



# Dignity-preserving dementia care: A metasyntesis

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## Abstract

Research indicates the essentiality of dignity as a vital component for quality of life, reconfirming the emphasis on dignity preservation in the international code of nursing ethics. Applying Noblit and Hare's meta-ethnography, the aim of the study was to develop a theory model by synthesizing 10 qualitative articles from various cultural contexts, exploring nurse and allied healthcare professional perception/practice concerning dignity-preserving dementia care. "Advocating the person's autonomy and integrity," which involves "having compassion for the person," "confirming the person's worthiness and sense of self," and "creating a humane and purposeful environment," was identified as a primary foundation for dignity-preserving dementia care. "Balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person," which involves "persuasion" and/or "mild restraint," was considered a crucial aspect in certain situations. "Sheltering human worth—remembering those who forget" was identified as a comprehensive motive and core value within dignity-preserving dementia care.

## Keywords

Care, dementia, dignity, meta-ethnography, metasyntesis, nursing

## Introduction

Dignity is seen as an important component of quality of life.<sup>1</sup> However, the concept of dignity and its practical applications for care have been criticized for vagueness and insufficient documentation.<sup>2</sup> Dignity is not easily placed under the microscope and defined. This point is illustrated by referring to Chochinov,<sup>3</sup> concluding after 10 years of research on the terminally ill and dying individuals that dignity means "different things to different people." The existential and philosophical complexity involved therefore seems to require a wider and more explorative approach in order to capture its true meaning beyond what any predetermined definition can offer.

The importance of dignity in professional care is emphasized in the international code of nursing ethics as well.<sup>4</sup> However, this document does not clarify the meaning of dignity, offering instead a vague understanding and subtle aspirations concerning opportunities for dignity preservation.<sup>5</sup> In their practice, nurses and allied healthcare professionals (HCP) may have an intuitive understanding of dignity. However, many often lack the in-depth understanding required to manifest dignity in real and practical clinical situations. Despite the stated intentions for dignity preservation, circumstances lead to dignity violations in some contexts involving care for older people. Caregivers should therefore seek a research-based understanding of the underlying components within dignifying care. Insight of this nature will better prepare them to challenge practices that violate dignity, and to recognize caring opportunities for dignity preservation.<sup>5</sup> As a basis for understanding dignity and its ethical implications, Gallagher<sup>6</sup> proposes a perspective of human beings as vulnerable, motivating caregivers to act on the basis of ethics of aspiration.

Dementia is characterized as a chronic disease with no curative treatment as of yet,<sup>7</sup> affecting 4.1% of persons aged 70–74 years, 5.7% of persons aged 75–79, 13% of older people between 80 and 84, and 24.5% of seniors above 85 years.<sup>8,9</sup> The total number of people suffering from dementia worldwide was estimated to be 35.6 million in 2010, and due to an aging population, these numbers are expected to increase substantially in the decades to come.<sup>10</sup> “Dementia” is a general term representing multiple related illnesses leading to a steady decline of memory and thought processes and reduced ability for orienteering and sound judgment coupled with a diminishing awareness of time, space, and direction. Shortly after developing the disease, the individual’s ability to plan and carry out simple daily tasks is affected. Synthesizing information and conversing coherently therefore becomes difficult for many. Alterations in emotional reactions are common, sometimes resulting in apathy, irritability, instability, or a diminished critical sense.<sup>7,11,12</sup>

Persons experiencing dementia develop an increasing need for external care as their illness develops from mild to moderate and advanced levels. Thus, developing dignity-preserving dementia care is important for meeting tomorrow’s healthcare challenges.<sup>7</sup> Dementia care practices must clarify whether the prerequisites for dignity preservation are present. Alongside a philosophical perspective of dignity preservation, an understanding of crucial aspects applied within dignity-preserving care practice may also be gained from empirical studies. Such foundation might be a valuable contribution for practice aiming to increase the quality of life<sup>1</sup> among the many who suffer from dementia.

This study is part of a larger project exploring crucial aspects of dignity-preserving dementia care. In this first study, dignity-preserving care is researched from the perspectives of nurses and allied HCP. In a second study, the individual perspectives of those experiencing dementia are explored. The third study concerns the perspective of spouses living with a partner suffering from dementia.

### *Study aim and purpose*

The aim of this study was to develop a theory model concerning crucial aspects inherent in dignity-preserving dementia care as perceived and practiced among nurses and allied HCP documented in previous empirical qualitative studies. Its purpose was the development of a unique understanding concerning dignity-preserving dementia care, making such knowledge available to practitioners, scholars, and politicians responsible for quality dementia care promotion.

### **Method**

Metasynthesis can be described as “research of research,”<sup>13</sup> a methodology that makes it possible to bring different qualitative studies together and break them down for closer examination.<sup>14</sup> Synthesizing the results of previous qualitative studies can reveal new and deeper understanding,<sup>15,16</sup> and constitute a strategic way to obtain increased understanding among politicians, scholars, and practitioners.<sup>17</sup> Philosophical

work is important to understand the ontology of dignity. However, synthesizing the results of empirical studies can be an important step toward improved practice.<sup>17</sup> Included studies should be chosen on the basis of their relevance to the formulated research question.<sup>13,18</sup> The number of studies should not exceed the researchers' ability to conduct an intensive analysis of the particulars included.<sup>18</sup>

