothers who is paying the residential home because my pension is not enough and I have no social support from services”.

Despite personal interests, leisure activities are restricted for financial reasons:

“Today there are things that I cannot have. Before I could travel and now I cannot do it anymore”.

3.9 Loss and loneliness

Death and loss of relatives and friends are also present in the discourses of our participants. Interpersonal and emotional loss emerged as a significant aspect of ageing constraints. In fact, dealing with the death of close family members and friends seems to be one of the most difficult transitions in old age:

“The loss of people is the worst in ageing; I lost my son and my husband”;

“The worst thing about ageing is the loss of people who are close to us”;

“Widowing was the hardest”;

“We lose people who are dear to us, people who have been with us all our lives”.

On another hand, living alone has implications in older peoples' well-being and safety:

“I'm afraid to be alone, to need something and not having anyone to help me”;

“I am alone at home; if something happens, no one will notice”.

Being alone is also a relevant factor for increasing vulnerability in terms of emotional suffering:

*"After the death of my wife I have no pleasure in life";
"I feel alone in this world".*

In some cases, pets are one possible opportunity to maintain a close relationship:
"I live alone with my cat and he is an important company to me".

4. DISCUSSION

These results are discussed based on the social sciences literature, namely through the paradigm of social representations, focusing on the psychosocial aspects of ageing.

The participants in our study had a mean age of 79 years, although men's mean age was considerably lower when compared to women (73 *vs* 80). As we recruited the sample at institutions for older people (day care centres and residential homes) this age range was expected, as people themselves and families only seek support when the risk of being at home alone is higher. Somehow we look at this group as belonging to a more fragile slice of the older population, as they have already felt the need to seek social help. The distribution between sexes was equally expected taking into account that life expectancy of men is lower than women in Portugal.

As suggested by Ferreira *et al.* (2010) and Pike (2013) we have identified two main themes (potentials and constraints of ageing) in the representations of the ageing process, which were based on the gains and losses in biological, psychological and psychosocial domains.

The dimensions identified in the positive domain are very much related with the ability to take care and maintain the previous lifestyle. These dimensions of meaning have been previously identified in other studies, such as the ability to care (Ferreira *et al.* 2010), keeping a close social and emotional network of support, as well as being personally autonomous (Santos *et al.*, 2013; São José *et al.*, 2013). Another positive aspect suggested by different authors (Gil and Santos, 2012; Santos *et al.*, 2013; Sousa and Cerqueira, 2005; Wachelke, 2009) is related to accumulated knowledge, wisdom and maturity.

However, the application of such knowledge and experience and the usefulness that it may bring to society at large, requires a society free of ageist conceptions and attitudes, which, we are aware is not the case, since experiences of discrimination towards older people, tend to increase with age in Portugal (Lima *et al.*, 2010). These attitudes are mainly based on a vision that older people are friendly but incompetent (Abrams, Eilola and Swift, 2009; Cuddy, Norton and Fiske, 2005; Ray, Sharp and Abrams, 2006).

The constraint dimensions identified by our analysis are also similar to those of other studies, being strictly linked with the loss of ability (physical or emotional). In addition, loss and loneliness seems to have a strong impact in older adults' lives. Various authors (e.g.: Reed, Satanley, and Clarke, 2004; Petrella, 2012) have emphasised that the change of lifestyle in modern society, as well as the changes in demography, have an impact on the ability to provide support, as requested by a more vulnerable group of the population as older people in this age range appear to be.

Loneliness is one of the aspects that have been identified as a trigger to greater vulnerability, which can affect safety and health of older people. The expectations that each person has with regards to the type, frequency and number of social contacts influence their feelings of loneliness. This is a subjective feeling, associated with the quality of social interaction and not with the quantity of contacts (Freitas, 2011).

However, this loss appears to be related with other factors such as socio-economic conditions, level of social inclusion, and availability of socio-familial supporting resources (Guerra and Caldas, 2010). This inter-connection of factors becomes very relevant in the understanding of perceptions and representations people have of their own process of ageing,

and our results reinforce this assumption. Cook (2004) has stressed that a stable financial support is important in determining the quality of older people's lives. It becomes relevant to highlight that our study was carried during the financial crisis in Portugal, and older people's financial resources have been heavily penalized between 2011 and the present.

An initial analysis of our data suggests that participants perceive their ageing process through the bio-medical model with a strong connection between illness and old age (Fee, Cronin, Simmons and Choudry, 1999; Sidell, 1995). However, social representations are created and transformed in social interaction and communication and therefore one can look at this as a potential modifiable representation.

The framework of Active Ageing proposed by WHO (2002) and that of the European Union (2012) present clear different focuses, being that the latter introduces economic and productivity related aspects. Looking at our results, this dimension is not present. Clearly the discourses about activity and productivity are not yet integrated in older people's self-conceptions and representations of ageing. On the other hand, different aspects such as opportunities for health, participation and security appear through the dimensions of potentials' theme, such as autonomy, or leisure activities and quality of life. This result suggest that these aspects of WHO discourse on active ageing is much more integrated in older adults ageing representations.

Nevertheless, the negative dimensions of the ageing process seem to be a relevant part of the discourses (financial constraints, dependency, loneliness) of participants in our study, suggesting that policies putting forward already 12 years ago (WHO, 2002) are still not fully assimilated and integrated in older people's identities.

In order to achieve the goals proposed by international policies, which is socially desirable, it is required a translation into law and a deeper transformation in people's attitudes. Ageism is characterized by negative attitudes towards people because of their age (Greenberg, Shimel and Martens, 2002). For older people, prejudice and discrimination are commonly associated to subtle ways of expression, according to benevolent or patronizing stereotypes of higher warmth and lower competence. This may be one important reason for the absence of meanings related to productivity in our results. Following from Abrams, Vauclair and Swift (2011), the risk that older people themselves assume these attitudes can increase the impact of ageist stereotypes in the quality of life of older people. That is to say, the use of age categorization may cause people to restrict their own activities and roles based on ageist assumptions.

5. CONCLUSION

This study enabled the collection of data related to older people's perceptions and representations of ageing and old age. It allowed an analytical approach towards the ways they cope with the ageing process and how they see themselves and other seniors.

Based on our results is possible to understand that elderly's conceptions and the embedded negative representations about ageing require a deeper intervention near this population, but also in society at large as it plays a key role in deconstructing the negative conceptions about ageing.

The main findings of our study also pave the way for future reflection on strategies that could raise awareness about the experience of ageing and to further develop social networks related to this phenomenon or strengthening the existing ones. Thus, one fundamental goal of health professionals, policy makers and social institutions should be focused on the promotion of positive attitudes and representations about the ageing process.

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MIGRANTS COPING WITH LEGALITY: THE VIEWS AND EXPERIENCES OF OLDER PERUVIANS AND MOROCCANS

Angeles Escrivá

ABSTRACT

Migrants' and their family members' living conditions in origin and destination countries have come to depend very much on how they cope with the laws and legal systems that affect them. Attached to the importance of acquiring a legal status, there are specific areas of juridical and administrative regulation that are of enormous interest for older people living in a family context of migration, such as pensions and the capacity to move to be closer to loved ones. Based on qualitative research with people aged 50 and over in Spain, Peru and Morocco, the article explores older individuals' responses to the legal frameworks, and, especially, inquires on the practices that help them benefit from or overcome the laws. It reveals that, as a result of states' unclear legal actions, together with the desire to overcome barriers in these specific areas, interviewees are forced to act against or at least partially behind the law.

Keywords: Mobility, Welfare Provisions, Legal Actors, Arbitrary Enforcement

JEL Classification: K490, J610, I38

1. INTRODUCTION

Laws and regulations determine individual and family life everywhere. Societies and groups within them, however, develop an array of norms and spaces for legality and illegality with different tolerance thresholds to deviances (Sampson and Bartusch, 1998). It is widely acknowledged that what is or is not acceptable or approved of depends on cultural as well as structural factors framing people's living possibilities. In line with the extent of crime that goes unpunished and the informal economy in developing nations in Africa or Latin America, Southern European countries like Spain have also been characterised by the high levels of irregularity existing in their labour markets, corruption and other offences (Sanchís, 2005). Nonetheless, in recent decades, as a growing number of the immigrant population has been settling on Spanish soil, an increasing regulation of non-Europeans' mobility, and of their access to economic and welfare resources, has also occurred (Zapata-Barrero, 2009).

In principle, more complex and diverse societies require increased regulatory effort in order to guarantee that the various groups live together harmoniously. Many people, however, perceive the intrinsic unfairness of laws that are protective for some and basically punitive for others (Tyler, 2006). In so far as individuals are positioned in stratified social structures, these social disparities are reflected in the legal systems that harm the less powerful social groups. Gender, ethnicity or age are main social markers that contribute to social inequality. Studies show that disadvantages tend to grow and overlap among migrant and ethnic minority populations (Bolzman *et al.*, 2004).

I presuppose this happens to older migrants in Spain and migrants' older relatives in their countries of origin. Fragility because of age, and ageism or discrimination towards the elderly, may interact with other sources of disadvantage, such as anti-immigration feelings or gender and ethnic discriminating norms and practices that transcend nation-state borders. It is therefore in the context of contemporary global interdependencies and transnational social fields of action where we can observe the opportunities and restrictions that laws pose for family life and more specifically for the wellbeing of the older generation.

Bearing these considerations in mind, a research project was carried out starting in Spain and following on fieldwork in Peru and Morocco between 2006 and 2010. While the research provided wider types of data and insights, in this article I go through a number of in-depth interviews in order to explore the connections between law, ageing and migration, and more specifically how families and older people cope with laws and regulations. In addition, I examine the legislation, official documentation and other information that was produced over the period in which these migration flows evolved. All the material is reviewed in order to address these two broad questions:

- What are the characteristics of law systems that (trans)nationally affect older individuals and their families inserted in migration processes?
- What are the responses from older individuals and their families to the legal frameworks, and, especially, to those practices that help them benefit from or overcome the laws, in order to improve older people's lives and chances?

In light of the data gathered, in the following sections, the legal systems' inner workings are characterised as mechanisms that are both weak and strong. As a matter of fact, a growing bureaucracy and a tightening of regulations and norms that govern all life spheres, including migration management, are often accompanied by a weaker and somehow arbitrary enforcement (HRW, 2002). Looking over the history of Peruvians' and Moroccans' migration to Spain there are plenty of cases where families have taken good advantage of favourable or lax law enforcement. There are, of course, many cases of failure to access the benefits of migration because of impenetrable legal controls. Nonetheless, selected examples in the final two sections show that as a result of states' unclear legal actions, together with migrants' desire to contribute to transnational family making in order to guarantee an acceptable level of wellbeing for their most vulnerable, family members try to cope with the legal constraints that older people face, in some cases acting against or at least partially behind the law. In this article, attending to the most specific areas in which migration affects older people's wellbeing, I focus on those legal practices undertaken to boost mobility and pensions.

2. LAW SYSTEMS AFFECTING THE GOVERNMENT AND LIVES OF OLDER PEOPLE IN MIGRANT FAMILIES

Throughout history, in their intention to control people's behaviours elites have conceived norms and structures that frame their subjects' life opportunities, running the destinies of the less fortunate or the more vulnerable (Mills, 1956). Modern countries are characterised by an impulse of a fast growing jurisprudence applied to those who nation-states consider as their incumbent populations. With increasingly centralised and powerful states, more and more control functions on aspects such as birth and death, health, housing, or education are assumed (Vázquez, 2009). Nowadays, many states' laws particularly address the circumstances of women, underage, senior citizens or non-nationals, generating differentiated social dynamics.

