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Review of a PhD dissertation entitled "Bridging the Expectations and Reality Gap? Formal Caregivers' Views on Challenges in Dementia Care" submitted to the Faculty of Sociology, Adam Mickiewicz University in Poznań written by MA Lilia Rosenfeld under the supervision of prof. dr hab. Jakub Isański

The author of this review has prepared it in response to an invitation from the Scientific Council of the Faculty of Sociology, Adam Mickiewicz University in Poznań, dated 19 May 2025. The reviewer is a medical sociologist and a practicing physician providing outpatient specialist care in diabetology, and also holds medical qualifications in internal medicine and family medicine. This background offers a unique perspective, allowing the issues addressed in the dissertation to be examined not only from a theoretical standpoint, but also from that of a medical professional actively involved in the provision of healthcare. Consequently, the reviewer's interest extends beyond the contribution of social research to the state of knowledge about society to include the applied aspects of sociology (sociology *in* medicine, according to the classical dichotomy proposed by R. Strauss [1957]) that can be utilized in medical practice. This perspective will be adopted in the assessment of the present dissertation.

The legal point of reference for the present review is the Act of 20 July 2018 — Law on Higher Education and Science, as amended, in particular Article 187, which stipulates that a doctoral dissertation should constitute an "*original solution to a scientific problem*" and demonstrate the candidate's "*ability to conduct independent scientific research*" as well as their "*general theoretical knowledge in the discipline*." These requirements will be treated by the reviewer as the framework for the present assessment. Accordingly, the empirical part of the dissertation and the findings presented therein will be discussed first, followed by an evaluation of the theoretical part of the dissertation.

I will begin this review with describing formal aspects of the dissertation. The work comprises 374 pages. Its structure is typical of doctoral dissertations and includes a theoretical introduction, a methodological section, and an empirical part. The introduction is extensive and contains 268 pages. It consists of four chapters devoted respectively to: the biomedical characteristics of dementia and a description of the specific caregiving requirements associated with this condition; the concept of quality of life and the ways it is understood in the population of older people, including those suffering from dementia; the third chapter attempts to apply sociological concepts of stigmatization and the total institution to the description of the situation of people suffering from dementia; and the fourth chapter situates the undertaken issue within a sociocultural context.

Analysis and evaluation of the empirical part of a dissertation

The empirical section includes a methodological chapter and a part containing an extensive presentation of the empirical material obtained in the course of focus group interviews. A valuable enrichment of the dissertation is a chapter containing the author's personal views on the subject, as well as a chapter presenting the author's own suggestions regarding the optimization of care for people with dementia.

The research problem selected by the doctoral candidate concerns the exploration of the attitudes and experiences of formal caregivers providing care to people suffering from dementia. A research problem defined in this way is situated within the field of several sociological subdisciplines: primarily the sociology of illness/chronic illness, the sociology of disability, the sociology of ageing, as well as the sociology of medicine in the strict sense ("sociology of medicine" according to the classic dichotomy authored by R. Straus [1957]), including the sociology of medical professions. Consequently, the contribution of the dissertation to these specific sociological subfields should be considered. Unfortunately, the author of the dissertation does not demonstrate in the work any clear self-awareness of belonging to or representing a particular sociological subdiscipline.

Moreover, the dissertation goes beyond sociology and refers to areas of interest of public health, geriatrics (clinical gerontology), and medical ethics (in its applied aspects). We are therefore dealing with an interdisciplinary research project that extends beyond a single sociological subdiscipline (although the main frame of reference for the dissertation appears to be the sociology of illness), and also beyond sociology itself—towards medicine and public health.

Already at this preliminary stage of the review, I would like to express the opinion that the dissertation makes an contribution to each of the aforementioned sociological subdisciplines, and that the research results additionally possess applied value in the field of medical care dedicated to older people.

I consider the research problem to be a strength of the dissertation. While the ways in which dementia is experienced from the perspective of both formal and informal caregivers of affected individuals are relatively well recognized in the literature (see: PubMed), there is a noticeable lack of studies focused on identifying the determinants of optimizing the quality of care for people with dementia—particularly with regard to the possibilities of providing personalized care tailored to the preferences of the person affected. And it is precisely here that very important issues, rightly taken up by the doctoral candidate, emerge: where and how can a medical professional obtain knowledge about a patient's preferences in a situation in which direct contact is no longer possible, and when the patient did not articulate such preferences earlier, during a period of cognitive capacity? Where is the point of balance between meeting the medical needs of patients with dementia and responding to their non-medical needs (again, often determined arbitrarily, given the lack of communicative possibilities)? And finally, the ethical dilemma: in the case of people with dementia, where does the boundary lie between legitimate, standard medical care and futile or persistent care that may intensify suffering without altering the prognosis?

