Dignity in the care of older adults living in nursing homes and long-term care facilities [version 3; peer review: 1 approved, 3 approved with reservations]

Dignity in the care of older adults living in nursing homes and long-term care facilities

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Abstract

Depending on the fields and actors involved, dignity may involve, signify, and encompass different meanings. This fundamental right can be subjectively experienced and rooted in a person’s perception of being treated and cared for. Care refers to a set of specific activities combined in a complex life-sustaining network, including long-term Care, which involves various services designed to meet a person’s health or personal care needs. However, older residents’ human rights have been disrespected and widened the gaps between theory and practice regarding the precarious protection of their rights and dignity inside long-term facilities and nursing homes. This paper aims to discuss threats to dignity and elucidate some strategies to promote and conserve dignity in care, including the person-centered practice in long-term care. Some barriers to the dignity of older residents involve the organizational culture, restraints of time, heavy workload, burnout, and lack of partnership between the residents, their families, and the long-term care homes’ staff. Person-centered integrated care quality frameworks are core components of a good quality of care in these spaces in high-income countries. Unfortunately, the COVID-19 pandemic highlighted how weak long-term care policies were and demonstrated that much progress in the dignity of care in long-term care facilities and nursing homes is needed. In low- and middle-income countries, long-term care policies do not accompany the accelerated and intense aging process, and there are other threats,

Any reports and responses or comments on the article can be found at the end of the article.
like their invisibility to the public sector and the prejudices about this service model. It's urgent to create strategies for designing and implementing sustainable and equitable long-term care systems based on a person-centered service with dignity to everyone who needs it.

**Keywords**
long-term care, older adults, dignity, aging

This article is included in the Sociology of Health gateway.

This article is included in the Dignity in Aging collection.

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Introduction

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and must act towards one another in a spirit of brotherhood.

(Uiversal Declaration of Human Rights, 1948).

Despite some controversial criticism, dignity remains a concept that is difficult to define, measure, and apply to healthcare, mainly because it intersects with other terms such as pride, self-respect, quality of life, well-being, hope, self-esteem, autonomy, respect, empowerment, and communication. Yet, it is a core concept that must be guaranteed to any human being, whatever their condition is.

Dignity, a flagship value, may involve, signify, and encompass different meanings depending on the fields and actors involved and expected reciprocity between them. For example, the perception of dignity for professionals and healthcare providers can sound different when compared to the perceptions of healthcare users, their families and policymakers.

Ostaszkiewicz et al. state that international reports identify a lack of attention to the dignity of older people in care homes and hospitals. Other authors argue that dignity may be a link that explains the interchange between promoting and protecting human rights and an individual’s health status. Recently, a substantial body of literature has been published reviewing and analyzing the concepts of ‘dignity’, ‘care with dignity’, and ‘dignified care’, reinforcing that dignity is considered to be a fundamental right, subjectively experienced, and rooted in a person’s perception of being treated and regarded as essential and valuable to others.

Care refers to providing specific activities combined to provide help, protection, or supervision in a complex life-sustaining network. It may involve distinct actors and actions, including self-care, caring for others, the caregiver, and the care recipient.

The increased demand for care occurs concomitantly with demographic shifts toward population aging (notably faster in low- and middle-income countries) and with changes in its provision: a declining number of carers (due to reduced family size), a higher proportion of single households, more opportunities for women in the labor market, and increasing migration rates and geographic separation between parents and children challenge the lack of support and financial subsidies for caring for their family members.

Long-term care (LTC) involves services designed to provide what is necessary to reach personal care needs, or to maintain their daily lives during a short or long period, particularly for those with limited capacity for self-care because of a chronic illness, injury, physical, cognitive, or mental disabilities. LTC includes assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), including dispensing and correct administration of medications, engaging in household chores and hobbies and self-care tasks.

In most countries, LTC provision involves a mix of state, for-profit and voluntary (third sector – formal or informal provision), though there are wide differences in the balance between these sectors in the context of national cultures and welfare traditions. In low- and middle-income countries, LTC is mostly provided by the third sector (typically by family and friends), even for the most vulnerable and functionally impaired older adults, despite the growth of public and private LTC services in many of these nations.
LTC services help people improve or maintain an optimal quality of life and physical functioning, including but not limited to help from third parties or assistive devices in various settings: in the community (adult daily service center); at home, from a home health agency, hospice, or family and friends; in facilities (nursing home or specialized infirmary); or other residential settings. According to the World Health Organization, “LTC homes are living spaces for adults with significant health challenges” in accessing 24-hour nursing and personal care.