As a matter of fact, European welfare states have, in Vallejo's terms, "submitted different populations to different subjectivation regimes" (2004). In a Foucaultian analysis of

the governability of migration, Vallejo attests that while domestic policies deal with the development of their “human capital” with protection and manipulation regimes (Rabinow, 1984), immigration policies are part of an assignation regime whose function is the provision and discipline of a cheap and flexible labour force in countries like Spain. In this context, governments show a preference for a younger immigrant labour force, discarding other age groups. Migrants’ older relatives who do not constitute the imagined targets for legal immigration are indeed denied entrance in many countries by law or by discretionary procedure in applications resolution. Likewise, laws addressing welfare provisions for aged migrants tend to be restrictive, encouraging return migration, and consequently a disengagement from the host country’s acquired citizenship rights (Böcker and Balkir, 2012). The biopolitics of older people¹ connected to migration is constructed on a highly utilitarian view, tightly linked to the fact that population ageing is regarded as an increasing demographic, economic and social threat for all states, but especially for the fast-ageing societies in Europe (Vincent *et al.*, 2006).

Additionally, any consideration of the biopolitics exercised on older people living in migrant families and contexts has to take into account the maintained transnational links between origin, transit and destination places. Although laws tend to be directed at those living in a national territory, and do not usually consider the circumstances of migrants’ relatives back home, transnational application and surveillance of laws seems to be in the limelight (Gamlen, 2006). Territorially-centred legal views are being over-ridden as migrant/expatriate communities grow in number and recognition. Both destination and sending countries struggle, on the one hand, with their desire to capture their economic, social or political potential and, on the other, with their aim to reduce migration’s unwanted social costs.

Having said this, a growing jurisprudence that regulates migration, either with national or transnational application, does not guarantee that this is perceived as coherent, timely and just. Bookshelves are full of regulations that have been approved at various stages, that then contradict themselves and require revision just a few years after being passed (Aja, 2010). The fact is that societies transform at a quicker pace than laws. Only in some instances laws precede factual societal changes. This happened to Spain at the time of its incorporation into the European Union as a wider legal framework, a process that needed the harmonisation of the national legal instruments (Borrás, 1995).

In addition to written laws, their enforcement is contingent on interpretations, resources and scenarios. Drawing from Pound’s classical conundrum between “the law in the books” and “the law in action” (1910), Schuck notes a third further distinction as the “law in their minds”. According to this author, the law as formally enacted almost always differs from the law as actually implemented (Schuck, 2008) because its meaning depends on the actions of the state and non-state entities charged with carrying out the law. The fact is that many groups of actors in the immigration system see different aspects of the system or see the same aspects differently. This situation aggravates by laws that define migrants in multiple, intersecting and often indeterminate ways (Coutin, 2011).

Moreover, the analysis of the implications of any law and its variations over time has to take into account as much the performance of law enforcers as ordinary people’s capacity to abide by or circumvent the law. Schuck (2008) provides the example of the US migration system that, according to him, is characterised by its “failure” to enforce immigration law, due to the different interpretations and considerations coming from officials in charge, the contraforce of human rights groups and ethnic solidarity networks and, no less importantly, an administrative overload or lack of resources.

¹ Biopolitics here translates Foucaults’ view of power centered on people’s bodies as a machine, intervening in its disciplining, the optimization of its capabilities, the extortion of its forces.

According to ethnographic studies, pseudo-legal practices have found a good market for their illicit business among many of those immigrants who have not been able to avail themselves of legalisation programmes, nor find any other means of obtaining legal status, but to buy fake documents and present them to their employers and the authorities (Calavita, 1998; Sabogal and Núñez, 2010). In the application of the laws legal actors are also confronted with a number of obstacles such as, people who make a business out of issuing permits for travelling to and staying in the destination country, or the inconvenience of persecutions that have turned into illegal, heavily penalised activities, despite humanitarian grounds. Authors such as Kyle and Dale (2008) have pointed out as well that it is not only criminal organisations but also other actors such as regional elites, states and corrupt state officials, employers (and “slave holders”) who drive increases in the levels of human smuggling or illegality. However, as our data show, and in accordance with Gonzales (2011), just as with ordinary citizens, immigrants’ experiences of illegality finally depend on specific, situational contexts, and only become salient when matched with experiences of exclusion. And thus, in line with studies on older people’s quality of life and wellbeing (São *et alii*, 2013), experiences of coping with the law are to be understood here through those older people’s voices that are often unheard in legal and social science research.

3. METHODS AND DATA

This article draws mainly on qualitative data gathered during the course of research on ageing and migration to Spain, from the 1990s up to the 2010s. First observations were collected early in the 1990s at a time when Peruvian migration to Spain started to be numerically important. The Moroccan case study was incorporated at a later stage, starting in 2006, with the aim of comparing both groups.²

For the core interview period we collected 25 and 23 narratives from each group of Peruvians and Moroccans aged 50 and over respectively. Interviewees were contacted through key informants and applying the snow-ball technique. Peruvians and Moroccans were selected on the basis of fulfilling one of the following profiles: a) one third have aged in Spain, b) another third have migrated to Spain at an advanced age, c) and the other third have children living in Spain. Interviews were recorded, transcribed, translated if necessary, and later analyzed using a thematic approach by codifying units of meaning with the help of Atlas.ti software programme.

The number of Moroccans and Peruvians falling into these categories has been difficult to determine. With regard to migrants who have aged in Spain, having arrived at a much younger stage in their lives, we have to acknowledge that the available data does not include those who have acquired Spanish nationality during this time. This number should not be underestimated, especially among Latin Americans, who, as a consequence of preferential legislative treatment, can apply for Spanish nationality after just two years’ legal residence. If it is difficult to find out with any accuracy how many live in Spain, it is even more difficult to know how many older parents remain in Peru and Morocco while their children stay abroad. Finally, data on later-life migration is obscured by the number of those who overstay their tourist visas and remain undocumented, or the impossibility of getting official figures on how many Peruvians and Moroccans have reunited with their older parents throughout the period.

All in all, the official statistics show that in December 2006, 91,000 Peruvians and 550,000 Moroccans were registered as residents in Spain (INE). In June 2012 those numbers

² In the period 2006-2009 the research topic benefited from a grant from the Spanish Ministry of Science. The research project awarded a grant was intitled ‘Growing older in a context of international migration’ officially conducted during 2006-2008, with the support of the Spanish Ministry of Science and Innovation [i+d SEJ 2005-04815] and European ERDF Funds. Early 2009 additional funds allowed follow-up activities.

had risen to 141,000 and 850,000 respectively (INE). Even if the percentage of those aged 50 or older is low – around 10 to 20 percent of total population – in absolute numbers these citizens are notorious for their quantity and characteristics (Escrivá, 2013b). Other relevant information was drawn from immigration officials and other key informants, as well as from documents such as legislation and agreements between countries, official evaluations, and non-governmental information sheets alluding to the legal situation of older people; a material that was checked and contrasted.

4. PERUVIAN AND MOROCCAN MIGRATION TO SPAIN: A LEGAL PORTRAIT

Over the past two or three decades Spain has been articulating a series of norms that regulate international migration as well as state social policy. According to López (2005), immigration has become a motor of institutional transformation and legal-bureaucratic production. In so far as Peruvians and Moroccans are among the longest-established migrant communities in Spain, these groups have experienced changing legal scenarios and have become more astute in the matter. Not surprisingly, two-generation migrant families refer to how the younger generation today suffers harsher legal barriers than the older first generation did when they entered Europe early in the 1980s and 1990s. Older people acknowledge these changes as they recall a time when no formal obstacles were enacted to crossing the border (by land, sea or air) into Spain, when controls were looser, or migrating was officially promoted and planned.

From the late 1980s to 2009, compared to other European countries' policies, migrants in Spain and their families benefited from a relatively more open system of newcomer acceptance and recognition of citizenship rights, applicable to people from a large number of countries and continents, albeit that there was special treatment handed out to individuals from Latin America (Izquierdo *et al.*, 2002). The historical links between Spain and its former overseas territories across the Atlantic had resulted in a number of bilateral agreements with almost all Latin American countries with regard to citizenship procedures, including a faster process in acquiring the host country's nationality and the possibility of maintaining double nationality. Early on, in addition to nationality laws, agreements with a few countries, including Peru, settled on a norm to avoid the discrimination of citizens from one signatory in the other signatory's labour market. As welfare systems developed, bilateral agreements including both Peru and Morocco came to incorporate social security provisions and pensions. In Spain the right to non-contributory pensions is fixed in a law of 1994, although to qualify there will soon be a legal requirement for non-Spaniards to have been in continuous residence in the incumbent city or region for at least ten years.

Further to specific agreements, immigration laws³ came to be less restrictive in their application to Latin Americans than to other groups, such as Moroccans, even though they were the most numerically important immigrant group in Spain. For a long time Latin Americans could access the country without a visa, and nationals from some countries still can. Once in Spain they could regularise their status and bring their loved ones to live with them, including their parents; and in spite of all the obstacles, their degree certificates and driving licences would be more easily recognised and validated; they would be first when it came to grants, social benefits and social assistance such as non-contributory pensions being assigned. Although many Moroccans also got to benefit from these improvements, a review of more than 20 years of Moroccan-Spanish border and migration management concludes that the will to soften the requirements and speed the bureaucratic procedures from both

³ See the *Ley Orgánica 4/2000, of January 11, on Rights and Freedoms of Foreigners in Spain and their Social Integration* plus successive amendments.

sides has come to depend very much on the changing climate of political and social relations between the two states (Sanchez and El Fathi, 2007).

The countries of origin's laws have likewise experienced adjustments in considering the effects of strong international emigration flows. Sending nations have legislated with regard to protecting their citizens abroad and their families at home, establishing stricter border controls in response to EU demands, or providing information and counselling to migrants, including incentivising remittances and return, among other issues⁴. Our informants highlighted, however, that the application and surveillance of the laws have been weak and prone to discretionary and corrupted use.

Trying to abide by or circumvent the law usually means spending money, an amount that far exceeds many families' economic possibilities and ends up impoverishing them. This money is devoted to paying taxes (i.e. consular fees) and social security costs, even if migrant workers earn very low salaries and, sometimes, under what is stipulated in their contracts. Additional resources have to be spent with intermediaries who facilitate the visas or any other kind of formality with either the Spanish or the country of origin's authorities. Practically every step in the migration's legal maze requires financial expenditure.

To make matters worse, officials and administrations have too often proved to be inefficient in the management of much of the paperwork that is essential for migrants. The analysis of how governments have brought into operation bilateral social security agreements between Spain and selected Latin American and African countries offers an excellent case. While in theory these agreements allow for adding the years contributed in the country of origin to those in Spain in order to accrue and calculate the amount of a pension, Díaz-Gorfinkiel and Escrivá (2012) detail how processes of recognition are often too long and complicated, due to lack of will, capacity or ability of national administrations to work beyond their territory. The whole process is deteriorating even further in the new context of recession and checkmate on public pensions, according to what our informants say.