The value of the dissertation therefore lies in the fact that the doctoral candidate has chosen a current and pressing research problem, one that is moreover socially significant, as it is closely linked to the consequences of the demographic ageing of societies. The study focuses on the exploration of *caregivers' perspectives on the quality of care provided to elderly individuals with dementia*. The research problem was formulated in the form of the following question: *"What are the attitudes of different caregivers (such as nurses, physicians, and caregivers in home care and old-age homes) regarding the quality of care given to dementia patients at the end of their lives in old-age institutions and hospital departments in Israel?"*

The doctoral candidate formulated a research hypothesis (although, in my view, this is unnecessary in the case of qualitative research), suggesting that there exists—what appears to be a truism—*"a great variety of attitudes among different caregivers regarding the quality of care and the performance of invasive activities that do not improve the quality of life and do not extend the lives of elderly dementia patients at the end of their lives."* The candidate also formulates an interesting assumption that *"nurses in hospitals will tend to hold negative attitudes on this matter, while nurses and caregivers in old-age homes will tend to hold positive attitudes."* The hypothesis also includes a third component suggesting that *"nurses and physicians in medical centers will tend to evaluate the quality of life of elderly dementia patients at the end of their lives as significantly lower than that of other patients in a similar situation."*

With regard to this part of the research hypothesis, as with its first component, I consider it to be a truism that does not merit the status of a research hypothesis.

As the theoretical frame of reference for the research undertaken, the doctoral candidate has selected Karasek's model of occupational stress, which emphasizes— as the author suggests — the importance of balance between job demands and available resources. However, Karasek's original formulation is the demand–control model, which was later expanded to incorporate available resources as a factor shaping the occurrence of occupational stress (e.g., the three-dimensional model additionally including social support proposed by J. V. Johnson [1989]). What is lacking is an explicit annotation that the author adapts Robert Karasek's original model in such a way as to emphasize the role of resources rather than control over the manner in which work is performed. Nevertheless, this is not considered a significant shortcoming, as in both cases the focus remains on the conditions under which work is performed.

The second theoretical model adopted by the doctoral candidate as the framework for her own research is the ABC Model of Attitudes, which highlights the affective, behavioral, and cognitive components of attitudes. This model draws attention to the individualistic, cognitive-emotional determinants of behavior and thus provides a valuable complement to Karasek's more environment and context-oriented approach. Taken together, the two selected models are complementary and jointly constitute a coherent and appropriate theoretical framework for the author's original research conducted for the purposes of the doctoral dissertation.

Given the exploratory nature of the research problem, the decision to employ a qualitative research method is, in my assessment, appropriate. The doctoral candidate made use of the focus group interview (FGI) technique, within which respondents participated in a moderated discussion on a predefined topic. The research instrument—namely, the guidelines for the focus group moderator—is presented in Appendix 1 to the dissertation (p. 372).

I consider the choice of research technique to be appropriate; however, the justification for this choice provided in the dissertation is overly concise (p. 283). I therefore ask the doctoral candidate to address this issue during the defense by answering the following questions: What arguments does the doctoral candidate advance in favor of selecting the focus group technique in the conducted study? In what way does this technique offer advantages over the potential use of individual in-depth interviews in relation to the objectives of the research?

There are ambiguities in the description of the participant recruitment process. The author notes that physicians were also planned to be included in the study; however, information about the project and the invitation to participate were posted "in a public WhatsApp group for nurses" (p. 284). I request that this issue be clarified during the defense of this dissertation. Limiting the study exclusively to nurses appears to result in a significant impoverishment of the findings, as the physician's perspective is absent (Eliot Freidson famously called for research on "the experience of doctoring"!).

Furthermore, the dissertation lacks a description of the procedure for processing and analyzing the empirical material obtained from the focus group interviews, particularly the transcripts. So I pose a question: How were the discussion data processed? Which qualitative analysis methods (e.g., thematic analysis, discourse analysis) were applied?

The remaining aspects of the description of the research methodology are, in my view, sufficient: the number and composition of the focus groups are provided, the moderation guide is disclosed, and the mode of conducting the interviews (online) is specified. It should also be emphasized that care was taken to ensure neutral moderation, as this role was not performed by the researcher herself.