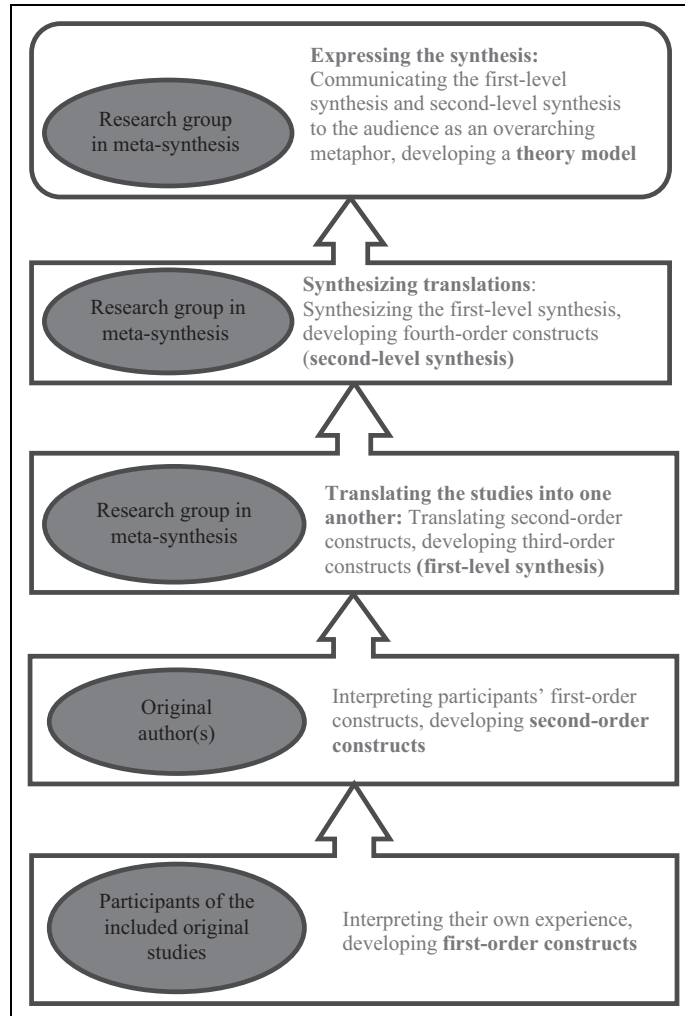
Today, there exist various approaches within this line of research. In this study, Noblit and Hare's<sup>19</sup> meta-ethnography was used. "Meta-ethnography" is a term referring to the methodology of interpretive synthesis of previous qualitative research that explores a phenomenon within different cultural contexts.<sup>19</sup> This seven-step approach is a reputable method within this methodology and is at present the most often applied method within this branch of nursing research.<sup>16</sup> Noblit and Hare's methodological recommendation does not include any standard methods or consensual procedure to follow when conducting a meta-ethnography.<sup>19–21</sup> We were encouraged by the work of Zimmer,<sup>22</sup> stating how Gadamer's concepts of the hermeneutic circle, the fusion of horizons, and dialogue with the text<sup>22,23</sup> can be valuable methodological tools for conducting metasynthesis. Within the hermeneutic methodology, an interpretive understanding of the text may be achieved through "dialogue with the text." Using the possibilities found within the hermeneutic circle process of reading the text over and over again, while conducting a reflexive dialogue with the text as a whole according to an understanding of its individual parts, gaining greater understanding of each part based on the context of the whole, a new understanding of the phenomenon may be gained. In this process, a fusion of the foreground horizon (our contemporary taken-for-granted meaning) and the background horizon (our historical experience that adjoins the present and makes the present conceivable) may occur, making new insight and understanding of the phenomenon possible.<sup>22,23</sup>

In this study, we explored the interpretation of dignity-preserving care reported in previous studies. These interpretations, conducted by the authors of each original study, were perceived as second-order constructs since they were based on the interpretation of nurses and allied HCP shared first-order construct (personal practice and perceptions of nurses and allied HCP). Thus, in line with Noblit and Hare,<sup>19</sup> the first concern of this study was the building of third-order constructs, in other words, developing a new understanding of dignity-preserving dementia care as a whole, based on the synthesis of the second-order constructs of previous studies. Thus, meta-ethnographic synthesis is founded on interpretation of interpretation of experience.<sup>24</sup> Moreover, as described later in the article, our third-order constructs involved a two-level synthesis. First, an initial first-level synthesis was generated. Thereafter, a second-level synthesis was developed building a fourth-order construct constituted by the various aspects found within the initial first-level synthesis (see Figure 1).

### *Conducting the metasynthesis*

*Getting started.* According to Noblit and Hare,<sup>19</sup> this initial phase involves identifying a theme of intellectual interest where qualitative studies might illuminate an area in need of further understanding. As a research team, we discussed and formulated the study background, aim, and purpose presented initially in this article. We then articulated the following research question: Which aspects of dignity-preserving dementia care are practiced and perceived as crucial by nurses and allied HCP employed in a variety of dementia care contexts, and documented in previous qualitative studies within empirical dementia care research?

*Deciding what is relevant to the initial interest.* Following Noblit and Hare's<sup>19</sup> recommendation of defining the study audience, the following target groups were formulated for this study: nurses and allied HCP, leaders responsible for dementia care, teachers responsible for dementia care education, and politicians responsible for quality in dementia care. The scope of a metasynthesis must be clearly restricted to avoid generalizations across separate fields. Efforts must be made to define the field and develop an overview of studies that may be included.<sup>19</sup> In this metasynthesis, studies were included if they were empirical studies, utilizing



**Figure 1.** Developing meta-ethnographic synthesis.

qualitative methods to explicitly explore nurse and allied HCP perception and practice related to dignity-preserving dementia care; were written in English or a Scandinavian language; were published between January 1990 and August 2011; and were published in a peer-reviewed journal, available at Scopus, PubMed, or Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. Combining the search terms “dignity” and “dementia” among studies concerning nursing care practice, the databases were investigated thoroughly during December 2010 with a follow-up search in June 2011 (Scopus) and in August 2011 (PubMed and CINAHL). Our database search yielded a total of 162 articles in Scopus, 125 in PubMed, and 127 in CINAHL. A substantial number of studies were overlapping. Additional database search utilizing available related article search column and reference list examination was also performed.

No metasynthesis was identified explicitly exploring dignity-preserving dementia care. A substantial number of studies provided theoretical perspectives and discussions. The number of studies fulfilling our inclusion criteria was, however, scarce, leaving a total of 10 articles to be included (see Table 1). These

**Table 1.** Chronologic presentation of the included studies.

Studies	Methods and participants	Cultural context	Aim
Zingmark et al. <sup>25</sup>	Phenomenologic–hermeneutic approach, interviews; 10 enrolled nurses/registered nurses	A homelike special care unit in Sweden	To enhance care workers' understanding of the meaning of offering care and a place to live for persons with Alzheimer's disease.
Randers and Mattiasson <sup>26</sup>	Content analysis, participant observations; 30 nurses/HCP	Two medico-surgical rehabilitation units for care of older people in Sweden	To examine the relationship between autonomy and integrity in interactions between older adult patients and healthcare workers in real-life care.
Borbasi et al. <sup>27</sup>	Interpretive realistic approach, semistructured interviews; 23 nurses/HCP	Three acute hospitals in Australia	To investigate and describe current practice and better/best practice in dementia care as perceived by HCP in hospitals.
Sävenstedt et al. <sup>28</sup>	Content analysis, interviews; 10 nurses/HCP	Home-based care and nursing home care in Sweden	To illuminate professional caregiver values and perceptions concerning information and communication technology applications.
Örjöv and Nikku <sup>29</sup>	Ethnographic study, observation; 6 assistant nurses	A facility for older people in Sweden	To explore conflict-solving dignity work performed by care workers in conflicts between residents suffering from dementia.
Rodriguez <sup>30</sup>	Grounded theory, ethnographic approach, participant observations/interviews; 65 nurses/HCP	Two nursing homes in Australia	To examine how professional caregivers used their attributions of agency as a rhetorical resource to construct dignity in dementia care.
Jakobsen and Sørlie <sup>31</sup>	Phenomenologic–hermeneutic approach, narrative interviews; 23 nurses/HCP	A nursing home in Norway	To illuminate ethical challenges experienced by care providers.
Manthorpe et al. <sup>1</sup>	Nominal group method; 70 nurses/HCP	Hospital, care home and older people's social center in England	To explore professional practitioners' moral decisions, practice constraints and perspectives toward maintaining dignity among persons with dementia.
Rodriguez <sup>32</sup>	Grounded theory, ethnographic approach, participant observations/interviews; 65 nurses/HCP	Two nursing homes in Australia	To investigate how care workers used emotions to construct dignity at work in dementia units.
Rognstad and Näden <sup>33</sup>	Content analysis, semistructured interviews; 12 nurses/HCP	A nursing home dementia unit in Norway.	To describe challenging situations meeting agitated persons with dementia, and the need for dignity care competence as perceived by professional carers.