5. MIGRANT FAMILIES' RESPONSES TO LEGAL CONSTRAINTS ON PENSIONS

The pension situation of older Peruvians and Moroccans in Spain and migrants' relatives in Peru and Morocco is diverse. In some cases the right for a pension had already been achieved before migrating. The case of Peruvian migrants is paradigmatic, as analysed in Escrivá and Vianello (2013). In the early 1990s Peruvians employed by the state, in public administration, banking, health and education services in Peru could, or were obliged to, retire with a small pension or one-installment compensation, after a certain number of working years. Given the low salaries, huge inflation and the wish to engage in self-employment activities in Peru, or to migrate and help others do it, I came across several cases during research conducted in the early 1990s of migrating pensioners who mostly found employment in Spain in the cleaning and care industries.

Interestingly, those migrants' pension incomes often remained in Peru and helped others survive, such as dependent children, partners or older relatives. In this latter case the money functioned as a sort of non-contributory pension granted not by the state but by ageing migrants⁵ to their often ailing parents in their seventies and over. This cession to the "left-behinder" kin of the right to claim a pension or a rent accrued in countries of origin has often been overlooked in studies on migrants' financial contribution. Rather these studies have made the monetary remittances that are transferred from abroad the focus, making the

⁴ For regulations and actions of both states see the WebPages of the Peruvian and Moroccan Ministries of Foreign Affairs.

⁵ The term refers here to migrants who first move abroad being between forty and sixty years old, similarly to those described by Deneva (2012), and who usually have children, even grandchildren, and older parents alive.

assumption that because many older people were not principal receivers of these currencies they had been marginalised from the distribution of family gains.

As is more often the case, migrants have arrived in Spain without having contributed at all or enough to a pension in their homeland, and, in fact, may not even have reached the minimum retirement age. The possibility of completing contributions for a pension, or of qualifying for a non-contributory one abroad, has depended on several factors, including the holders' ability to keep a legal status gained individually or thanks to their families, and their economic capacity.

A good example is that of a Peruvian man with whom I have met on several occasions over the last ten years. Before arriving in Barcelona in the 1980s he had taught and worked as a journalist in Peru. In Spain he performed many different tasks, mostly self-employed, although when I first met him he had been working as a concierge for a while. More recently, and approaching his 65th birthday with no decent health and job prospects, he realised that due to mishandling of his work records in Peru, he did not have enough years of contribution accrued on the social security scheme. As a last resort, and in order to comply with the required contributory period for a pension in Spain, he persuaded his ex-wife, owner of a well-known restaurant in Barcelona, to contract him for a few more years.

Given the relatively moderate number of contributory years that had been required for a pension in Spain (minimum 15 years) before pensions' reform started, Peruvians and Moroccans aged 65+ who had been working in the formal economy until circa 2010 nowadays enjoy a pension. Immigrant pensioners we interviewed are resentful, however, that their monthly income tends to be below the Spanish mean amount, given the fewer years accumulated, the lower salaries, or the limited contributions accrued by their employers in their previous occupations. Besides that, in the midst of an economic downturn, eligibility requirements for a pension are on the rise, while difficulties in continuing to contribute are abundant, because older migrants are doubly disadvantaged due to ageism and xenophobia. This explains their high un- and under-employment rate in the informal economy.

"I worked in Almeria for more than 15 years until I became unemployed because, being older, no one wants to employ me... Older people could get contracts but since last year, not anymore. I returned to Morocco and I have been receiving the unemployment money for a year. Now I have travelled to Madrid to fix my pension papers" (Moroccan man, 65 years old, recent returnee to Morocco, worked in agriculture in Spain).

Even if pensions amounts are low they are central to facilitating the return projects of older migrant workers. Contributory pensions and the rights attached to them in principle can be carried both to Peru and Morocco as signatory countries of social security agreements with Spain. Relatives attached to the pensioners may enjoy these rights as well as help meet the requirements, as shown before. Nonetheless, in addition to the administrative incapacities, and in spite of the legal possibilities of transferring pension benefits to close relatives, sometimes migrants' legal tricks undertaken in order to gain access to work and migration abroad, or to smooth transnational living, end up catching them out in later life, as in the following case.

"My wife never wanted to come with me to Spain, she does not like travelling. If she had come, now she would have papers... Because they asked me if I had a wife and I answered no, knowing that if I had said yes, they would have asked me to bring her and bring her papers. But she doesn't have any, so I answered that I was not married... Now I am worried about what will happen to her tomorrow (if I die) because she will not be able to keep my pension" (Moroccan man, 65 years old, recent returnee to Morocco, worked in agriculture in Spain).

This testimony contradicts the general view offered in literature about how Moroccan men reject regrouping with their wives in destination countries (De Hass and Fokkema,

2010) with obvious implications for women's options in qualifying either for a contributory or a means-tested pension. Here the informant regrets not having officialised his marriage situation in Spain before, and, as a result, he has searched for legal advice to try and modify it now to comply with Spanish regulations.

Likewise, older Peruvian and Moroccan parents who were officially reunited with their adult children and had no chance of working for a salary in Spain have the option to claim for a means-tested pension. While this money has become essential in completing family income, there is, as yet, still no legal possibility for pensioners to take this type of pension with them out of Spain and that restricts the elders' living options. Previously, fewer border controls allowed pensioners to move back and forth without losing any rights they had accumulated. More recently, stricter controls by the local police and at airports have started to make it more difficult to overcome travel barriers.

In this complex scenario, and as a precaution to return to the country of origin or harsher pension conditions, fieldwork showed that some migrants continue contributing to their country of origin's social security system, or combine contributing to the public and to a private pension scheme in order to guarantee good support both here and there. These cases are more abundant among Peruvians, given that, in my view, Moroccans tend to trust more in the state's protective function as a result of different experiences in origin and destination countries.

"I try to save all I can and I expect to get a pension, a Spanish one and a Peruvian one. I continue paying in Peru. It is not much, I may get about 120 euros a month later, but it is something... I do want to keep living with my wife and remain economically independent" (Peruvian man, 54 years old, 17 years in Spain, 2 grown-up children in Peru).

It would seem that, life abroad entails a transforming experience that helps contribute to a better preparation and evaluation of the different options when it comes to retirement. Contributions to more than one pension scheme and the practice of asset diversification might be considered excessive in a legal and political context that promotes social security agreements between Spain and countries such as Morocco or Peru in Latin America. Interviews reveal, however, that people distrust or are unaware of the agreements' terms and guarantees. An increasing number of cases of claiming pensioners who cannot get their condition recognised is causing alarm among their compatriots about the administrative difficulties of making the law work in practice. Moreover, maintaining transnational lives, it is recommended that one should secure minimum coverage wherever it is available.

In a different position are those older persons who remained behind and, though could not make savings or contribute to a pension, they trust on the inter-generational solidarity. As the following informant exemplifies, older people place their hopes on their migrant children who become the security for tomorrow's family income.

"As I get old I expect that all my children will help us. All will send an amount. Every month a different one remits... I am positive about the future. We had a bad time before but now we are OK, my children will help us" (Moroccan man, 60 years old, Tanger, 4 children abroad).

For this reciprocity money to flow an array of conditions is necessary, to name but two of the most essential: the migrant children have to obtain enough income to cover their own basic needs and those of the new families they constitute (Baykara-Krumme, 2008); and the sense of obligation and devotion toward the older generation has to be maintained over time in spite of the distance. Continued communication and physical visiting, whenever possible, help to keep family ties vivid.

6. MIGRANT FAMILIES' RESPONSES TO LEGAL CONSTRAINS ON MOBILITY

Family members who can afford regular or occasional visits to their kin living abroad are sometimes the middle generation, but more often than not are from the older generation. As a time- and money-consuming task, travel is often impossible for adult children who have to work for a salary or for the family and who do not enjoy much spare time. By contrast, older people who are in good health may have better availability, they may even get tourist visas more easily and be entitled to discounts. Indeed, older people's capacity to move between the country of origin and destination is very much praised among our interviewees. The seniors can visit their children and relatives living in another country and be there for the important occasions: weddings, births and child rearing, or sickness. Sometimes they give a temporary hand with housework or with the family business. On other occasions, the older people are the ones that seek company from their loved people, including emotional and material support (Díaz-Gorfinkiel and Escrivá, 2012; Nedelcu, 2011).

Over the years, I have come across migrants in Spain, especially of Latin American origin, who have been able to call upon their older parents to come and stay with them for short or long periods, depending on their visas and stay permits. The idea of moving more or less temporarily to Europe and specifically here to Spain is fuelled, not only by the presence of the children but also by the desire to travel to what are considered more developed nations, those offering quality services for everyone, especially for the elderly. A good portion of our informants staying in Morocco or Peru hold the idea that their contemporaries who live abroad are in a better situation than themselves, as the following words reveal.

"Older people who live abroad are in a better situation. There are subsidies for the elderly, for everything. When I was younger I did not think about moving out, and now that I have grown old I would like to, but I am not healthy enough to go and work" (Moroccan woman, 58 years old, Tetuan).

Older people's bad state of health, however, is often not the main impediment for travel. In spite of the older cases of successful visa-applicants, many other advanced-age Peruvians, and especially Moroccans, are and have been denied authorisation to enter Spain over the years, under the assumption that their intentions are to stay permanently, to search for a job or overuse public services. This presupposes that everyone wants to go further than simply benefiting from temporarily visiting each other, which is, of course, too much of a generalisation.

"I applied for a visa but they denied it. They said that they could not be sure that I would return home, because we do not have enough means to live on here, according to them (to Spanish Consulate officials). They asked me to certify an amount of money in the bank... Yes... If I have to go to visit my children, of course I will do so, but not to stay there, I could not get used to living there" (Moroccan woman, 65 years old, Tetuan, 4 children in Spain).

Visa-applicant families find themselves, in fact, in rather different situations according to their economic and social status. Being able to prove a substantial amount of money and valuable property, as well as having good connections inside the consulates, help enormously in obtaining the legal authorisation to enter Spain. Nevertheless, there is a contradiction between the requirement for older persons of proving "sufficient" economic means for a visa to visit their children, and the opposite that is proving no personal economic means at all, to enable family reunion with an older parent, under the following terms of the law.

The Spanish Royal Decree-Law 557/2011 of April 20, 2011, article 53, section e) states: "Alien citizens may reunite their direct ascendants with them in Spain if the applicants are in charge of them, they are over sixty-five years of age and there are reasons that justify the need to authorize their residence in Spain (...) Authorities may consider as such the fact that the ascendant was living with the applicant in the country of origin at the time that the

latter obtained his permission, that the ascendant is not able to live alone, and guardianship was granted by the competent authority in the foreign country to the resident or their spouse or regrouped partner, or when the ascendant is not objectively able to provide for their own needs. It is understood that the ascendants are economically dependent on the applicant upon proof that, at least during the last year of the applicant's residence in Spain, he or she has transferred funds or incurred costs of his family, representing at least 51% of gross domestic product per capita, calculated annually, of the country of residence of the latter". (*My translation*).