A major strength of the dissertation lies in the findings of the empirical research, which reveal the perspective of medical professionals engaged in the provision of formal nursing services to people living with dementia.

Now I will draw attention to selected findings. Particularly salient is the expressed need for humanized care for people with dementia, oriented toward improving their quality of life. Within this framework, some respondents voice doubts about undertaking "aggressive" medical interventions that increase suffering without contributing to an improvement in prognosis. Resolving this dilemma goes beyond the scope of sociological research. At the same time, it is noted that the medical system's offer to people with dementia is largely limited to medical interventions, often preceded by the sedation and immobilization of patients in order to enable the implementation of medical procedures (p. 297).

Respondents express a strong need to complement medical interventions—perceived as invasive and as increasing suffering—with a humane, human-centered approach: "Touching softly and slowly. Talk to them even when there is no answer" (p. 298).

There is also a clear observation that providing care for people with dementia is extremely emotionally burdensome for caregivers and may lead to professional burnout. Particularly compelling is the diagnosis of the causes of this situation, which respondents locate both in the specificity of interaction with the patient (or rather its absence as a result of dementia) and in the organizational context of nursing work (low wages, excessive workloads, systemic deficiencies, etc.). What resonates strongly is the thesis that the medical system itself is responsible for the dehumanization of care, as well as the dominance of reparative medicine, with its focus on acute interventions (cure versus care).

Since the thesis is framed around the idea of "bridging the gaps," the key question becomes how to move beyond merely declarative calls for the humanization of medicine toward their practical implementation. This is a very difficult question; the thesis does not provide (and arguably cannot provide) definitive solutions, although it actively seeks such answers.

The problem is undoubtedly broader: practical medicine as a whole faces—and has probably always faced—the challenge of finding a balance between effective, competent biomedical treatment (cure) and attending to the non-medical needs of patients (care).

The study also notes that caring for people with dementia is an extremely emotionally demanding task for caregivers and may result in professional burnout. Particularly noteworthy is the author's analysis of the causes of this burden, which respondents identify both in the specificity of interactions with patients (or rather their absence as a consequence of dementia) and in the organizational context of nursing practice, including low number of nurses, excessive workloads, and systemic shortcomings.

A strong critical stance emerges in the respondents' attribution of the dehumanization of care to the medical system itself, as well as to the dominance of reparative medicine, with its emphasis on acute interventions (cure versus care).

Given that the thesis is framed around the concept of "bridging the gaps," an important question concerns how the author moves beyond declarative calls for the humanization of medicine toward possibilities of practical implementation. This is an inherently difficult issue, and while the thesis does not - and arguably cannot - offer unequivocal solutions, it does demonstrate an attempt to engage with this challenge.

The problem addressed is clearly broader in scope: practical medicine as a whole has long struggled to balance effective, technically competent biomedical treatment (cure) with attention to patients' non-medical needs (care).

The author so invites reflection on the expectations placed upon medical professionals. In many clinical contexts, such as surgery, technical proficiency is prioritized over communicative competence. Whether this hierarchy of values should be reconsidered in the context of dementia care remains an open question. Although ensuring biomedical safety and treatment remains essential, the analysis suggests that in dementia care the relative weight assigned to relational and supportive dimensions of care may warrant further critical examination, rather than being treated merely as an adjunct to biomedical intervention.

A moral dilemma emerges particularly forcefully in the study: whether, and under what circumstances, life-saving acute procedures should be performed in patients “at an advanced stage” of dementia (p. 303). The respondents articulate conflicting positions, ranging from the conviction that “everything has to be done” (p. 302) to the question, “for what should he continue to suffer?” (p. 303). Neither the doctoral candidate nor the reviewer is in a position to resolve dilemmas related to the concept of futile or overly aggressive medical treatment, as this issue clearly extends beyond the remit of sociology.

One of the key strengths of the thesis lies precisely in posing the question of where, in the treatment of people with dementia, the boundary lies - the point at which therapy becomes futile. Closely related is another important question raised by the study: what constitutes “a dignified death” for this group of patients. The respondents themselves actively seek answers to this issue, often concluding that the hospital setting does not provide the conditions for a dignified death - an observation well documented in medical sociology. They further emphasize that patients with dementia require a specific, needs-adjusted system of care, analogous to the way palliative care has been tailored to the requirements of terminally ill patients.

