

FROM PERSPECTIVES OF THE ELDERLY: QUALITY OF CARE IN GERMANY

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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 (Pflegerstatistik, 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 (Pflegetatistik, 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 Kneuöhler (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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