In response to these new requirements in the family reunification law, together with the new economic scenario in Spain, migrants who still expect to obtain stay permits for their older parents have intensified their remitting efforts. Instead of saving, spending or investing in Spain, they remit the maximum they can, apparently only for consumption at home, in order to generate as much cash flow as possible with kin living in their countries of origin.

Another restriction on family reunification and visiting has been imposed on the basis of being able to provide adequate housing for the elders intending to be brought to Spain. This adequate accommodation has to be offered in a separate room within a flat of the regrouping person's own property. "We could not go to visit my brother in Spain because he still doesn't own a place. We would love to but we can not because in order to get a visa to visit him he has to own a house" (Moroccan man, 50 years old, Tanger, a son and other relatives in Spain).

The requirement of home ownership, in addition to the facilities to get a loan, has, over the years, impelled migrants to buy instead of rent a flat in Spain. By complying with the law, such an extended practice has allowed the mobility of close relatives for a given period. But because of the difficulties in reselling these properties, home ownership has more recently obstructed migrants' new mobility needs within and outside the national territory as they search for work in the heat of the recession.

Finally I would like to add that, in the absence of valid travel documents or in order to stay for longer in Spain, some interviewees support the use of fraudulent alternatives. In response to permit restrictions, such as stay permits of regrouped parents that do not allow absences from Spain of more than six months, families have been arranging, for example, for the relative to re-enter European Space through another country where permit conditions are unknown. Obviously, case by case, airport officials have become more aware of the exit limitations and entrance requirements imposed by the Spanish authorities and have started denying entrance to passengers in transit, according to a statement from a Peruvian lawyer in Barcelona who deals with cases of deportation.

In addition to irregular border crossing, a frequent route for entry into Europe has been to obtain, by any means possible, a valid visa for tourism or family purposes and then overstaying. As the following case illustrates at length, this action causes the older person to be in a state of semi-legality (Kubal, 2013), starting with the means used to obtain the permit, then infringing the destination country's "Law on Aliens", and leading ultimately to unwanted consequences for people's life possibilities. Constraints on mobility indeed affect not only the first entry to a desired new location but also the capacity for the unauthorised person to leave and make new entries.

"When my sister and her husband wanted to travel to Spain, the Consulate rejected the visa. They spent a lot of money on that for nothing. Then an acquaintance of theirs who also had contacts there intervened. The Consulate called them to go on Wednesday and on Friday the visa was ready...

...After two months of my sister and brother in law's trip to Spain, the Consulate (in Morocco) started calling and asking where they were, telling me that they would be

denounced for not having returned. I told them that I knew nothing about it and that I could do nothing and they stopped calling me...

...My sister is now awaiting her residence papers. She only wants her papers to be able to come and go whenever she wants to visit her children. Now, for example, her son is getting married here in Morocco and unless she receives her documents she will not be able to come"

(Moroccan woman, 68 years old, lives in Tetuan at her sister's house. The sister and respective family -husband and four children- live in Spain).

Two things from this case have made a particular impression. One is that legal actors such as the authorities in origin and destination countries are also involved in irregular procedures. We don't know if there is any real prosecution of those who, inside or under the protection of official premises, facilitate visas and other valid or fake documents, against the payment of extra money or other favours. Indeed, we are only alerted to any law infringement by pieces on the news, and in politicians' speeches. Infringements by ordinary people who may ultimately have far fewer bad intentions than the corrupt officials and other "professionals" who make their business out of other people's woes. Secondly, the state of migrants' semi-legality can be reverted or be maintained over time depending on the broader contexts with regard to migration and the economic and political situation. The current scenario in Spain and Europe more broadly threatens to lead people on towards an increasingly precarious state.

Although the previous testimony does not offer a continuation of the wedding party in Morocco, it leads me to draw a parallel with the impressive case of a very risky border crossing, told in González Iñárritu Hollywood movie, "Babel" (2006). This movie tells the story of an undocumented Mexican domestic worker in her late 40s or early 50s in the United States who travels to Mexico for her son's wedding, and during her attempt to return ends up in jail accused of kidnapping her employers' children. The picture is a clear example of how every actor in the scene has a different understanding of events and reacts to them accordingly: the US authorities accusing her of all possible offences and punishing the undocumented migrant; the Mexican woman who tries to keep both commitments with her son and her job, astonished and ashamed for being unfairly accused of illegal activities; the children's parents with indulgence, as they have just dramatically experienced hardship in their struggle with the US and the Moroccan social, political and legal (dis)orders.

7. CONCLUSION

The growing corpus of norms and regulations regarding incoming and outgoing international migration in the three countries revisited contrasts with the weaker enforcement or corrupt nature of the system that has enabled different ways of combatting the legal barriers on migration controls, or of benefiting more broadly from welfare and social protection that new restrictions impose.

Law infringement and the profiting of legal loopholes are not necessarily regarded by Peruvians and Moroccans as illegitimate acts, in fact, since they do not differ all that much from the irregularities which other, legitimate, migration actors carry out (employers, public servants or police) as part of a continuous space of "semi-legality".

As a matter of fact, older people are not simply victims of norms that govern societies. They can act within the interstices of the system, because the system fails and offers these opportunities. Following Kubal's considerations (2011), I can confirm that migrants' interaction with the law ranges on a scale between opportunism and exploitation. Throughout the article I could illustrate how families adapt to, or circumvent the law in the areas of pensions and circulation.

The article goes on to remark on individuals' agency within given legal limits, in order to make good use of the opportunities that are available. For this analysis I used elsewhere the asset accumulation frame that enables the confirmation that in their objective of improving their lot and the well being of loved ones, family members have to accumulate and transfer assets intra- and inter-generationally and over time (Escrivá, 2013a). The law is a main factor facilitating or inhibiting these asset accumulation strategies. Rights and entitlements acquired because of legislation applicable to citizens of immigrant origin are also assets that are transferable to relatives living close by or far away, in direct or indirect ways (Zechner, 2010).

However, not everybody has enough information or the ability to use the available resources strategically. There is a real danger that more restricting immigration and social policies as well as further border militarization will put families in greater risk. As our follow-up activities show, these situations have aggravated in Spain on the heat of recession. In addition to laws, there are other factors that undermine the possibilities of favouring the significant others. Although these questions could not be further explored here, economic constraints as well as social or personal considerations about what is appropriate for each gender or generation in a family are also influential.

What is specific to the cases presented here is how legislation approaches a specific age group and how other social and economic factors still condition the possibilities of older people, protecting some and disfavours others. Yet, while old age pensions have gradually become a central mark of any developed society that aims at promoting justice and integrity for their older population, it has also become a very contested and controversial area in which lower-class citizens have more to lose, and non-authorised migrants most of all.

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SHE IS A VERY SPECIAL PERSON: MALE CAREGIVER IN THE INTERSECTION BETWEEN INFORMAL AND FORMAL CARE

Torbjørn Herlof Andersen

ABSTRACT

This paper presents the story of a Norwegian man in his mid-70s, primary caretaker for his wife who suffers from Alzheimer's disease. Focus is on the cooperation with home-based public health-care services. The case is part of a larger qualitative research project on the topic.

The story has come into being through narrative interviews followed up with telephone conversations and is analyzed with Antonovsky's Sense of Coherence as a frame of reference. Three topics are highlighted: 1) The carer's journey during the time of his wife's illness; 2) His description and construction of meaning and ways of coping; 3) The interaction between him as a caregiver and professional health workers.

The research project aims to highlight the rationality of caring facing the organizational/bureaucratic framework conditions of home-based public health care.

As the caregiver is watching his loved one being changed into someone who is unrecognizable he needs to adjust to a new reality of which a working relationship with home-based public health care is an element. Concerning the latter, a very important factor is the respect for the uniqueness of the couple's story and situation, as well as the acknowledgement of the caregiver's expertise – or lack thereof.

Keywords: Male Caregivers, Informal Care, Rationality of Care, Sense of Coherence

JEL Classification: I12, I14

1. INTRODUCTION

Informal male caregivers with a responsibility for spouses/partners with long-term care needs, in which the care is home based, is a significant area deserving of more interest than it seems to receive. The primary purpose of this paper is to call attention to challenges that might arise from the interaction between the informal male caregiver and the formal home-based service.

Male care is easily associated with being a father or with men in caring professions. In spite of the fact that approximately 30% of the caregivers in private care are men, there is not a lot of Nordic research that deals with this matter. In Romøren's (2001) longitudinal study on the development of the helping needs of elders related to public and family care, it appears that in 27% of the cases the closest caregiver is a man. This roughly corresponds with numbers from the US (Houde, 2002; Russel, 2007), and the percentage seems to be growing (Sanders & Power, 2009). A recent study from Portugal on elderly informal care shows some surprising figures, suggesting 56.4% of spouses who were informal carers were men (Pego & Nunes, 2014).

Considering an anticipated future situation, an increasing number of old people will make family-based care vitally important. Male caregivers are an important group in that respect, though the lack of knowledge about the situation of this group calls for more research. Since it is evident that when the care is based on a joint effort by formal and informal caregivers, the quality of the care is influenced even more by how this working relationship functions. This also applies to how the informal caregivers experience and cope with the situation.

Traditionally, care research, in which men as (informal) caregivers is a topic, has been marked by a comparison of men and women, with gender socialization as a point of departure (Ducharme *et al.*, 2007; Thompson Jr., 2005). In that context, men tend to function as a contrast group to female caregivers (Kramer, 2005), but the female caregiver constitutes the norm. Using somewhat short and apt wording, men's experiences as caregivers are examined as deviating from the normative female experience (Bokwal *et al.*, 2005). The point is that the female caregivers constitute the norm and the men are judged by how close to that "golden standard" they come.

In the current project, the male caregiver's situation is explored on its own terms and not as a contrast to a predefined standard. As far as how the concept of caring is understood in the current project, in addition to being informal (Andersen, 2011), it can also be said to be based on a *rationality of caring* (Wærness, 1999). Rationality of caring is rooted in the unique characteristics of the caring relation, and is connected to "[...] a way of thinking that is contextual and descriptive rather than formal and abstract" (Wærness, 2004:275). In order to exercise good care, the caregiver needs to hold not only personal knowledge, but also a certain ability and possibility of identifying with the care receiver's situation as a basis for practice. The perspectives laid out above, which might be said to characterize the caring relations we deal with in this project, could also be said to contrast a results-oriented, means-end thinking.

2. OBJECTIVES

The thematic frame around this project is voluntary, family-based care. The center of rotation is the collaboration between a municipal, home-based service and a voluntary and family-based care by men, with a considerable responsibility for spouses/partners with long-term care needs living at home. User perspectives, meaning family members, are crucial. Generally speaking, the aim of the project is to learn about how this reality is understood and described by the male caregivers (Kvale & Brinkmann, 2009). How do these men cope with their life situation, what are their needs for assistance and how are these needs understood and met by public social- and health care? More specifically: How do men with a caring responsibility for their spouse/partner experience and describe their situation as caregivers? Secondly, what are the challenges that arise in the encounter between public home-based service and private informal (male) care? Last, but not least: What do the male caregivers express concerning their needs for assistance in order to be able to maintain and manage their care work?