In sum, this highly engaging reflection on medicine - firmly situated within the tradition defined by Robert Straus as the “sociology of medicine” - brings to the fore the need for the humanization of medical practice, while simultaneously confronting it with the systemic and organizational realities of healthcare delivery. As the author convincingly demonstrates, in the context of caring for patients with dementia, this fundamental dilemma: the tension between biomedicine and a humanized model of medicine, assumes a particularly dramatic significance. It may be argued that the experiences of Israeli nurses can be seen as a lens through which the core dilemmas of contemporary medicine become sharply visible, especially as it is increasingly challenged by the consequences of population ageing.

Analysis and evaluation of the theoretical part of a dissertation

I will now turn to the theoretical part of the thesis, highlighting both its strengths and its shortcomings. As previously indicated, in the introductory section the doctoral candidate addresses both social and biomedical issues. This approach is consistent with the specificity of the medical sociology, in which social analyses of health and illness must be grounded in sound medical knowledge of the phenomena under investigation. For this reason, the field of medical sociology has historically included medical professionals, including the founder of Polish medical sociology Professor Magdalena Sokołowska (herself a physician and a nurse), whose disciplinary perspective was informed by a solid biomedical background. The doctoral candidate adopts a comparable point of departure, drawing on prior biomedical knowledge as a foundation for her sociological analysis.

The first chapter of the introduction is devoted to a discussion of the biomedical aspects of dementia, including its etiology, diagnostic tools, and treatment possibilities. Unfortunately, the latter is based largely on somewhat outdated literature, predominantly from the years 2015–2016 and 2019. The chapter also addresses the requirements of institutional care for these conditions, rightly emphasizing the inadequacy of palliative care models in meeting the needs of patients with dementia and pointing instead to the importance of home-based care. This is followed by remarks on staffing shortages in nursing in Israel and other OECD countries, as well as on the specific burdens associated with dementia care in both informal and formal settings.

A clear strength of this part of the discussion lies in its emphasis on the psychosocial needs of people with dementia. In this way, the author leads the reader toward an analysis of the concept of quality of life from a sociological perspective (Chapter 2). At this point, however, the sociological grounding appears almost entirely absent. There is no reference to the contribution of functionalist and interactionist approaches to quality-of-life research. As a result, the discussion of quality of life presented in the thesis overlooks key elements of sociology's contribution to this field. In a doctoral dissertation in sociology, greater attention to these theoretical traditions would have been expected.

In the subsequent sections, the reader is presented with insightful observations on the measurement of quality of life among people with dementia who, due to cognitive impairments, are unable to articulate their own assessments or preferences. In line with the overall profile of the dissertation, the author devotes relatively more attention to the specificity of quality of life in old age, appropriately highlighting the social determinants of a "good life" in later life. This discussion leads directly to the core topic of the dissertation: the quality of life of people with dementia. The author convincingly links patients' quality of life to the quality of care, which in turn is shaped by the destructive consequences of caregiving for caregivers themselves, including serious psychological consequences such as depression and burnout. In seeking to explain whether – and how - caregivers may maintain a good quality of life and effectively cope with the stress associated with their role, the author draws on Aaron Antonovsky's concept of salutogenesis, with its emphasis on a sense of coherence, conditioned in part by access to interactional resources.

In the subsequent third chapter of the introduction, which juxtaposes two opposing ways of conceptualizing the patient as an object versus as a subject, more explicit sociological references become visible - the reviewer notes it with satisfaction. In this part of the dissertation, the author cites and discusses the concepts of Michel Foucault and Erving Goffman, rightly presenting them as sociological voices advocating for the patient as a person. These stances constitute a critique of dehumanized approaches to patients rooted in the assumptions of biomedicine (Foucault) and in models of institutional care for people with mental disorders (Goffman).

This is followed by an analysis of caregivers' attitudes toward elderly, which is situated within sociological reflection on contemporary societies. The author links the quality of care provided to older persons with the attitudes of those who deliver it, viewing these attitudes as a reflection of broader societal orientations. The discussion also draws on Talcott Parsons's concept of the sick role in the context of the author's reflections on the specificity of caregivers' professional identity. Read between the lines, one may infer that Parsons's vision of the emotionally neutral medical professional stands in tension with the model of the real caregiver, who inevitably experiences difficult emotions in the caregiving process.

Particularly valuable is the section devoted to the phenomenon of stigmatization of people with dementia. The author begins by recalling the classic arguments of Erving Goffman and Susan Sontag, while also engaging with more recent sociomedical reserarch on stigma (e.g. by Link and Phelan). She identifies dementia as a form of "super-stigma," leading to the social separation of those affected, and argues for the implementation of inclusive approaches toward people with dementia within institutional care for older adults. While normatively compelling, this vision appears highly idealized and raises serious questions about its feasibility in everyday institutional practice.