Despite global and regional initiatives in favor of strengthening strategies to promote respect and dignity of older adults, such as the Decade of Healthy Aging, LTC facility residents do not seem to have the same priorities and guarantees as their counterparts. The disrespect for older residents’ human rights during the recent period of the COVID-19 pandemic, for example, widened the gaps between theory and practice regarding the precarious protection of their rights and dignity.

This paper aims to discuss threats to dignity in LTC facilities (LTCF) and nursing homes (NH) and elucidate some strategies to promote and conserve dignity in care, including the person-centred practice in LTC. In addition to reviewing factors that threaten dignity in LTC homes (like inflexible routines, reduced perceptions of the importance of dignity, ageism, and low concern for communication skills/right to privacy), we will present attitudes and care that preserve it in this context (like person-centred care), examples of observational studies and interventionist investigations, and real-life studies with interventions and practical recommendations to support the care that favors and fosters dignity.

**Threats to dignity in LTC homes**

Even though care is provided proficiently or technically competent, residents and family members may perceive it as lacking dignity. The concept of dignity for older people living in LTC homes relates to feelings of comfort, autonomy, meaning, interpersonal connection, hope, physical and spiritual state, and belonging, and is influenced by their social interactions and positively or negatively affected by others.

The Nordenfelt’s theoretical dignity model, developed within the Dignity and Older Europeans Project, provides a comprehensive definition of dignity that is very useful to understand how fostering a culture of dignity impact on older residents. It distinguishes between intrinsic and contingent value in four concepts as follows: “Dignity of merit: related to a person’s formal or informal status in society; Dignity as moral stature: linked to self-respect and dependent on the conduct of the individual; Dignity of identity: attached to the person’s identity as a human being, which others or external events can alter; Dignity of Menschenwürde: a German word meaning innate or inner dignity that is afforded all humans.”

The first three concepts of dignity described by Nordenfelt can vary and often depend on individuals’ conduct, autonomy, integrity, and the people they interact. In the context of aging or illness, dignity of identity is probably the most important of the previous concepts. In contrast, Menschenwürde’s dignity deals with innate dignity, which we all possess equally.

Despite some differences in the causes of admission to NH and LTCF in low- and high-income countries, it is common for many residents to significantly reduce their cognitive and functional abilities, depending on third parties to perform ADLs and IADLs. According to some authors, dependency affects their dignity (of identity), because it can reduce their control and choice.

Rigid or inflexible technical and organizational routines depersonalize care in LTC homes, depriving residents of expressing their opinions and desires. Due to time constraints, resources, and caregivers’ propensity for task-oriented care, the depersonalization of care often compromises the resident’s dignity, who is forced to “obey” mealtimes, hygiene standards, and continence, participation in social activities, and sometimes even control over one’s belongings.

According to Kitwood, the ‘medical model’ produces bad care practices and a range of interactions between care staff and persons living with dementia (including those living in LTCF) that detract from a person’s personhood. What Kitwood defined as ‘malignant social psychology’ is often unknowingly embedded in the care habits of formal care settings. The author concludes that identifying the care staff’s observed behaviors detracts from an individual’s personhood and highlights those behaviors that enhance an individual’s personhood. But even when residents have their cognition and desire for autonomy preserved, tension may emerge when organizations decide to maintain a ‘risk-free environment’ by forcing staff and residents to obey rules that limits autonomy and control.

Particularly among residents living with dementia, multiple studies suggested that stigmatization, labeling, and objectivation were found to be related to dignity violation. These authors found that undignifying aspects of care are characterized by unsuccessful processes of acknowledging and conciliating with the changing person with dementia.
Caregivers’ communication with older residents (or other workers) about themselves or their peers can also threaten the dignity of LTC, even when a resident has impaired communication skills. Using potentially stigmatizing or ageist labels, diminutives or nicknames when referring to a resident is highly undesirable, as well as publicly exposing personal information due to hearing impairment in collective settings.\(^{1,18,19}\)

Dignity in LTC must always be linked to values of personhood and unique identity and disaggregated from using of any form of physical or chemical restraints. The “zero tolerance” culture of abuse against older residents must be an organizational dogma understood and practiced by all staff, including volunteers.