3. DATA & METHODS

Participants for the study are recruited in collaboration with municipal home-based service. The criteria for inclusion are male caregivers doing home-based care for their spouse/partner with considerable needs for care, and being in some type of cooperation with a home-based service. We talk about purposeful sampling and expect to interview approximately 20 persons (Malterud, 2011). The participants are interviewed in an open fashion, i.e. with life

history/life story interviews consistent with the approach known as BNIM (The Biographic-Narrative Interpretive Method). Based on a single opening question, the participants are encouraged to tell their story as much as possible without interruptions or questions from the researcher (Wengraf, 2001).

In general, and more specifically in connection with the choice of methodological approach in the project, an important point here is the awareness of how “gendered” pre-understandings can be an obstacle for comprehending what the interviewee wants to get across (Sandberg & Eriksson, 2009). The interviews aim to obtain the caregiver’s experience, understanding and description of his lifeworld, as well as what his need for assistance and support related to his care work may be. Openness is necessary to develop an understanding based on the phenomenological experience of the interviewees and not on pre-constructed categories.

The analytical approach leans on Interpretative Phenomenological Analysis (IPA), which is described as “a two-stage interpretation process or a double hermeneutics, in that the findings convey the researchers’ interpretation of the participants’ interpretation of their experience” (Smith *et al.*, 2009). “The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008).

IPA can be used to examine a single case, as is done with Arne, whose story this paper is based on. Arne was interviewed twice face-to-face and several times via telephone. The latter were shorter conversations, in which the intention was both to ask specific questions and to follow up on how things were developing in a more general sense. The interviews were transcribed verbatim by the interviewer. In the first interview, Arne talked freely about the time from when his wife turned ill until the present day. He told of his experiences and the challenges he faced and how he handled these, in addition to his experience with home-based service related to his wife’s condition and his position as an informal caregiver.

Reflections and questions that arose during the transcription of the first interview provided the basis for the second interview. The first telephone interview was done as a follow-up after a couple of months, while the second was conducted about six months after the last face-to-face interview. This case was then compared to others in the group, and the discovery of additional themes led to a turning back to the original case for further analysis – which was an iterative process.

Working with individual stories is rewarding in many ways, as it is striking as to how an individual story can shed light on phenomena that go beyond the particular. The sociologist Pierre Bourdieu uses the phrase “[to] grasp particularity within generality and generality within particularity” (Bourdieu & Vaquant, 1992: 75), and further, “A particular case that is well constructed ceases to be particular” (op. cit: 77). Individual narratives are sources of knowledge about how cultural and structural factors make their deposit in a person’s self-perception. This knowledge can contribute to the development of theories and extend our understanding of offense/acknowledgement experiences as both an individual- and social phenomenon. Furthermore, it sheds light on how this is influenced by social and political factors, and how it could contribute to a political discourse about the relationship between agent and structure (Chamberlayne, 2001). The latter is something that would definitely be a desired result.

Through the unique autobiographical stories about their lives, persons create meaning and identity. This point is made topical by Antonovsky (1987) in a way that is also relevant in relation to the current project. Referring to Cassel (1979), he warns against the danger of focusing on the pathology, and not on the human being who has a particular medical problem. Secondly, he stresses the importance of knowing the person’s history in order to

know how to meet and help the person. Let me add that this is also true concerning the caregiver.

Using narrative structures to make sense of experiences also applies to the researcher. The participant gives away his story, his understanding of himself and his social world, and the story goes on to re-interpretation, analysis and re-presentation, a process of re-telling and re-writing with a second-order narrative as a result (Mishler, 2004; Elliott, 2005). This stands in contrast to a first-order narrative, in which the person talks about himself and his experiences. The version constructed on the basis of the interview material is the researcher's interpretation of their interpretation.

On the remaining pages, we will first look at "Arne's history," meaning a "factual" description of what took place in his and his wife Astrid's life in the period relevant for this paper. Next follows "Arne's story," i.e. the way he experiences and describes this period of their life together. Nonetheless, the story is not untouched by the researcher, who organized it under headlines in order to make it more accessible and easier to read. Lastly, "the researcher's story" presents results and understanding/interpretations within a salutogenic frame.

4. ARNE'S HISTORY

Arne, a participant in the current project, is a retired teacher of 76 living in a home in the countryside with his one year younger wife, who suffers from Alzheimer's. They have two children living elsewhere with families of their own. Up until three years ago, Arne lived a life characterized by nature experiences, outdoor life, painting and music, which were areas of interest he shared with Astrid, his wife of 50 years. Moreover, they both have a past within the educational system. Arne is creative, interested in art and is also a performing musician, playing a string instrument in a local orchestra and doing oil paintings.

Arne uses the term mental tsunami to describe what has taken place in his life during the past two-three years. It contains dramatic situations that have brought about a total change and readjustment of life and reality. Another name for it is Alzheimer's. Two days prior to their golden wedding anniversary two years ago, Astrid received a definitive diagnosis. Quite some time before that she had been having some physical symptoms (feebleness, dizziness, etc.). Then on a rather easy skiing trip a half year before she received the diagnosis, she felt unwell and they had to return home. She had diffuse symptoms, became confused and did not recognize Arne. He tried in various ways to help her remember who he was, but his efforts were in vain. He finally had to contact their daughter on the phone and get her to help, and this tactic worked. The following day they went via the public health center to the nearest hospital, where a stroke with a temporary comprehensive loss of memory was ascertained. Arne thought that she would recover, but now says that "it was the first sign of Alzheimer's." She had several acute incidents of memory loss during the spring, and Arne started to mark the incidents on a calendar. The crosses became more and more compressed until it all culminated in the early summer with the Alzheimer's diagnosis. The symptoms had been present over a long period of time and to an increasing extent, so the conclusion was hardly any surprise. Four months after the diagnosis was made, he sat down with his daughter and looked at x-rays of Astrid's brain, which he described as a frightening sight. The doctor stated that the illness had already developed considerably, and recommended that Astrid be placed in a nursing home.

The Alzheimer's diagnosis offered Arne an explanation for Astrid's inexplicable episodes. After the diagnosis was made, the illness developed rapidly, and Arne experienced her repeatedly losing control and having severe panic attacks. Arne was given several medical

explanations (a couple of extra diagnoses in addition to Alzheimer's) as reasons for these attacks, something that possibly made it a little easier to understand and relate to. The panic attacks seemed to be connected to her believing that he had disappeared, with Arne saying that the latter has been an ongoing subject. He also experienced several times that Astrid believed that he was replaced by an identical looking person, as other persons could be trusted, but not the person who looked like the one who was not there (called Capgras syndrome).

There had been several instances in which the situation had been saved by a phone call to their daughter, who has managed to adjust Astrid's perception of reality, hence becoming an important support person.

Arne was recommended by health professionals to get Astrid into a nursing home, which occurred after a medical check approximately four months after the initial diagnosis was made. He accepted the advice, feeling that there was no other option, as for him to take responsibility for Astrid at that time was not a choice.

For various reasons, they chose a reputable nursing home in a larger town. He and their daughter spent a good deal of time at the nursing home, attempting to closely monitor Astrid's situation. He thought his presence was necessary in order to stabilize the situation and make her safe in the new environment, which often meant sleeping overnight on a folding bed in her room. Based on his knowledge of Astrid after 50 years, he also tried to hint to the staff what he thought she needed, but unfortunately he found that this was not paid much attention to.

Astrid had been in the nursing home for a couple of months when he was asked to meet with the home's management. He was told to stop being so involved, and that from then on they were to act as ordinary relatives, coming for visits and going for walks with Astrid. The nursing home regarded itself as being qualified to take care of what was necessary regarding Astrid's needs. Arne also got a clear impression that he was looked upon as a burden and a pain in the neck. Arne found the situation so difficult that he made up his mind to terminate the agreement with the nursing home and instead apply for a local placement. He informed the management about his decision and returned to his home, and immediately after arriving back home he made contact with the local nursing home. While having a conversation with the management there, he got a phone call from the staff at the nursing home where Astrid was still living. She was having a severe anxiety attack, as the situation was out of control and they had to call and get his help to handle it. Arne talked to a totally terrified Astrid on the phone, the result of which was that he immediately took her out of the nursing home and brought her home.

Soon after returning home, she settled in and seemed satisfied and at ease. Because of that, the local placement she was offered was put on hold. He made up his mind to try to take care of her, a decision that was supported by the local health system. Arne has been Astrid's primary caretaker for more than a year and a half, which is still the current situation. Arne has agreed with the local health service that the situation is as good as it can possibly be at present. The municipal home based service has come in, primarily milieu therapists, whose task by and large is to make it possible for Arne to take time off, do things on his own or just get a break and relax.

Arne is eager to be helpful in our conversations, wondering what I am looking for and what I need to know. He regards talking with me as "going a step further," and is at my disposal if it can be of any help.

5. ARNE'S STORY

In many ways, Arne's story forms a "thick description" that contains a sum of the experiences shared by several of the participants in the project. Thus, he can be thought of as representing the group of male caregivers in the current project. Subsequent to this, (main) factors taken from a wider selection demonstrate how one story offers important lessons about the coping and meaning-making process for a male caregiver.

5.1 Turning Points

Within a frame of narrative concepts and understanding, turning points in a story play a vital part. Generally speaking, turning points are incidents or transitions that seem to have had a considerable influence on a person's life and/or view of life. Turning points mark where the story "turns" in a new direction. The new direction is usually caused by a choice or dilemma faced by the characters. The concept is used in somewhat different ways. In the current context, it is more of a phenomenological/hermeneutical understanding that focuses on the subject's interpretation. Denzin (1989) uses the term *epiphany*, characterizing epiphanies as interactional moments, "which leave marks on people's lives" (p.70). These are often moments of crisis.

In Arne's story, there have been a series of powerful events. Based on his description, some experiences are of a character that could qualify for a status as turning points or at least defining moments. The epilogue was the first time Astrid, the person closest to him, did not recognize him, and he strived to try and find ways to convince her. This first time was interpreted as a stroke that would heal itself, but in retrospect it was a crucial point in the story.

Two days prior to their golden wedding anniversary, the Alzheimer's diagnosis was established, which was a symbolically heavy incident, prompting Arne to say: "Golden wedding anniversaries are usually celebrated if people stay together long enough. Some divorce and lose the chance to do so. I have also lost this possibility to raise glasses with relatives and friends. Life is vulnerable and unpredictable. We have stayed together, but nevertheless cannot celebrate." This is an event with strong feelings that have left their emotional mark. Getting an explanation was a relief, but at the same time it was a fateful sentence over their life. What they had shared was not washed away, but their future perspectives were dramatically changed, and they could never return to the life they used to know.

What seems to stand out as *the* turning point is what took place at the nursing home. Arne gradually took in that the illness had developed to the point that something had to be done. What he described as the intense and sick character of the situation led to this solution because she was psychotic, after all. There also appeared a noticeable decrease in social contact with a feeling of isolation and aloneness after the illness showed its ugly face. He thought she eventually would quiet down at the nursing home, and that life could be normalized. This was "the way people handled situations like this," but in the nursing home everything turned out badly. He will never forget Astrid desperately calling his name over the phone, describing the experience as horrifying, as a traumatic situation and as the reason for the direction that everything took. From believing that the nursing home was the only reasonable answer, he has now gone in the opposite direction. This has led to a change in his outlook on life, altering his relationship with other persons and surroundings, thereby causing changes in his self-understanding. Concerning the latter, he has discovered and developed capabilities he did not now he had, capabilities that the situation has made possible.