HCP: healthcare professionals.

Study sample: totally 249 participants in 9 studies (10 published articles). Participating nurses were registered/clinical nurses. HCP included enrolled nurses, auxiliary nurses, student nurses, assistant nurses, certified nurse assistants, clinical nurse consultants, nurse unit managers, managers of nursing homes and home care, director/assistant director of nursing, physiotherapists, social workers, occupational therapists, activity assistants, speech therapists, and senior medical officers.

articles were based upon nine studies and generated empirical data from diverse dementia care settings, namely, home care, older people's social center, nursing home care, and hospital care. The studies were conducted in various cultural settings, originating in four different countries on two continents: four from Sweden, three from Australia, two from Norway, and one from England. A quality assessment of each primary source study included in our meta-analysis was conducted using the Consolidated Criteria for Reporting Qualitative Research (COREQ).<sup>34</sup> The studies were evaluated as high-quality research according to the recommended COREQ-standards related to the following three domains: research team and reflexivity, study design, and data analysis and reporting.

*Reading the studies.* Each study was carefully read several times to identify key concepts and themes (second-order constructs) used by the original authors to formulate their results. Second-order constructs document "what is taking place. These are the things to translate across studies."<sup>19</sup> All findings directly related to dignity-preserving care were carefully investigated by the three researchers separately. A matrix was developed to document the original authors' second-order constructs, using the original authors' own words whenever possible. Each researcher analyzed the identified similarities and differences, separately. On this basis, we, thereafter, as a group, formulated the crucial second-order constructs of each study (see Table 2).

Awareness of one's own preunderstanding is required to obtain a deeper insight into the meaning of the phenomenon under investigation, given that preunderstanding is viewed as an important foundation for interpretation.<sup>23</sup> Focused attention on our own preunderstanding, and on the research process as a whole, was emphasized to increase study transparency<sup>35</sup> and trustworthiness.<sup>36-38</sup> All three researchers had previous professional experience in dementia care, and in conducting qualitative research within dementia care and/or dignity in care. Our preunderstanding was firmly anchored in a perspective of dignity-preserving dementia care based on the professional caregivers' humanistic values, attitudes, and perceptions of worth, among individuals who suffer from dementia. Katie Eriksson's theory of caritative caring was applied as theoretical framework for this study.<sup>39-47</sup> A theoretical discussion of the results will therefore be conducted in the discussion section.

*Determining how the studies are related.* Studies conducted in different contexts may be related in three ways: directly related and comparable through a process of reciprocal translation, related as the studies present a lines-of-argument translation, or indirectly related due to the accounts' refutable and relative oppositional perspectives. How the second-order constructs from the original studies are constituted decides which analytic approach is most appropriate. Whatever the choice, it is most important to identify the core meanings that can accommodate a homogeneous theoretical understanding.<sup>19</sup> The principles of the hermeneutic circle, the fusion of horizons, and the dialogue with the text when conducting metasynthesis were followed.<sup>22</sup> Each member of our research team explored each study separately at first, then later in a group effort, to determine how the studies related to one another.

We identified studies conducted in different contexts that argued for dignity-preserving dementia care from two seemingly separate angles: Group A included nine articles arguing the importance of respecting the will and choice of the person experiencing dementia. There were three articles in Group B, two of which were also represented in Group A. The Group B studies emphasized how decision making on behalf of the person in certain situations could be necessary to avoid undignified consequences. In this process, we identified 34 second-order constructs across the 10 articles included in our study: 26 second-order constructs in Group A and 8 in Group B (see Table 2). In order to preserve wholeness, we found reasons to bring the synthesis process forward, utilizing reciprocal translation of the studies into one another in Groups A and B separately, before drawing them together in a final lines-of-argument synthesis.

**Table 2.** Reciprocal translation of second-order constructs into third-order constructs (first-level synthesis) in two identified groups (Group A studies and Group B studies).

Studies	Second-order constructs	Reciprocal translation of second-order constructs into third-order constructs (first-level synthesis): crucial aspects in dignity-preserving dementia care
1. Zingmark et al. <sup>25</sup>	Looking for the resident's personality, confirming and preserving the resident's sense of self and the feeling of being of value, discretely proving help, sheltering the resident from disrespectful treatment, and preserving the resident's external appearance	<p data-bbox="1043 556 1262 661"><b>Group A studies advocating the person's autonomy and integrity</b></p> <ul data-bbox="1043 722 1272 953" style="list-style-type: none"> <li>– Having compassion for the person</li> <li>– Confirming the person's worthiness and sense of self</li> <li>– Creating a humane and purposeful environment</li> </ul>
2. Randers and Mattiasson <sup>26</sup>	Empathizing with the patient, enhancing the patient's resources with respect to social exchange and reminiscing glimpses of own life history, confirming the patient's authentic autonomy, and supporting negative and positive autonomy in ways respecting his or her integrity as a state of wholeness	
3. Borbasi et al. <sup>27</sup>	Creating a purpose built environment that also includes taking time to talk to these patients and being knowledgeable, flexible, and willing to give the extra effort required of their care	
4. Sävenstedt et al. <sup>28</sup>	Using ICT to promote the person's security, freedom, and control, not as unworthy surveillance and confirming the person's worthiness in social interactions using ICT	
5. Öruly and Nikku <sup>29</sup>	Choosing an appropriate way of handling dignity-threatening conflicts between residents, noninterference, wait-and-see, forestalling, or immediate interference and then, executing a suitable strategy, direct confrontation, avoiding–confirming strategy, separating the residents, confirming–justifying strategy, or encouraging “good conduct”	
6. Rodriquez <sup>30</sup>	Understanding when verbal and physical violence are illness related and unintentional and enduring such events without anger or regret	
7. Jakobsen and Sørli <sup>31</sup>	Going out for walks to reduce experience of lost freedom due to locked doors	
8. Manthorpe et al. <sup>1</sup>	Talking to him or her in ways that enable him or her to find the best way to break the news of diagnosis to the family; maintaining the person's trust and confidence by respecting his need to feel in control; despite apparent deception, finding and retaining the person's sense of status in own eyes; supporting the individual in a person-centered way to understand the subjective elements of the person's dignity; respecting the person's need of sex and intimacy in a context of worthiness; being self-reflected and think about what you have wanted if put in a similar situation; acting as the person's advocate; and developing and implementing an agreed care plan based on cooperation involving the person, the relatives, and healthcare professionals	
9. Rodriquez <sup>32</sup>	Using emotional attachment as a resource to construct dignity experience in themselves as caregivers, and in the residents and treating residents as dignified individuals who deserve respect and are worthy of care, even if it may appear otherwise	

(continued)

**Table 2.** (continued)

Studies	Second-order constructs	Reciprocal translation of second-order constructs into third-order constructs (first-level synthesis): crucial aspects in dignity-preserving dementia care
7. Jakobsen and Sørli <sup>31</sup>	Exerting a certain degree of weak restraint when the patient is unable to make considered decisions concerning their own needs and finding the right time for using persuasion to preserve the person's self-determination	<b>Group B studies balancing individual choices in persons no longer able to make sound decisions, against the duty of making choices on behalf of the person</b>
8. Manthorpe et al. <sup>1</sup>	Considering the person's needs as well as his rights and balancing the person's individual choice with his or her needs and the duty of care	
10. Rognstad and Nåden <sup>33</sup>	Balancing autonomy and the necessity of making decisions on behalf of the resident; in some situations, using a certain degree of mild restraint in accordance to given restraining order; accomplishing restraining orders as forbearing as possible; and acting in a calm and trusting way to avoid agitation and aggression	
		In certain situations, in order to meet the person's essential needs; <ul style="list-style-type: none"> <li>– Employing persuasion</li> <li>– Exerting a certain degree of mild restraint</li> </ul>

ICT: information and communication technology.