The right to privacy includes concepts of respect for the dignity of identity also in the promotion of assistance during the control and rise of continence, respecting the resident’s desire for service provided by caregivers of the same sex, for example. The right to privacy includes reducing exposure to the body or assistive devices (such as prostheses or urinary catheters).

Even in environments where economic deprivation can substantially impact access to inputs and food, ensuring frequent, healthy, and palatable meals must be essential. Disregarding food consumption preferences, especially during the approximation periods after entering an LTC home, can significantly impact the perception of dignity and outcomes related to weight loss, sarcopenia, and, consequently, worsening of functional abilities.

**Dignity-conserving care in LTC**

Few intervention studies have examined care that maintains dignity. A qualitative study including in-depth interviews with residents of LTC homes in Japan found dignity to be related to nursing care facilities, and the nursing care system involves teams/organizations from elements of the staff side at the individual level.\(^{23}\)

Some authors suggested best practices for compliance related to resident dignity,\(^{22}\) focusing on requirements that include respecting care needs, maximizing the dining experience, living in a secure facility, participating in activities, and respecting residents’ personal space.\(^{24}\) Best practices may include, for instance, assuring residents’ preferences related to personal appearance are consistently honored, developing a policy for selective use of clothing protectors during meals, and an environment to ensure that direct staff can comfortably assist with feeding, besides addressing residents by their names and providing meaningful activities considering the residents’ abilities and past interests.

It is important to highlight that the dignity of older residents cannot be promoted without reciprocal partnership between them, their families and the LTC homes’ staff.\(^{7}\) Despite previous studies found that organizational culture, restraints of time, heavy workload and burnout have been cited as barriers to a dignified care,\(^{7,25,26}\) providers must make sure that the care and treatment they provide ensure people’s dignity, including having privacy when they need and want it, treating them as equals and providing the support they might need, including involving them in the local community activities.\(^{27}\)

A Canadian study with Dignity Therapy, a psychotherapeutic intervention for patients near to the end of life, found 75% of participants reporting an enhanced sense of dignity.\(^{28}\)

Person-centred integrated care (PC-IC) quality frameworks are core components of a good quality of care in LTC. It is possible to build a 4-stage goal-oriented PC-IC process,\(^{18}\) including (a) personalizing goal settings, (b) care planning aligned with goals, (c) care delivery according to plan, and (d) evaluation of goal attainment.\(^{29}\) A theoretical framework for person-centred practice in long-term care (PeoPLE) is another example of providing a comprehensive guide to empirical inquiry, education, and practice development in LTC homes, serving as a low-threshold starting point for practice development.\(^{30}\)

In addition to constructs in the framework of person-centred practice, previous authors have found significant associations between self-rated health, mobility, and dementia and perceptions of dignity and well-being.\(^{31–34}\)

Using a modified Delphi process to prioritize essential ‘dignity-conserving care markers’, Thompson and colleagues\(^{18}\) found the following practices to be good markers: staff make residents feel valued as a person; staff are compassionate in providing care; residents can trust staff; staff do not make residents feel like a burden to others; residents are able to make choices in their everyday life;\(^{29}\) assistance with hygiene and personal matters is adequate and sensitive; there is freedom to complain without fear of repercussions; staff does not talk about residents in front of other residents; the personal space of the residents and the need for privacy are respected; efforts are made to make residents feel safe.

The COVID-19 pandemic highlighted long-known weaknesses and shortcomings, continually postponed in terms of public and social relevance in its resolutions. It demonstrated that we need to make much progress in the dignity of care in
LTC. The challenge of caring for older residents is particularly felt in low- and middle-income countries, where the development of LTC policies does not accompany the accelerated and intense aging in a context of marked social and gender inequality.  

However, given the lack of a national LTC policy, this gap’s most explicit practical expression is the reduced and heterogeneous offer of institutional care in these countries.  

When considering the provision of comprehensive and person-centred care in LTCF, fundamental aspects must be considered by the workers, families, and managers. Among these aspects, the life project (i.e., the direction the individual wants to take according to their beliefs) stands out; preferences and their scale of values; the story of life, with which we can get to know the person more deeply and pay close attention. Finally, individualized service plans facilitate the detection of needs, turning LTCFs into units of conviviality closer to a domestic environment in terms of organization, schedules, and spaces.  