5.2 Arne vs. Alzheimer's

It was in their outdoor life that Astrid's illness first appeared with limpness, cramps and dizziness. They were unaware of the illness lurking in the shadows, and outdoor activities, a skiing trip, were also the context for the first time that Astrid did not recognize Arne. However, this was understood as an isolated incident. Sometime after the first "stroke," he managed to rationalize away her forgetfulness and confusion, and for as long as possible he refused to take in what the symptoms represented. "I did not allow myself to believe that she was ill. I explained it as a minor stroke that would be normalized and become ok." He denied the warning signs for as long as possible, though he gradually came to understand that something was fundamentally wrong. This made him join classes for relatives of persons with dementia. Even so, none of the lessons or seminars he attended on the subject offered descriptions of attacks like some of the worst that Astrid had gone through, neither from lecturers or from other participants.

From a certain point, things accelerated. Arne summed up in the changes in Astrid in this way: "Avalanche after avalanche, like a dike bursting open. I thought it was scary and weird. I have never experienced anything as scary and weird in my life. A healthy, vigorous girl like Astrid being hit by an illness that develops in such a way. It was... I can hardly find words to describe the development of the illness and what it did to her." Arne has been a bystander who witnessed a dramatic change in his wife, with him describing it as something that takes total control over you, and which over time causes you to lose your ability to reason and your personality. When the situation arose that she did not recognize him, he found no way to convince her of who he was. "I could not help, no matter what I tried to say. I thought I was going nuts. I had to join her in looking for me while she was talking with our daughter on the phone." At times, the situation was surrealistic, like some type of absurd theatre. In retrospect, he finds it difficult to understand how he managed to pull it off. The situation went downhill so quickly that Arne was simply unable to adapt to the situation, in addition to losing the aforementioned ability to reason. Life was turned upside down in a matter of few months, which he described as almost being like a long-lasting state of shock. He was unable to adjust to the new reality. "And... it came so suddenly, and right in my face, it is such a shocking experience that I, I have put a solid lid over it because I almost don't ... I hardly dare to mention what, what it, how I experienced it and what it was like. But I do not risk going into it. If I do, I am afraid I will need professional help, though I still might need that in the future."

Arne's perspectives and his outlook on life have changed through all of this, but he finds it difficult to put words to how it has influenced his ways to think and act. The reality is that there is not always a correct answer, which must be doubly underscored. He says, "There has come a new kind of fear and anxiety into my life, witnessing what this illness is capable of doing." From being a creative and active person, Astrid has turned into something completely unrecognizable. She has jumped off over the edge and been taken out of circulation.

From his position as a witness, Arne describes Alzheimer's as "frightening and cruel, an alien, a monster or a creature that absorbs you in the end." It has changed and destroyed the person he loves the most, being like an external enemy ready to attack. How can you defend yourself against something that you cannot see? It seems as if he has a fear of being afflicted by the illness, and that it can overpower and overwhelm him and make him unable to act. To be able to relate to the illness, and to protect himself, he has to create a distance. He has had to take a step back and objectivize it, attempting to understand it as a medical phenomenon and thereby control it.

5.3 Local Care

At the time that Arne decided to take Astrid out of the nursing home, he contacted the local health-care service. Here, he felt that he had been met and listened to, and he was granted a placement for Astrid. He says that, "She was in such a bad shape that I didn't entertain the possibility of being responsible for her in our home." By a fortunate coincidence, the emergency call from the nursing home where Astrid was came while Arne was having a conversation with the section leader. Besides being a demonstration of the situation for the local health-care system, it was a confirmation of his evaluation of the situation. To terminate the agreement with the nursing home and take Astrid out was the correct decision. In many ways, this symbolizes the incident as a turning point. It was emotionally charged and called for action. She called his name in desperation, and he answered.

He talks now about how the situation is just fantastic compared to what it had previously been. There is no acting out on Astrid's part, and he wonders if the illness has come to a calmer phase, if she has somehow burned all the gunpowder.

The relationship with the local health- and home-based service is an open one, with a leader who seems to understand, as Arne feels seen, respected and heard. He feels that there is an openness to learning about the particularities of the situation. Thanks to Arne's efforts, the leader describes Astrid's current (caring) situation as optimal. They contribute with skilled persons to assist Arne so he can get some time off from time to time. The appreciation they show, as well as their concern about him becoming overloaded, has given him a good feeling and a sense of meaning.

Arne has experienced that the desirability of routines in home-based service is a challenge when it comes to getting through with his picture of Astrid as a special person who needs special treatment. He has had to take several turns. "They are benevolent and wish the best, but I have to explain to them what works and what doesn't based on my knowledge about Astrid. If it is not adjusted, if it does not work for her, it doesn't work for me," says Arne. Understanding her as a person is a precondition for getting her the best possible help. She was one of a kind before she became ill and is no less so in her present condition. He thinks it important that those dealing with her know who she was before she became ill in order to give her the proper help. It is not about bedsores and physical care, it is about mental wounds.

Taking Astrid home was an emergency solution that has become permanent. In no way was it planned like that, but Arne's understanding of the situation has changed. The nursing home experience is a reference point in that respect, while the present arrangement with Astrid living at home is in concert with the local health-care system. Her placement in a local nursing home is on hold, and has been given to someone else for the time being. Arne comments that, "She calmed down very fast when she came home. She has a far better life now, and as a consequence, I too have a far better life."

The understanding on the local level is very different from what he experienced at the nursing home, which is something Arne believes is related in part to the local community as being smaller and more transparent. There are many persons (health personnel) who know them and know what Astrid was like before she became ill. He has been open and told them about Astrid's background (traumas, childhood), including her GP. On his initiative, a group meeting was held so he could inform them about the time before the illness appeared, the period before the nursing home, the experiences at the nursing home and the time after. They were free to ask, they talked and the whole setting was very constructive and clarifying. It is about being seen and heard. Additionally, he has met with the staff at the institution that might be a future home for Astrid.

Arne has spent a lot of time being Astrid's spokesman and advocate. The relationship with the local health system has been "a good experience, actually," and he feels that they

have been treated like individuals (Høilund & Juul, 2005). It is a context in which the professionals appear as being flexible and understanding, which is in contrast to how Arne experienced the nursing home.

5.4 Relationship

Arne was born outside Norway by missionary parents, and he met his wife through a mutual friend. They both lived in Oslo at that time and were frequenting the same youth group in a religious setting. He tells about how when they met, the chemistry immediately was just right. He thinks they suited each other so well that he wonders if it was meant to be. Is there such a thing as accidental circumstances?

Now the situation has totally changed, as the illness has made him unsure of who he is to her. Does she recognize him? At the same time, he has become more important in her life. "After 50 years of married life, I have a whole new set of duties and experience, a totally different reality."

Arne describes his wife as a fantastic person in so many ways. "She has accomplished so much, and that has made me so grateful." She was a very special person when she was well, with Arne using the phrase "the illness took her." She was spontaneous, open, philanthropic and preoccupied with a nearness to people in a natural way. However, now she is nearly the opposite of what she used to be; she has become unpredictable and finds herself in a world that cannot be understood. "This is a reality I have had no possibility to foresee or imagine" he says. In reality, she is an anxious person. While she was in good health, this was something she managed to keep a lid on, instead concentrating on caring for others. He thinks it is terrible and unfair that she should be stricken by this, but he wishes to hold on to the picture of who she was and what they shared through 50 years. So doing creates a motivation to do the best possible for her. She is a person with Alzheimer's, not the Alzheimer's itself. She was one of a kind before Alzheimer's took her, and that is also true now that she is ill. She is still in there somewhere, even if the illness has done so much to change her.

The old Astrid can still appear in glimpses, and Arne strives for that to happen. It is like the troll has kidnapped her into its cave, and he is trying to get her out of there. It is possible if he finds the right means to do so. He feels that he can sometimes beat Alzheimer's by reaching her with, e.g. music. Managing to catch sight of her gives him an experience of succeeding. He also thinks that the illness' progress can be delayed by enhancing her quality of life, something he claims to have scientific arguments for. She used to be someone who stood out from the crowd, and she has not ceased to be very special. He exemplifies this with the story about the nursing home, in which she took the blame and apologized for what happened that led to her leaving the place.

5.5 Construction of Reality

Arne describes their life before the illness manifested itself as being predictable and regular. He could cultivate his interests, creative activities like painting and music. Life was characterized by double underscored answers like in math. Regularity provided balance and a quality of life, thus making it possible to look forward. There was no need to think of other possibilities. Now all of this has been "flooded and absorbed in the illness." "I try to maintain as much as possible of the old life, but nevertheless it gets very different."

The acute incidents caused by Astrid's condition could be quite intense with much confusion and bafflement. A red thread in this was the panic attacks she was having because she thought he was gone. "So I have the role of being a life preserver." Being afraid that he was gone is connected to her past history, and is marked with loss (she has lost many important persons in her life, including two children). He thinks that her past may have triggered the illness, being almost like a Nemesis. She has suppressed and pushed aside

these experiences, though now they catch up with her and cause illness. “I feel that this is predestination really, a consequence of her life history in total. From what I have learned about this, dementia can be activated by, e.g. depression. It is not just about genes, heredity and age. As such, I feel that psychological processes can also lead to dementia.”

For him as a caregiver in this situation, Arne says it is about finding attitudes that can keep him going mentally, mobilizing the instinct of self-preservation. He plays a major part in her drama, and tries as much as possible to be a life preserver. When everything surfaces, he needs to be there for her.

5.6 Caregiver's Identity, Self-care and Self-perception

As previously mentioned, Arne is a creative person with interests within both music and art. At times, his language is almost poetic, and he has a rich repertoire of striking metaphors. These sides of his personality have largely had to be set aside insofar as the way the situation has developed. His engagement is intact, however, and some of it can be revitalized if he finds ways to take care of her. He is preoccupied with finding creative solutions to get Astrid as good a quality of life as possible, while at the same time giving him some elbow room. “I try to hold on to my creativity, to who I am,” he says. When he finds a loophole (when she has gone to bed at night or is resting in the middle of the day, or when the home-based service comes around), he tries to consider these interests. Nonetheless, these areas of interest, e.g. visual art, are to a large degree on hold.

When it comes to mental challenges, the situation is comparable. Problems and needs emerging from his experiences related to the illness, as well as from the caregiving process, have to be set aside in order for him to be her helper. One could say he sacrifices this for her. He thought of getting some therapy when she was admitted into the nursing home, but then she returned home. He has decided not to give in to difficult feelings or psychological needs around the situation. He feels he has accepted the state of affairs, mobilized a defense, and that he is no longer as vulnerable and excoriated as before. Factual knowledge from lessons he has attended for relatives of people with dementia have helped, and he does not let the scary stuff come too close. He cannot go too deep into how this whole thing has afflicted him because this would be too painful and difficult. “I just feel shaky when we touch the subject,” he says. It is like he is afraid of losing his grip if he goes into this. He has built a defense and tries to be realistic, and he knows there is a progression and no return when it comes to Alzheimer's.

He has turned down offers of practical help from the home-based service. “It is very important for me to know that I am on my own two feet and healthy. I can live like I used to in relation to all practical things. I want to go on feeling like that.” Accepting the offer will make him feel handicapped and that he is bending for the illness. It would weaken his capacity or his feeling of sufficiency – living up to the stereotypes of helpless men. After all, he is healthy and in good condition.