Equally compelling is the author's reflection inspired by Goffman's critique of total institutions, within which she examines where the boundary lies between paternalism - applied in its most extreme form in total institutions - and respect for patient autonomy. In seeking to resolve this dilemma, the author develops, on the basis of the literature, the concept of a moderate form of paternalism, defined as a "constant assessment of the risk–benefit balance in treating dementia patients." At the same time, she explicitly stipulates that a paternalistic approach, as I understand her argument, in any form should not be applied in the care of individuals in the early stages of dementia, who remain capable of expressing their own autonomy.

This is followed by a more general sociological reflection on the specificity of contemporary societies which, according to the author, reduces the prospects for meeting the needs of older people, given its strong orientation toward the pursuit of individual happiness through consumption, travel etc.

In the subsection devoted to globalization, however, the discussion includes reflections that are only loosely related - or not clearly related at all - to the theme indicated in the title. These include, for example, observations on families' difficulties in fulfilling the role of informal caregivers, as well as more general considerations concerning the social role of older people and the need for its redefinition. The chapter does not provide a clear justification of how these issues are analytically connected to the concept of globalization as announced in the subsection title.

The structure of the dissertation further includes a discussion of the demographic situation of Israeli society and the healthcare needs arising from its demographic ageing. At this point, the author redirects the analysis toward ethical dilemmas concerning whether therapies that require patient cooperation (such as dialysis) should be implemented in individuals with dementia when such cooperation is no longer possible. She also raises important questions about the mechanisms of decision-making in situations where the patient is unable to express autonomy through communication. The author rightly notes the absence of evidence-based medicine (EBM) data relating to people with dementia, as they are typically excluded from clinical trials for ethical reasons. The author once again asks what purpose is served by implementing acute, complex medical procedures in patients with dementia when such interventions do not lead to improvements in either quality of life or life expectancy. At this point, the role of nursing is again emphasized as offering a humanistic approach to treatment.

Particularly interesting in the context of the Israeli–Palestinian conflict are the author's remarks on the importance of cultural competence for accurate diagnosis and effective communication with patients within multiethnic and multicultural communities.

In the final sections of the introduction, the author addresses the issue of elder abuse, drawing attention both to definitional challenges and to the scarcity of data on the prevalence of the phenomenon, partly due to the dependence of victims on their abusers.

In summary, the introduction is multi-faceted and interdisciplinary. However, its grounding in sociological knowledge is uneven, as some passages lack explicit sociological references. Questions may also be raised about the structural composition of the dissertation, particularly regarding the repeated discussion of certain topics in multiple sections. For instance, ethical dilemmas related to the use of gastrostomy in older adults are addressed in a similar manner in different parts of the dissertation (pp. 195 and earlier, pp. 180–190). Ideally, such discussions should be located in a single, dedicated section to avoid repetition. Other themes, such as the need for humanization of care or the balance between paternalism and partnership in caregiving for older adults, similarly recur in various parts of the text. Likewise, the discussion of the cultural connotations of stigma in section 3.4 reappears in section 4.6. While both analyses are interesting and valuable, they would have been more effective if consolidated into a single section devoted entirely to this issue.

The literature utilized in the dissertation is extensive, well-selected, and appropriately applied, comprising a total of 248 references. In terms of editing, language, and formatting, the dissertation is carefully prepared.

Conclusion

Assuming that a doctoral dissertation is expected to make a contribution to the current state of knowledge within its discipline, this requirement has been fulfilled in the present case. The dissertation presents an original exploration of how dementia, an incurable chronic condition, is experienced from the perspective of formal caregivers, while also identifying the multiple institutional, organizational, and ethical factors that shape caregiving practices. In the theoretical section, the dissertation provides a critical analysis, synthesis, and systematic organization of knowledge on dementia from various scientific fields.

The conclusions of the dissertation are of an applied nature and may be relevant to the fields of public health and healthcare management, as they highlight conditions for optimizing medical and nursing care for people with dementia, provided that potential stakeholders have access to the candidate’s findings.

In summary, the candidate has offered an original solution to a sociological research problem, demonstrated the ability to conduct independent research under the guidance of her supervisor, and shown theoretical competence in sociology sufficient to qualify for the award of a doctoral degree. I consider that the requirements set forth in

Article 187 of the relevant legislation have been met and recommend that the candidate be admitted to the subsequent stages of the doctoral procedure.

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