According to the person-centred practice framework, significant associations were found between the attitudes of staff, thriving in the indoor-outdoor-mealtime environment, and perceptions of dignity and well-being. This approach targets the attitudes of staff and the care environment, which could be used when designing interventions to promote dignity and well-being.  

Practical recommendations for LTC homes care providers must consider including PCC-IC, respecting care needs, personal space, and the right to privacy, including care of people with dementia, discussing options and interventions for dying with dignity, and decision-making with dignity.  

In conclusion, dignity in the LTC goes through the recognition of its need and the support of public policies that, in addition to monitoring, promote more significant knowledge about the reality of the care offered. This also means the confrontation of prejudice about this service model and the urgent creation of strategies for designing and implementing sustainable and equitable LTC systems that ensure a person-centred service with dignity to everyone who needs it. Considering the urgency of fostering long-term care systems in aging societies by involving public opinion and policymakers, countries can design and implement LTC systems centered on human rights and integrated into the overall health system, encouraging multisectoral collaboration to strengthen national and regional efforts in dignity and healthy aging.  

**Data availability**  
No data are associated with this article.

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Elaine Webster
University of Strathclyde, Glasgow, Scotland, UK

Thank you for the opportunity to review this article, ‘Dignity in the care of older adults living in nursing homes and long-term care facilities’. It addresses a topic which remains highly significant. The paper’s stated aim, to ‘discuss threats to dignity in LTC facilities (LTCF) and nursing homes (NH) and elucidate some strategies to promote and conserve dignity in care’ is valuable. As an opinion piece, including a non-systematic review, it provides an accessible introduction and serves to keep this critical issue on the agenda.

The following comments, relating to clarity and evidence base, provide suggestions to further enhance the article:

The authors may wish to clarify that in ‘discussing’ threats to dignity, the paper both shares some of the authors’ own views – such as on restraint, responding to incontinence, and food provision, which are not linked to specific existing sources – and provides an overview of some of the threats to, and means of respecting, dignity that have been identified in research.

In terms of existing research, one of the key sources in the discussion of dignity is somewhat dated – the Nordenfelt and Edgar source which dates from 2005. Some further explanation of why this remains the most useful conceptualisation, almost 20 years later, may strengthen the piece.

It may add to the discussion if the authors were to unpack the ‘controversial criticism’ referred to in the opening line. The authors might also consider rewording this sentence as the controversy referred to seems incongruent with the statement that dignity ‘remains’ difficult to define.

The authors start from the basis that ‘dignity’ encompasses a range of meanings and might be perceived differently depending on one’s perspective/experience. This is indeed demonstrated in literature. It would thereby be helpful to see more precise use of the term ‘dignity’ within the article itself. In my view, the terminology of ‘dignity’ and ‘rights’ is used quite loosely whereas these can be distinct if overlapping terms/concepts/policy and practice frameworks. There is reference to ‘dignity’ as a fundamental right and to ‘dignity and rights’ as different categories.
Another concept also mentioned is personhood. At the same time, it is not always clear whether the authors are fundamentally interested in ‘dignity’ specifically, or rather in the related idea and practice of person-centred long-term care. The authors may thereby wish to consider whether the focus could be sharpened in this respect.

Some additional evidence could be given for the point relating to low- and middle-income countries in the introduction and in the section on threats to dignity in LTC homes. In the introduction, for example, the closest sources, cited in notes 11 and 13, do not appear to speak to the issue of LTC in low- and middle-income countries.

It would also be helpful to have more precision regarding the sources for the following points by adding additional reference detail, as it is not currently clear whether these terms/findings are reported in the source cited (in note 2) or are original findings of that source: ‘dignity remains a concept that is difficult to define, measure, and apply’, and that dignity ‘intersects with other terms such as pride, self-respect, quality of life, well-being, hope, self-esteem, autonomy, respect, empowerment, and communication.’