*Translating the studies into one another.* A translation is an interpretive explanation and an especially unique synthesis because it protects the particular, enables comparison, and respects holism, including “making a whole into something more than the parts alone.”<sup>19</sup> Thus, Gadamer’s hermeneutical methodology was most helpful, underlining the importance of constant awareness on how the parts (various second-order constructs) influenced the whole, and how the whole influenced the individual parts when translated into one another through a hermeneutic circle leading to a fusion of horizons.<sup>22,23</sup>

*Synthesizing translations.* Studies translated into one another can imply translations that are able to encompass those of other accounts. In these cases, a second-level of synthesis is possible.<sup>19</sup> Exploring our Group A and Group B first-level synthesis, we identified lines-of-argument relationships between them; anchored in different contextual situations, both argued for dignity-preserving dementia care practice. A lines-of-argument synthesis translates comparable similarities and dissimilarities of the first-level synthesis into a new and holistic context. This approach is “essentially about inference: What we can say about the whole (organization, culture, etc.) based on selective studies of the parts.”<sup>19</sup> In our study, this second-level synthesis helped us to formulate an overarching metaphor, that is, a theory model on dignity-preserving dementia care (Figure 2).

*Expressing the synthesis.* Noblit and Hare<sup>19</sup> underline the importance of expressing the synthesis in a language the chosen audience will understand. We emphasized to formulate this metasynthesis in a way that we believed would clarify and illustrate crucial aspects within dignity-preserving dementia care to our study audience. The synthesis will be presented below. Tables and figures were used in this study to enhance study transparency and make scientific reading easier for the audience.<sup>48</sup>



## Results

### *First-level synthesis of Group A articles: advocating the person's autonomy and integrity*

Of the 10 included articles, 9 articles, involving 26 out of the total 34 second-order constructs, were included in this first-level synthesis from Group A (see Table 2). The empirical data from these studies conducted in Sweden, Australia, Norway, and England revealed the professional view of advocating individual autonomy and integrity as a primary foundation for dignity-preserving dementia care, involving three different yet supplementary aspects: having compassion for the person, confirming the person's worthiness and sense of self, and creating a humane and purposeful environment.

*Having compassion for the person.* A genuine interest in the individual person, combined with professional knowledge and caring attitude, was recognized as caregiver qualities and competence crucial for dignity-preserving dementia care.<sup>1,26,27,30,32</sup>

In their study, Borbasi et al.<sup>27</sup> found how professional knowledge concerning the fundamental needs in persons with dementia in general, supplemented by knowledge about the individual person hospitalized in particular, were fundamental insights toward helping nurses and allied HCP to advocate the individuals' autonomy and integrity. Randers and Mattiasson<sup>26</sup> found this base of knowledge essential for caregiver ability to see the patient as a unique individual in a unique situation. They underline the importance of empathizing with the person as a foundation for dignity preservation, advocating his autonomy and integrity as a state of wholeness:

(Observation): An older gentleman is walking up and down the nursing home corridor. He is behaving in a confused manner [...] moving things back and forth [...] saying; [...] "my wife is coming on this train and I've promised to meet her," is situated at the railway station. The nurse says: "Come here Karl! Why don't you sit in the waiting room (pointing towards the dayroom) and wait there until your wife comes, I'll go with you. You can have a cup of coffee while you wait." Karl responded directly; "That sounds very nice." [...] He continues to sit there and finds some peace of mind.<sup>26</sup>

Knowledge and empathy were also the main results in Manthorpe et al.,<sup>1</sup> showing how professional caregivers emphasized person-centeredness in dementia care. They identified professional insight into the elements that constitute each person's subjective dignity as crucial in enhancing dignity in dementia care. The study highlighted the importance of professional caregivers' self-reflection and awareness of one's own needs and wishes, placed in a similar situation. Moreover, Rodriquez<sup>32</sup> found that "instrumental caring *for* activities" (doing *for*) alone were not sufficient in dignifying care. Also an ethic of "caring *about* the person" should be present. Sharing similar life-defining experiences with the person cared for helped strengthen caregiver empathy generating meaning toward dignified care. Connecting with the person's life story in a personal and intimate way helped lay a foundation for emotional attachment and a sense of "being like family." Developing emotional bonds was identified as an important resource among caregivers, helping them to construct dignity experience between themselves and the person cared for: "And it was difficult, but she was happy [...] She felt she had her daughter back, and I gave that to her and I was very pleased to be able to do so."<sup>32</sup>

Rodriquez<sup>30</sup> also showed the connection between caregiver knowledge, empathy, and the understanding of the often unintentional, illness-related behavior among persons suffering from dementia, for example, in the case of verbal and/or physical outbursts or aggression: "[...] But then you go to the classes and you see they have no control over those emotions, over how angry they are. Or how they're responding to things. It's just—it's part of their dementia."<sup>30</sup>

Treating each resident with respect and as worthy of care, independently of her or his behavior, was found to be essential in generating dignity.<sup>32</sup> Professional insight derived from knowledge and empathy helped the caregivers to endure such events without anger or regret, enabling them to uphold a professional

dignity-preserving perspective in challenging situations.<sup>30</sup> As found by Randers and Mattiasson,<sup>26</sup> dignity preservation often called for professional flexibility and willingness to give the extra effort required. Manthorpe et al.<sup>1</sup> showed how dignity can be preserved when caregivers converse with the individual experiencing dementia in a way that enables the person to make autonomous choices according to his or her own subjective needs. Maintaining the person's trust and confidence by respecting her or his need to feel in control was identified as an important foundation for dignity-preserving dementia care.