This does not mean that it has been a joyride. He says that the task is mentally exhausting, there is sometimes a lack of sleep, and that he has to get up several times during the night, “Sometimes I am so worn out that I....” The sentence is not completed. However, he likes to think of himself as a stayer, someone who does not easily give up or give in. If it gets too complicated, he lets it rest for a while, “I sort of look a little at it from a distance and then I approach it again, and it seems like I often then succeed in accomplishing it. On the question, “Are you afraid of going down yourself?” he replies: “I do not dare to think that thought. No, I say to myself, I am a stayer, yes as long as... I nearly said if God willing. Much of the reason why I say it like that is that I have followed her through her entire life history, her story from when she was born, right? They put her in an orphanage. And later it happened so... Oh God it is, you just have to manage.”

Arne shows me a clipping from a magazine in which the interviewee expresses having lost her life because her spouse got Alzheimer's. He uses this as a starting point to maintain an opposite point of view on his own behalf. Arne rejects the martyr position. He views it as a position of powerlessness, "With an attitude like that, you deprive yourself of the possibility of doing something with your life. It is about attitudes and about choosing an outlook on life." Shortly thereafter, he states: "Realize the situation and choose a focus." He thinks that he has a propensity towards depression, but chooses instead to focus on the small things that give joy and light. He says that, "I experience a special love for a person that becomes more and more helpless and needs me more and more. I experience a new kind of closeness." He sees himself as someone who knows Astrid and is able to communicate what is good for her. To say that the brakes are on mostly regards her life. "For her, it means a full stop eventually, but maybe not for me?" It is about creating a distance to the illness, to not let it scare you or get too close to you. "You must not let what has happened overshadow what life offers and lead you to avoid looking around in the landscape," he says. It is about not losing sight of the possibilities that exist. "If I just see the illness, I miss a lot. I will lose my creative power, that which I can use to better her life." If you avoid blinding yourself to reality, but instead open up, you will experience new ways of thinking, feeling and being. You also develop creativity in relation to challenges that arise as a result of the new life situation.

5.7 Coping

Initially, Arne's thoughts were traditional: Astrid needed to get into a nursing home and settle there. This was how situations like these were handled. He had to reorganize his life and go on living, start his own life again, get it normalized. However, now his intention has changed. He has started anew with Astrid living in the house. Arne has installed an internal video surveillance system, where he has cameras in four of the rooms in the house. With this, he has found a way to monitor and take care of her at the same time as he can consider his own interests and needs. When he can be in control in this way, or when he gets external assistance from the home-based service, when she is safe and taken care of, he can relax.

In many ways, Arne has a practical approach to getting his life together. Building a foundation made of stone for a garage is one example, while practicing his music in the evening is another, "It is about being in motion, mentally and physically, not allowing room for heavy thoughts." Arne says that he attempts to avoid situations that cause this. It is easy to end up with your thoughts going in a circle like a mental rotary. "I can become very sad and feel sorry; first and foremost by the thoughts of her, what life has done to her. My God, what kind of life does she have ahead of her?" The defense is to put a lid on it, "If you talk about it, it manifests itself. Therefore, I cannot go into it. If I do, I'll be in need of help."

He finds it difficult to answer the question about how this has influenced him or will influence him in the longer term. He escapes the question; he cannot give it room, "I do not dare to think of it." To avoid ending up in depression, he must try to seize the day, picking flowers along the road, "Make life as meaningful as possible today, now, right: I try to do that, the small things close at hand, right. To get a distance to what is dragging you down and to get closer to what is pulling you up." He almost does not dare to think beyond the current situation, considering all the knowledge he has concerning the illness. To focus on what can be done for her today is a defense against all these frightening experiences. Mobilizing positive energy, to "win over" (or at least challenge) the illness, is about focusing on where she is in her process and adapting to that in as a meaningful manner as possible, all the way through the process. Try to think creatively, find solutions, and then arrange and make them possible. To the extent that he feels that he has succeeded, he talks about a "a little feeling of happiness." It works as a counterweight against the illness, which is

so frightening. He knows that the illness will have its way, but it is a motivation that the progress can be delayed by her having a harmonious and meaningful life.

The agreement (with the home-based service) is to keep it going as it is now for as long as it goes. He feels that he has no choice, as he is in the situation and that is where he has to be. The question is then what you chose to do in the situation. She has had enough in her life and the question of why this happened to him is of secondary importance.

5.8 Current Need for Help

There are limitation as to what can be done from the side of the local nursing home or the home-based service at present. It took some time before they understood that the assistance he needed was not of a practical kind like nursing things or cleaning the house. The practical aspects are minimal compared to the mental strain. He is clear that the need for assistance is on a psychological level, i.e. about meaning and contentment for Astrid. The rest he can take care of, saying that “It is no sweat. He also finds it natural and okay to take care of her personal hygiene. She gets uncomfortable if someone else does it, and this is something he can handle.

At present, the assistance he gets with regard to “stand-ins” at home, i.e. qualified staff is working well. There has been a decision to get more help for him, but there is a lack of qualified personnel. There is good will, but they are short of staff. They take Astrid for a walk, talk with her, spend time with her and so forth, which is about all they can do. That also gives Arne a chance to talk and discuss things a little with skilled people, who are specialists on dementia. What he needs is to feel relief and really take some time off, but that is not possible unless he knows that she is OK. It is not an option to place her temporarily in a sheltered care department in a nursing home just to give him some time off to relax, as she will become anxious and panicked. This would be awful for both her and for him, which is understood and accepted from the home-based services.

5.9 Network

His daughter is a close collaborating partner, although she lives quite some distance away. His son is more absent in this picture since he is busy with his life and family. Father and daughter are a team, and they have no relatives close by. Arne has two younger brothers and one sister who back him up as best they can. However, they live many hours away, though one brother in particular has been helpful in securing surveillance cameras to help monitor Astrid.

Arne tells that their network has shrunk since Astrid became ill, and he wonders if the diagnosis has scared people and turned them off, saying “I can meet people outside or in the store, and they cannot avoid asking how things are going. It happens that they ask stupid questions or demonstrate some strange reactions.” A few friends have been loyal, but he experiences little concrete support in the local context. He uses the term, “I have put his behind me.” Here, Arne draws on more generalized knowledge, what others have experienced in similar situations. “I have experienced what many others do. But my focus is not on that, I want to concentrate on what works,” he says.

He takes Astrid along to the store from time to time, which on a good day can be quite a positive experience. She used to be very social and knew a lot of people. Some of that can appear when they are out, but lately this has not happened so often. He needs to use the opportunity when he has assistance at home to do the necessary errands.

6. THE RESEARCHER'S STORY

In my memory (or my fantasy), there is a video of Edith Piaf. It is in black and white. She is standing on a stage singing. The spotlight is on her, while around her it is dark. She is alone in the picture. At one point, the lights and camera start moving around, and you can see that there is an orchestra and an audience.

At all stages of the process, research is about choosing what to highlight, what to make visible and what to leave outside the circle of light. In the above, we have followed Arne and Astrid's history and story the way it was heard by the interviewer. Despite the intention and ambition of letting the participant tell his story the way he wanted, the interview situation is a co-product, in that it is told to a specific person at a specific time in a specific context. Another researcher might have come out with a more or less different version, even more so when it comes to analysis and re-presentation, in which the researcher is attempting to make sense of the participants trying to make sense of their world.

In the current research project, the perspective is salutogenic (Antonovsky, 1987), which implies the question: Who are these men that stay in a (often demanding) position as caregivers and seem to manage, and what lessons can we learn from their stories about being able?

One important addition: When the focus is on the intersection between informal and formal care, one question arises: To what extent is the context the informal caregivers operate in a salutogenic one, an environment for health? (MacDonald, 2005). Viewpoints from Axel Honneth (1996) are made use of concerning the manner in which a professional or public health service meets the informal carer. Here, the concept of recognition is central. The knowledge the men in the project communicate shows that ways to "survive" or manage are diverse. This emphasizes the importance for the researcher to respect and recognize the uniqueness of individual stories. This is where we start.

6.1 Acknowledgment and Disregard

At the nursing home Arne experienced that his intimate knowledge and expertise was not paid attention to. Astrid's need for safety, contact and attention was not taken into consideration by the staff. Several times when he returned after having been away, he noticed what he perceived as major deficiencies in the care Astrid was receiving. He says he became worn out because it did not work for her, that there was too much to repair. If he was not there, she went wandering around alone in the corridors at night looking for him "It took a while before I realized that it did not work. A nursing home should work as a relief for relatives, but it ended up with exhaustion instead," he says.

A crucial moment in the story is when Arne and his daughter were told to start acting like ordinary relatives, and that the nursing home should "take over." This was experienced as a major lack of respect that added to a general feeling of not being seen or recognized. According to Arne, "We were not seen as a resource, but as a burden and troublesome freeloaders. I hold this as an allegation against the nursing home. We were personal assistants for a patient that needed attention, something they were not able to compensate for. We were not wanted and were squeezed out." It was not any kind of dialogue or understanding; it was more like an ultimatum, a penalty – a red card. He felt the attitude from the side of the nursing home as being very mortifying, with a total lack of acknowledgment. "We were not in it for our own pleasure." Arne's description captures what Høilund & Juul (2005) call not being regarded as a morally autonomous person. A certain understanding was forced on him, his self-understanding was neglected and overlooked and his intimate knowledge was not regarded as relevant. His final answer was to terminate the relationship with the nursing

home. This sort of reaction can also be explained as an outcome of feeling disregarded (op. cit.).

Alternatively it can also be described as a conflict between two different, and may be in some contexts, incompatible forms of rationality, a rationality of caring and a rationality based on a means-end thinking. In an institution, or in services based on rosters, marginal staffing, procedural regulations and so forth, conditions are often not optimal for a rationality of caring. At times, this approach is rather instrumental and limited by time. Quite a few of the project participants reported about home-based services with tight time schedules that only allowed room for specified tasks, whereas a formal decision had to be made for any operations to be added.

It is interesting to see what occurred when Arne brought Astrid back to their local context. His intention was not originally to take care of her at home, but to find a local placement, as he did not think himself competent as a main caregiver. Like many others, Arne thought that this was too complicated and demanding, a task for public health service and professionals. This is also what he thought to be proper and good care. This is very much a general and predominant understanding, reinforced and maintained by a modern health-care system. However, when Arne heard Astrid call on him, he was mobilized on an existential emotional level and responded to the calling, which was an ethical demand that overruled the cognitive and “professional” (Løgstrup, 1971). He did not think of the future, he just wanted to help her. When he decided to take care of Astrid, he experienced a professional service that respected him and was willing to listen. He felt an openness toward his attempt to explain who Astrid was/is, as well as an interest in learning about the unique sides of the situation. Over time, he felt that they had reached a mutual understanding that worked, and that he was recognized. Leaning on Axel Honneth’s work, Høilund & Juul (2005) lay out the importance of recognition. Their phrasing is “to be recognized as the person you regard yourself to be” (p. 30, author’s translation). If that is the situation, the suggestions and contributions from the professional side will more likely be listened to.