*Confirming the person's worthiness and sense of self.* A genuine respect for the person as a unique human being, with an inherent desire or right to make choices according to her or his subjective needs, was found to be fundamental in advocating autonomy and integrity. Confirming the person's worthiness and sense of self in this way was identified as crucial in dignity preservation.<sup>1,25,26,28,32</sup>

Zingmark et al.<sup>25</sup> showed how HCP emphasized discovering the personality of each person suffering from dementia. This insight was an essential foundation in their everyday efforts to confirm and preserve each resident's sense of self and feeling of value. As an example, this insight made it possible to preserve one person's dignity with regard to upholding the residents' external appearance by assisting the persons to dress and to style their hair the way they were used to. These findings are in line with Manthorpe et al.<sup>1</sup> who documented how caregivers perceived dignity as a phenomenon involving two central perspectives: an inherent self-respect and feelings of worthiness, together with being respectfully recognized and confirmed by others. Interpersonal caregiver-resident negotiations were reported to be very much a part of dementia care practice. Interactions where caregivers supported autonomy and integrity, helping the person retain a sense of status in her or his own eyes, were perceived to be crucial in preserving this person's dignity.<sup>1</sup> Ethical challenges often occurred in these interactions. Professional caregivers valued residents' experience of subjective dignity and personal self-worth so highly that they sometimes found it in the best interest of the person not to tell her or him the objective truth, a perspective also documented by Rodriquez.<sup>32</sup>

Randers and Mattiasson<sup>26</sup> showed how nurses and allied HCP put emphasis on enhancing the residents' resources in social interactions. Within the context of social exchange, residents were stimulated to regain both interpersonal as well as intrapersonal contact reminiscing glimpses of their own life history. Documenting a person's previous life history helped caregivers to better understand and to maximize the person's authentic autonomy, thus, to advocate autonomy and integrity by promoting choices consistent with the individual's authentic character. Dignity-preserving care also involved solving ethical challenges related to negative and positive autonomy in the person. In some situations, dignity was protected by supporting the person's negative autonomy, standing back and not overruling or interfering with the free choice and action of the person. In other cases, however, supporting the person's positive autonomy was identified as a way to preserve dignity, using interventions to promote integrity and further individual freedom of choice. The results of Manthorpe et al.<sup>1</sup> also underline the importance of supporting each individual in a personal way, enhancing her or his subjective dignity-related elements.

Also Sävenstedt et al.<sup>28</sup> documented the importance of social interaction in dignified dementia care, including each resident within a relational and caring fellowship, confirming their value as human beings worth communicating with. Facing both the possibilities and challenges related to the ever-increasing development in information and communication technology (ICT), caregivers emphasized a distinction between ICT, which supports humane and dignified caring intervention, and ICT utilized primarily as a tool for remote surveillance, actually violating human dignity: "We cannot create systems that treat older people like parcels. They have to feel that they have a value as a person and that their value can be confirmed in their social interactions with others."<sup>28</sup> Caring for bedridden persons with advanced dementia unable to communicate verbally, Rodriquez<sup>32</sup> documents how perceiving and treating these persons as dignified individuals, worthy of respectful care, constitute a crucial aspect within dignity-preserving care.

*Creating a humane and purposeful environment.* Studies indicate that professional caregivers caring for persons suffering from illness-related decline of memory and reduced ability of orienteering should focus attention on environmental factors within the caring environment. Many nurses and allied HCP perceive the contextual milieu and climate (the atmosphere created by the physical environment) as crucial aspects within dignity-preserving care. Thus, creating a practical environment designed to meet human needs for freedom and safety in everyday life was emphasized to enhance autonomy and integrity of the individuals residing there. Caregivers reported that caring environments should be grounded on humanistic perspectives and values, respectful of basic human nature.<sup>1,25,27–29,31,32</sup>

Dementia care is often practiced behind locked doors, an often frustrating practice, as documented by Jakobsen and Sørliie.<sup>31</sup> Environmental factors leading to loss of freedom were problematic within a caring context, undermining the basic humanistic values of personal autonomy and integrity. Professional care providers often experienced their patients' reaction to physical hindrances as they stood behind a locked door waiting for it to be opened. In order to preserve personal dignity and reduce the experienced loss of freedom, autonomy, and integrity, going for frequent walks was given high priority.<sup>31</sup> In some contexts, the use of ICT was perceived as a valuable contribution toward increasing environmental opportunities to enhance residents' personal autonomy and integrity. Sävenstedt et al.<sup>28</sup> documented nurses' and HCP's finding that electronic tagging enhanced personal freedom, promoting security for older people who like to go for walks yet sometimes become confused and lose direction. However, dignity-preserving ICT as an environmental aspect in care should be individualized according to the individual's personal needs and severity of dementia:

We have to think through the use of these electronic devices so that we only use them when we believe that it will benefit older people. If you have severe dementia you don't need an electronic tag, you need a staff member to show you the way.<sup>28</sup>

Persons suffering from this complex illness syndrome are often vulnerable due to reduced capacity for clearly presenting important needs and desires. Therefore, Manthorpe et al.<sup>1</sup> found that professional caregivers placed emphasis on developing person-centered environments, which advocated and promoted individual autonomy and personal integrity. Incorporating and implementing these aspects into an agreed-upon individual care plan formulated in cooperation among the individual, the relatives, and the HCP were recognized as essential for developing dignity-preserving environments. Zingmark et al.<sup>25</sup> documented how caregivers perceived environmental promotion of residents' feelings as valuable human beings as a crucial dignity-preserving aspect. Developing environments that focus attention on identifying individual needs for assistance and then offering discrete personal help were perceived as essential.

The caregivers also emphasized awareness for creating environments for sheltering residents from disrespectful treatment from others. In contextual settings, within a nursing home facility, persons experiencing dementia naturally relate to one another. In these residential interactions, conflicts may occur, threatening or violating dignity of one or more persons. Since fellow residents may also experience such conflicts as burdensome, situations of this nature constitute a potential problem for the nursing home environment as a whole. In their research, Örvulv and Nikku<sup>29</sup> showed how caregivers emphasized dignity-promoting conflict-solving using micro-ethical coping strategies, choosing between noninterference, wait-and-see, forestalling, or immediate interference. They executed, thereafter, what they determined to be the most suitable strategy of dignity preservation by choosing among direct confrontation, avoiding–confirming strategy, separating the residents, confirming–justifying strategy, and encouraging “good conduct.”<sup>29</sup>

Borbasi et al.<sup>27</sup> documented how nurses and allied HCP in acute hospital settings requested an entire organizational shift in thinking, offering these patients a person-centered and “dementia friendly” environment. First, secure areas with highly qualified and motivated HCP who understand their patients' conditions

and needs should be provided. Second, a higher caregiver–patient ratio would allow the creation of a purposeful, dignifying environment in which they could sit down, spend time, and talk to these patients. Rodriguez<sup>32</sup> showed how nurses and allied HCP encouraged the development of emotional attachment to patients for a more homelike caring atmosphere in their nursing home setting, developing a milieu that helped the residents to live as comfortably, enjoyably, and dignifiedly as possible.

### *First-level synthesis of Group B articles: balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person*

Of the 10 included articles, 3, involving 8 out of the 34 second-order constructs, were included in the first-level synthesis of Group B articles (see Table 2). These studies, conducted in Norway and England, found balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person, to be a crucial aspect within dignity-preserving dementia care. These studies showed how the holistic human caring perspective led to conflicts of interest as professional caregivers aimed to advocate their patient's personal autonomy, while simultaneously preserving their personal integrity. In applicable situations, autonomy preservation was perceived as a caring perspective, which if emphasized, in certain situations, actually led to integrity aggravation and dignity violation. When persons experiencing dementia were unable to take care of their own essential needs, and no longer were able to make sound decisions, professional caregivers felt an ethical duty to protect them from harmful consequences violating their physical integrity, and integrity as a whole. Thus, in such delicate situations, persuasion and/or mild restraint were sometimes perceived as necessary interventions toward upholding personal integrity, as a foundation for dignity preservation.<sup>1,31,33</sup>

*Employing persuasion in order to meet the person's essential needs.* Jakobsen and Sørli<sup>31</sup> documented how certain aspects of dementia care involved complex, ethical challenges, for example, when people experiencing dementia were unable to make sound decisions, while professional caregivers are trained to promote respect, autonomy, and self-determination among their patients. Also Rognstad and Nåden<sup>33</sup> found that nursing staff often met these ethical dilemmas in various settings, especially related to residents' need for hygiene and medication. A basic caregiver perspective was that these individuals were suffering human beings in need of dignifying care. Jakobsen and Sørli<sup>31</sup> showed how the caregivers labored to find the right time for persuasion as a care intervention aiming to stimulate the person's inherent resources and self-determination, and strengthening her or his ability to cooperate in this situation:

She refuses to shower and cut her nails, but we usually manage to persuade her. Her sister wants us to force her to do it at regular intervals, but we think it's better to consider how she is on a particular day and who's at work.<sup>31</sup>

*Exerting a certain degree of mild restraint in order to meet the person's essential needs.* The utilization of persuasion did, however, not always solve the ethical dilemmas concerning personal integrity and dignity. Caregiver attempts were at times denied by the person cared for. However, allowing persons unable to make decisions based on sound judgment to go their own way was also perceived as problematic and inappropriate within a professional dignity-preserving care perspective. In certain situations, caregivers found that they had no choice but to take responsibility for choosing the best course toward preserving the personal dignity of each resident, even when the individual had expressed another course of action.<sup>33</sup> This is in line with Jakobsen and Sørli<sup>31</sup> who found that caregivers perceived exerting weak restraint in certain situations as their duty toward dignity preservation, when caring for persons unable to make reflected choices according to their own health situation or basic hygienic needs. Manthorpe et al.<sup>1</sup> indicated the necessity of

considering both an individual's needs as well as human rights. HCP experienced major ethical dilemmas when responsible for protecting their patient's right to make choices, while simultaneously having the duty to ensure their essential needs were being met. As documented by Rognstad and Nåden,<sup>33</sup> in everyday application, this often meant choosing between advocating personal autonomy and, in accordance to an authorized restraining order, exerting a certain degree of mild restraint, in order to meet a person's essential needs, thus promoting her or his integrity and dignity: "You can't let a patient lay in bed with a diaper full of excrement just because they don't like to be washed and changed."<sup>33</sup> Moreover, within a dignified care perspective, mild restraint was also a part of the everyday dilemma in administering prescription medications. Caregivers felt a strong obligation to ensure that patients received their necessary and often vital medication, even though some resisted, not understanding possible serious consequences: "Shall I force patients, or shall I lie? There are many who crush the tablets and mix them with jam to get the restless patients to take their medicine."<sup>33</sup>

Rognstad and Nåden<sup>33</sup> also identified illness-related aggressive behavior as a dignity-threatening challenge within dementia care. In their efforts to preserve dignity in professional dementia care and avert this type of behavior, nurses and allied HCP emphasized the need to act calmly and in a trusting way to avoid agitation, aggression, and subjective burden in individuals experiencing mild restraint.

## Discussion and final considerations

### *On study limitations and methodology*

In terms of limitations, although applying a systematic database search as well as manual reference list search, additional studies may exist containing supplementary perspectives. If we had included relevant work documented in gray literature and books, including nonarticle-based dissertations, additional aspects on dignity-preserving dementia care could possibly have been revealed. Moreover, focused attention on similar data from various studies may have led us to overrepresent certain second-order constructs, while other aspects may have been overlooked. We also recognize the inherent interpretive process of metasynthesis and the possibility that a different research team could have developed an alternative theory model.

Nevertheless, the meta-ethnography of Noblit and Hare<sup>19</sup> was evaluated as a most helpful approach when conducting this metasynthesis. Their process description for conducting a metasynthesis from initial idea to final synthesis expression was a valuable guide. Based on our experiences, we believe other researchers may also find this methodology useful, when examining various ethical issues involved in everyday dementia care. Using the Gadamerian hermeneutical approach<sup>22,23</sup> strengthened our study structure, giving us a framework for data interpretation. To avoid confirmation bias, thorough data analysis search for disconfirming evidence was performed. We emphasized analyzing the empirical data to identify caregiver experience that could contradict our preunderstandings, recognizing the possibility that this approach may lead to either positive or negative resident experience. The critical appraisal of each article, performed separately by each of the research team members, enhanced the rigor of the synthesis.

This metasynthesis, based on the results of 10 articles from Sweden, Australia, Norway, and England, comprises a wide range of empirical data on how a total of 249 nurses and allied HCP practiced/perceived what constitutes dignity-preserving care within various dementia care contexts. The result indicates how dignity preservation is a complex challenge involving both congruence and diversity in caregiver perception/practice across caring context and culture.

### *On the results*

*The Group A first-level synthesis* showed how caregivers perceived/practiced advocating the person's autonomy and integrity as a primary foundation for dignity-preserving dementia care. Autonomy concerns

a person's capacity for self-determination and self-governance and is highly relevant within the dementia care context,<sup>49</sup> while integrity by origin means being whole, sound, and/or unharmed.<sup>50</sup> Nurturing and preserving each patient's integrity is a guiding principle in all geriatric care. This includes confirming each individual as a holistic being complete with physical, personal, and social integrity within one dynamic synergy that care helps promote and strengthen.<sup>50</sup>

In this metasynthesis, we found three separate yet supplementary aspects inherent in "advocating individual autonomy and integrity," namely, "having compassion for the person," "confirming the person's worthiness and sense of self," and "creating a humane and purposeful environment." First, synthesizing the results of Manthorpe et al.,<sup>1</sup> Borbasi et al.,<sup>27</sup> Randers and Mattiasson,<sup>26</sup> and Rodriquez,<sup>30,32</sup> we found how genuine interest in each individual combined with caring attitude and knowledge formed caregiver qualities and competence from which compassion could be derived. This first-level synthesis suggests that having compassion for the person is a crucial prerequisite toward caregiver ability for autonomy and integrity advocacy, thus a primary foundation for dignity-preserving dementia care. Compassion or "sympathetic pity and concern for the sufferings or misfortunes of others"<sup>51</sup> is seen as a fundamental moral dimension in nursing<sup>52</sup> and worldwide ideal for professional care practices.<sup>53,54</sup> The first-level synthesis indicates that personal understanding of each person being cared for was perceived as crucial for caregiver ability to see the patient as a unique individual, and essential for developing empathy and compassion for the person. Within this context, emotional bonds could develop as a resource toward helping them strengthen dignity within the caregiver-resident relationship. Person-centeredness, or connecting with the individual's life history in a personal way, seemed to help caregivers develop insight into the essential elements constituting the subjective dignity of each resident/patient. On this foundation, an ethic of caring *about* the person seemed to develop as a crucial dignity-preserving alternative to more instrumental *doing for* approaches. Treating each resident with respect and as one worthy of care, independently of her or his behavior, seemed to be a natural result within this context. Professional competence coupled with compassion helped caregivers find new insight, enabling them to develop increased tolerance for verbal and physical outbursts or aggression by patients, recognizing such behavior as unintentional and illness related. Caregiver respect for the individual's need to feel in control seemed to be crucial for maintaining trust and confidence. Thus, caregiver ability to quietly endure moments of verbal or physical abuse, without anger or regret, was identified as crucial for dignity-preserving care.