It is clear that the positive and open attitude from the home-based service has been an energizer in Arne’s case, making him feel competent and able. In a situation that seems difficult and challenging, Arne is able to focus on what gives meaning. “Subjective appreciation of life” might be an appropriate term to use in his case (José et.al., 2013:189). He also feels that he has been growing with the task. At the nursing home, he tried to be of assistance to the professionals, subordinating their professional knowledge. That failed. In the current situation, he is Astrid’s primary caregiver. He is the expert with professionals assisting him. In other words: In this case, the rationality of care is the basis for cooperation.

6.2 Sense of coherence

The results of the analysis are read through salutogenic lenses, i.e. Aaron Antonovsky’s concept of a *Sense of Coherence* (SOC) (1987). The concept was developed to explain why some persons became ill under stress, while others seemed to cope well. Antonovsky defined a Sense of Coherence as:

...a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: (1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement (p.19). Rephrased in a shorter way: the SOC is comprised of the three components: *Comprehensibility, Manageability,*

*Meaningfulness.*¹ These three components are reference points in the remaining part of “The researcher’s story.” In accordance with the SOC, one seeks to understand “how people manage stress and stay well.”

6.2.1 Sense of Comprehensibility

Arne is a realist. As a teacher, he used to work with math and the like. As he phrased it himself, he used to think that every question has a right answer, doubly underscored. When Astrid started to act in unusual ways, he did not know what to think or how to understand it. His term “mental tsunami” indicates a chaotic situation, and in order to survive a tsunami you first need to get your feet on solid ground. You can then attempt to get an overview, start to re-orientate yourself and re-establish yourself in a reality that might have changed considerably.

When he began to suspect that Astrid’s “episodes” were not incidental, he started marking the episodes on a calendar. This can be seen as a familiar way to gain some control. The Alzheimer’s diagnosis brought sense into the picture. It explained former incidents. Getting Astrid’s situation laid out as a medical phenomenon gave a direction for collecting knowledge, as now he knew a little more about what he was dealing with. In his search for information, he also learned about psychological factors in the development of Dementia/Alzheimer’s. His knowledge of Astrid’s past has made him believe in “predestination,” i.e. her past is catching up with her. He has realized and accepted that the future is not as predictable as he used to think it was. It cannot be controlled. Sooner or later, Alzheimer’s will have its way.

For him, the point is not only to understand Astrid, her condition and her reactions, but just as much to make sense of his position. He understands himself as playing a major part in her drama. He believes

that she lives in sort of a parallel universe that becomes easily filled with her former losses. He does not know much about what this universe is like, but he knows her story. When everything surfaces, he is her life preserver. It is him she is looking for, and she is afraid he is gone. He tries as much as possible to be this lifepreserver, but he is also her advocate and translator. It is his duty to explain who she is and act on her behalf in order for her to get the help that is right for her, the help that she needs.

He also needs to take in the fact that their network has shrunk considerably. One way he deals with that is to refer to this as a phenomenon that has various causes, and that “people in their situation” often experience. Actually, by using the phrase, “I have left this behind,” he means that he has accepted it as the state of affairs. He has to concentrate on his task.

In summary, Arne has acquired knowledge about Astrid’s condition. He feels he has reached an understanding of the background, and maybe also some of what has caused it. He has an idea as to what the illness contains, meaning some of Astrid’s experiences and feelings. He is the closest one to read her and her needs, and this knowledge determines and gives direction for his position and duties. He feels that the working relationship with the home-based service makes sense, and he has come to terms with the changes in the network. Even if he does not approve, he can understand how and why it has changed. He has accepted that this situation calls for a different kind of logic, a lack of predictability means that the future is today. To plan means to plan for the day, which is “surrender” to the situation. In one way it is to take control by letting go, not letting the lack of predictability control you.

¹ Comprehensibility: A belief that things happen in an orderly and predictable fashion, in addition to a sense that you can understand events in your life and reasonably predict what will happen in the future.

Manageability: A belief that you have the skills or ability, the support, the help or the resources necessary to take care of things, and that things are manageable and within your control.

Meaningfulness: A belief that things in life are interesting and a source of satisfaction, that things are really worth it and that there is good reason or purpose to care about what happens.

6.2.2 Sense of Manageability

In the process Arne has been through, he has discovered and developed capabilities he did not now he had, which were made possible by the process he has gone through and the situation that exists. His sense of manageability depends on several factors. He feels that he is in a good shape, physically and mentally, and that he is able to handle the situation under the current circumstances. He demonstrates this by his rejection of assistance from public services regarding practical- or care-related tasks. The recognition and acknowledgement communicated by the home-based service is essential, with the same being true of their support and assurance of being there for him if needed. He feels competent, able to cope and in control of the situation. This is in accordance with what Høilund & Juul (2005) call “human flourishing,” a result of being seen and acknowledged.

For him as a caregiver in this situation, Arne says it is about finding attitudes that can keep him going mentally, thus mobilizing the instinct of self-preservation. To be able to maintain his sense of manageability, he must avoid going too deep into the emotional aspects of the situation. That will weaken his capacity, make him less able to focus and reduce his ability to act in a rational way. He cannot look back on all the complicated experiences or into the future with its prospects. Today is what matters. Concentrating on today gives a feeling of control and achievement.

The video equipment is a good support for the feeling of control. He attempts to make workable routines in his care work, and uses his fantasy and creativity to find ways to reach Astrid and improve her quality of life. By opening up for all possibilities, Arne experiences new ways of thinking. He develops creativity when confronting the challenges arising from his new life situation.

One strategy that Arne seems to share with several others as a defense against the illness is to objectify it. Rephrased, this means to study it like you would study your opponent in order to beat him. Attending classes for relatives, doing literature studies and talking to others in a similar situation all help you do something in relation to the illness. You recognize things you have heard or read, which makes it more “controllable,” which is close to what is called externalizing (White, 2007). As is known in therapy, externalizing is about finding new positions where you can deal with the problem as an acting person, as an actor in your own life instead of being a victim of the oppressive problem.

So in sum, being in good shape mentally and physiologically, having external support and a “guarantee” of extra support if needed, the ability to control the dark sides of the situation (thoughts, memories, feelings) and externalize the illness make Arne feel that he can handle the present situation. Added to this, having technical equipment makes it possible to relax and still be in control.

6.2.3 Sense of Meaning

Arne’s way of describing the importance of meaning making seems to echo what Victor Frankl (2006) advocates. Frankl claims that everything can be taken from a man but the freedom to choose one’s attitude in any given set of circumstances, to choose one’s own way. Somewhat oversimplified, it is about finding a way to describe and understand the situation that gives meaning. This is also what Antonovsky describes as the most important of the three components in the SOC. The meaning dimension is the motivational element and forms a pre-condition for comprehensibility and manageability. It is about what “makes sense” in the emotional, and not only the cognitive meaning, of the term.

The way Arne explains what gives meaning and motivation in the situation covers what many others have told me in different ways. To put it simply: Astrid is worth it. Arne says: “It might sound strange, but it gives life meaning. It gives meaning to be able to give her a good life.” It also does him good to know that he will have no reason to regret, as this is the

person he has shared his life with. Holding on to the picture of the Astrid he used to know, as one of a kind, makes it meaningful to do the best possible for her. He says that, “A small victory gives energy to go on.” In essence, this is how Antonovsky characterizes the meaning dimension, as giving energy to the two other SOC dimensions. The “original” Astrid is still somewhere in there. She has meant so much for him for 50 years, and she deserves the best. To be able to outsmart Alzheimer’s by reaching Astrid in creative ways or doing things for her that improve her quality of life is rewarding and give “small moments of happiness.” In a positive sense, he has no choice. He does what he must do. Should we simply call it love?

Being told by professionals that Astrid’s situation at present is optimal strengthens his sense of meaning and adds to it.

7. SUMMARY AND CONCLUSIONS

Antonovsky has an interesting term, “the deviant case.” He asks, “Who are the smokers that don’t get lung cancer?” (1987:11). In other words, who are those making it in spite of the risk factors? Modified for our use: Who are the men that seem to be able to handle a demanding caregiver situation? Antonovsky emphasizes the importance of developing a theory of coping (op.cit.:13). So what can we learn from Arne about coping in a life situation such as his?

We learn about a process of avoidance and adaption, in which adaption seems to be the dominant reaction. From trying to cope with confusing and unintelligible incidents, it culminates in a medical explanation with a traditional solution (nursing home) as the answer. Then follows a dramatic change, which results in an entirely new understanding and arrangement. This process requires a re-construction of- and adaption to a new reality. He has to re-map the terrain and not least, redefine his own position. This would most probably have turned out differently without a local context communicating a respectful and recognizing attitude. The working relationship with local health-care and home-based service works in a salutogenic manner, and makes Arne’s project practicable. It functions as a complementary relationship that serves a purpose of care. In that connection, the social network is often affected when a serious or long-lasting illness appears, as Arne’s story bears witness to. This increases the significance of the professional helping systems.

Arne represents a very important group. More often than not, informal care is predicted to be of increased importance in a future situation – in combination with public care. Arne’s story illustrates the difference between an ideology marked by effectiveness and a means-end rationality, and a rationality of care based on intimate knowledge.² The latter rises beyond medical and technical needs, and is different from “effective care.” He teaches us about emotional and cognitive understanding and coping and the importance of openness and willingness to listen from the side of professional helpers. To be able to function in a salutogenic way and enter into a trusting working relationship with the informal caregiver, the professional helping systems need to be open to the uniqueness of the particular story. The needs for assistance are varied. They can be instructions and training (instrumental skills, knowledge about sickness or medical conditions, etc.), psychosocial needs such as being seen and acknowledged, respite care to be able to participate in social activities, direct professional social- and health-related assistance, etc.

Having an “illness focus” without paying attention to the caregiver’s non-instrumental needs has a pathogenic effect, and will ultimately exert a negative influence on the care receiver’s situation. Arne is one of several who underscore the need for getting off and doing

² In our context, this is understood as, “a particular, but totally fundamental kind of knowledge building on a person’s ability to enter the other one’s world, and from there establish an understanding of the situation (Høilund & Juul, 2005:71 My translation).”

their own thing. Generally speaking, this seems to be a challenge for the professional caring systems, even if it is quite clear that caring for the caregiver pays off for the care receiver. To be salutogenic, the focus needs to be relational, family- or couple based, not individualistic- and illness focused.

Incidentally, gender has not been a topic in this paper simply because it has not been a topic in my talks with Arne. He has not regarded it as being of relevance in his case. As a matter of fact, this is a general experience in talking to male caregivers. They do not question it. If this is done, it is by the environment. They simply do what they feel is right. For a lot of them, the task is not gendered.

We might ask then: Will this work in the long run? How long can Arne keep it going? Of course, there is no definitive answer to that question. However, what we do know is that this does not only rest on Arne.

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Volume(Issue): first page-last page.

Ex: Sadiq, M. and Alam, I. (1997). Lead contamination of groundwater in an industrial complex. *Water, Air and Soil Pollution*. **98(2)**: 167-177.

Book:

Last name of the author, First initial. (Publication year). *Book title*. Additional information. Edition number, Publishing house. Publishing place.

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Book Chapter:

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Online Document:

Last name of the author, First initial. (Publication year). *Document title*. Accessed in: day, month, year, in: URL.

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