Second, after synthesizing the results of Manthorpe et al.,<sup>1</sup> Randers and Mattiasson,<sup>26</sup> Rodriquez,<sup>32</sup> Zingmark et al.,<sup>25</sup> and Sävenstedt et al.,<sup>28</sup> we found that caregiver respect for the person experiencing dementia, confirming her or him as a unique human being with resources, needs, and rights to make choices of their own was a crucial aspect of autonomy and integrity advocacy within dignity preservation. This first-level synthesis thus indicates how confirming the person's worthiness and sense of self appears crucial in advocating autonomy and integrity as a primary foundation for dignity-preserving dementia care. Previous research indicates how persons experiencing dementia may suffer gradual loss of identity and personal dignity, leading to social isolation and depression.<sup>55</sup> However, even persons suffering from severe dementia may exhibit episodes of lucidity, especially when professional caregivers emphasize person-centeredness in caring, affirming the resident/patient as an individual with personal value and encouraging meaningful expressions of experience.<sup>56</sup>

This first-level synthesis suggests how caregivers perceived dignity in their residents/patients as a phenomenon involving two central perspectives: an inherent self-respect with feelings of worthiness and being respectfully recognized through the confirmation of others. Caregivers underlined the importance of discovering the personality of each person, an essential insight when aiming to confirm and preserve each resident's sense of self and feeling of value. In concrete, everyday life situations, such insight made it possible to preserve dignity for those they cared for, for example, by upholding the physical integrity and external appearance according to the resident's/patients' own preference. Documenting previous

lifehistories enabled caregivers to better understand and to maximize their patients'/residents' authentic autonomy. In this way, autonomy and integrity advocacy were strengthened through promoting choices more consistent with the authentic character of each individual.

Caregiver–resident negotiations were very much a part of dignity-preserving interactions, as caregivers supported the individual's sense of status and self-worth. In some situations, they found it crucial to support a person's negative autonomy, not interfering with or overruling her or his freedom of choice. At other times, supporting a person's positive autonomy was identified as the most dignifying action, as intervention helped promote individual freedom of choice. Ethical challenges seem to be very much a part of these caregiver–resident interactions. For example, some caregivers choose not to use reality-orienting, refraining from revealing the objective truth in order to avoid greater confusion. Within the frame of professional training and person-centeredness, this may be regarded as an ethical decision, confirming the suffering individual's self-worth as outweighing telling her or him an objective truth. In addition, nurses and allied HCP underlined the importance of including each person within a social and caring fellowship, enhancing personal resources, and confirming personal value as a human being through social interactions. Concerning the use of modern ICT, caregivers emphasized the importance of utilizing ICT toward supporting humanity and dignity only, never as a tool for dignity-violating surveillance.

Third, synthesizing the results of Manthorpe et al.,<sup>1</sup> Borbasi et al.,<sup>27</sup> Rodriquez,<sup>32</sup> Zingmark et al.,<sup>25</sup> Sävenstedt et al.,<sup>28</sup> Örluv and Nikku,<sup>29</sup> and Jakobsen and Sørli,<sup>31</sup> we identified environmental conditions as a crucial part of a caring culture toward preserving resident/patient dignity. This first-level synthesis suggests how nurses and allied HCP perceived the creation of caring environments built on humanistic values, and what is purposeful for the persons living therein, as crucial for autonomy and integrity advocacy as a primary foundation for dignity-preserving dementia care.

According to the International Council of Nurses, humanistic care involves respect for the human rights of every human being. Therefore, nurses have a formal and fundamental responsibility to promote health, prevent illness, restore health, and alleviate suffering.<sup>4</sup> Already in the pioneer work of Florence Nightingale,<sup>57</sup> the importance of appropriate physical surroundings on human health and well-being were well documented. Following Nightingale's lead, environmental context and patient–caregiver relationships have been recognized as crucial elements for healing throughout the history of caring, also in dementia care research.<sup>58,59</sup> There is often a gap between the remaining resources of a human being experiencing dementia and environmental demands.<sup>60</sup> Dementia is associated with a reduced quality of life partly caused by environmental factors. Purposeful environments that complement activities of interest and meaningful connection with others may increase quality of life.<sup>61</sup> Environments should be calmer, more homelike, and make it easier for persons with cognitive impairment to interpret.<sup>62</sup> Building specifically designed and purposeful environments means to form surroundings in ways that help compensate dementia-related loss of function for those who reside therein. Anchored in a humanistic tradition, this perspective focuses on supporting and preserving the remaining resources of each individual.<sup>60–62</sup>

This first-level synthesis indicates how nurses and allied HCP perceived the creation of physical surroundings as crucial toward meeting the special needs of persons with dementia. They underlined the importance of creating people-friendly, practical, and purposeful environments designed to meet their residents'/patients' human needs for orientation and freedom of choice, while still feeling safe in everyday situations. However, caregivers emphasized that a purposeful environment consists of more than adjustments within the physical surroundings. Creating a humanistic climate within this context strongly accentuates optimal conditions for a positive, socially inclusive environment, confirming both physical and social environments as crucial for developing a dignity-preserving culture. Caregivers underlined the importance of a caring culture, sheltering residents from disrespectful treatment, such as being forced to live behind locked doors, or being exposed to dignity-violating interaction among other residents.

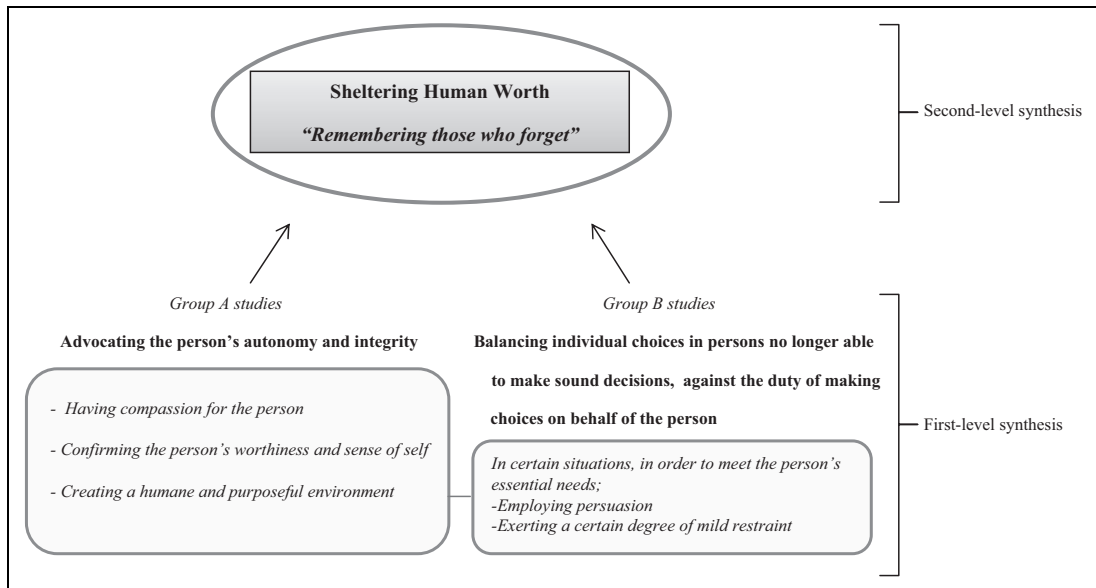
*The Group B first-level synthesis*, based on the results of Manthorpe et al.,<sup>1</sup> Jakobsen and Sørli,<sup>31</sup> and Rognstad and Nåden,<sup>33</sup> showed an ethical yet paradoxical caregiver dilemma concerning balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person. This first-level synthesis indicates that nurses and allied HCP observed how individual autonomy advocacy alone in certain situations actually could threaten a person's dignity. This perspective has also in recent research been documented within other caring contexts concerning acute, chronic, and life-threatening situations.<sup>63,64</sup> In this study, it was found that dementia could cause an individual to lose her or his ability to make sound decisions, especially when concerned with personal hygiene or vital medication. Caregivers perceived their professional duty as upholding the physical integrity of those being cared for, promoting the overall integrity of each person.

As a starting point, our first-level synthesis indicates how caregivers, well aware that their actions incurred an ethical dilemma, in certain situations employed persuasion in order to meet the person's essential needs. Waiting for the "proper moment," caregivers utilized persuasion in ways that could strengthen their patients'/residents' ability to cooperate, by stimulating their inherent resources and self-determination in a given situation. Second, the first-level synthesis suggests how certain situations encouraged caregivers to make decisions on behalf of the patient, exerting a certain degree of mild restraint in order to meet the person's essential needs. This was identified to be the case for persons who as a consequence of their illness no longer were able to understand the necessity of taking care of their own vital needs, and also lacked the ability to give their personal consent based on sound decision. Although this ethical dilemma was experienced as both personally and professionally challenging, caregivers argued that in certain situations, interventions of this nature were crucial for dignity-preserving dementia care. As documented, being touched or washed by another human being, especially without prior consent, can be experienced as a violation of one's physical integrity.<sup>50</sup> Thus, paradoxically, some forms of integrity violation, in certain care situations, seemed to be a crucial consideration in order to maintain integrity promotion as a whole, as caregivers aimed for dignity preservation. In cases where caregivers found it necessary to violate their patient's physical integrity, other vital values of respect for the vulnerable individual were asserted in order to protect personal integrity as a whole. Two out of the three studies<sup>31,33</sup> exploring these aspects emphasized legal aspects as well, stressing the importance that such interventions must be founded upon authorized restraining orders according to existing law. Moreover, from a dignity-preserving perspective, caregivers emphasized the need for calm, respectful, and trustworthy caregiver behavior to avoid amplifying agitation, aggression, and subjective burden upon persons experiencing mild restraint.

Based on this discussion of Group A synthesis and Group B synthesis, the revealed knowledge might be of practical relevance for nurses and allied HCP when dealing with complex challenges in their everyday efforts to preserve the dignity of persons with dementia. The results of this metasynthesis are based on studies conducted in four different countries, on two different continents. We do not exclude the possibility that these results may also be transferable to cultural contexts outside the ones included in this study. However, this possibility needs to be further explored in future studies.

*Developing a theoretical understanding.* In the process of constructing a theoretical understanding of nurse and allied HCP practice/perception on dignity-preserving dementia care, Katie Eriksson's *theory of caritative caring* was deemed a helpful theoretical framework.<sup>39-47</sup> *Caritas*, according to Eriksson means *love and charity*, which she concludes are the fundamental motives for true caring for the *suffering human being*.<sup>39,40,42,45</sup> Thus, *caritas* can be seen as a foundation for caregivers in their endeavor to preserve the dignity of each human being suffering from dementia. *Dignity* is a basic concept within the *ethos* of caritative caring where *absolute dignity* is an inherent and inviolable part of human holiness, granted through creation, involving the right to be confirmed as a unique human being. *Relative dignity*, however, is a changeable and violable dimension of human existence, influenced by external context and





**Figure 2.** Expressing the synthesis: A theory model of dignity-preserving dementia care as perceived/practiced by nurses and allied HCP. HCP: healthcare professionals.

culture.<sup>39,43,45,46</sup> Caritative caring is an approach toward bringing *faith, hope, and charity* into each patient's life. Through *tending, playing, and learning*,<sup>39,43</sup> caregivers aimed to advocate the suffering human beings' autonomy and integrity as a foundation for dignity-preserving dementia care. Through caritative *invitation*,<sup>39,44,45</sup> those who experienced dementia were welcomed into an intimate and stimulating *caring communion*, characterized by *respect, warmth, closeness, tolerance, hospitality, and honesty*.<sup>39</sup> Caregivers' aim was the establishment of a *humane caring culture* in which *responsibility, compassion, and confirmation* of individual *worthiness*,<sup>39–47</sup> and sense of self could find room for growth. Nursing as an art generates genuine confirmation, bringing the suffering patient forward in the healing process, including being seen, trusted, and validated. By not being seen or taken seriously, a patient's dignity is undermined.<sup>44</sup>

Based on the caritative *ethos of love, responsibility, and sacrifice*, caregivers aimed to preserve their patient's dignity by emphasizing the creation of a *caring culture of room in time and space*, a physical and social environment anchored in *design, traditions and rituals* well-known to their residents/patients.<sup>39</sup> Establishing humane and purposeful environments for patients/residents, with practical designs geared to meet their need for easy orientation and a feeling of freedom, as well as safety within their everyday lives, is therefore very much a part of dignity-preserving dementia care.

The nature of dementia sometimes leaves suffering individuals unable to make autonomous decisions. Being *responsible* for the promotion of that which is *good* as well as resisting *evil*,<sup>39,41,42,45</sup> caregivers felt in certain situations an *ethical obligation* to employ persuasion or mild restraint to ensure that each person's essential needs were met. When approached in a respectful way, according to authorized restraining orders and existing laws, caregivers aimed to reduce patient/resident levels of *suffering related to illness* as well as *suffering related to care*. Thus, in certain situations, balancing individual choices among persons no longer able to make sound decisions, against the duty of making choices on behalf of the person, was identified as a crucial aspect of dignity-preserving care. Finally, while synthesizing the first-level syntheses of Groups A and B into second-level syntheses, using a lines-of-argument approach, a theory model on dignity-

preserving dementia care was developed. Inspired by Eriksson's theoretical framework on caritative caring for the suffering human being,<sup>39–47</sup> in a time of the greatest trial and vulnerability, our second-level synthesis “Sheltering human worth—remembering those who forget” was formulated as an overarching principle and metaphor for dignity-preserving dementia care as perceived and practiced by nurses and allied HCP.

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