**Is the topic of the opinion article discussed accurately in the context of the current literature?**
Yes

**Are all factual statements correct and adequately supported by citations?**
Partly

**Are arguments sufficiently supported by evidence from the published literature?**
Partly

**Are the conclusions drawn balanced and justified on the basis of the presented arguments?**
Yes

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Human rights law, Meaning and role of concept of ‘dignity’, Dignified care and human rights-based approach in nurse education.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.
Wendy Van der Geugten
University of Humanistic Studies, Utrecht, The Netherlands

Abstract:
This article discusses dignity threatening care activities within long-term care and care conventions and activities fostering dignity of residents, with a focus on person-centred care.

Overall remark:
- I think the authors want to be sensitive for context, mostly in referring to differences between high and low-/middle-income countries. Although in general the awareness of these socio-political context is appreciated, I do not understand the importance for repeating these statements/comparisons in light of the overall argument of this article. This is also partly about referring to the COVID-19 pandemic, it seems that both context indicate the importance of improving and prioritizing LTC but I do not follow the line with the main topic of the article (dignity conserving and person-centred care).
- When the authors indeed want to make a point of LTC within low-/middle income countries and how dignity and person-centred care needs to improve, then they have to point this out more clearly with substantiated with studies (or a lack of research into this topic).
- I was a little confused on the placements of the parts below, which deviates from the line of argumentation above concerning person-centred care and personhood, as well missing references. The authors might consider these aspects of (in)dignity in care to be placed earlier in the article before working towards their statement.
- “The right to privacy includes concepts of respect for the dignity of identity also in the promotion of assistance during the control and rise of continence, respecting the resident's desire for service provided by caregivers of the same sex, for example. The right to privacy includes reducing exposure to the body or assistive devices (such as prostheses or urinary catheters)”
- “Even in environments where economic deprivation can substantially impact access to inputs and food, ensuring frequent, healthy, and palatable meals must be essential. Disregarding food consumption preferences, especially during the approximation periods after entering an LTC home, can significantly impact the perception of dignity and outcomes related to weight loss, sarcopenia, and, consequently, worsening of functional abilities.”
- Is this correct? “Few intervention studies have examined care that maintains dignity”. – in the following text I miss studies into Dignity Therapy, and the ground work of Chochinov into dignity-conserving care practices, there is only one sentence referring to this body of work. It might be interesting to see if this research can help your article.
- I think that the argument that person-centred care is improving dignity of residents needs to be fully clear before presenting studies into PC-IC under ‘dignity-conserving care’. The authors might firstly present all studies into dignity and dignity-conserving care, than present the theory of Kitwood and PC-IC studies, to bring along the reader in line of the argument and makes it easier to compare both.

References needed (beside the above mentioned topics):
- “In low- and middle-income countries, LTC is mostly…”
- “….. LTC facility residents do not seem to have the same priorities and guarantees as their counterparts”.
- “When considering the provision of comprehensive and person-centred care in LTCF,”
fundamental aspects must be considered by the workers, families, and managers. Among these aspects, the life project (i.e., the direction the individual wants to take according to their beliefs) stands out; preferences and their scale of values; the story of life, with which we can get to know the person more deeply and pay close attention. Finally, individualized service plans facilitate the detection of needs, turning LTCFs into units of conviviality closer to a domestic environment in terms of organization, schedules, and spaces”.

Is the topic of the opinion article discussed accurately in the context of the current literature?
Partly

Are all factual statements correct and adequately supported by citations?
Partly

Are arguments sufficiently supported by evidence from the published literature?
Partly

Are the conclusions drawn balanced and justified on the basis of the presented arguments?
Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dignity, long-term care, COVID-19, palliative care, dementia, spiritual care

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

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Sergej Kmetec
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The article "Dignity in the Care of Older Adults Living in Nursing Homes and Long-Term Care Facilities" provides a comprehensive overview of the challenges and strategies related to preserving the dignity of older adults in long-term care settings. Given the growing ageing population globally and the issues the COVID-19 pandemic has exacerbated, the topic is of utmost
importance. The article is well-structured, informative, and addresses a critical issue. However, there are some areas where it could be improved:

1. **Clarity and Structure**: The article's structure is clear, with distinct sections discussing dignity in LTC, threats to dignity, and dignity-conserving care. However, it might benefit from a more explicit introduction section that provides an overview of the key points to be discussed. This can help readers grasp the main objectives and structure of the paper more easily.

2. **Citation and Evidence**: While the article does mention previous studies and models related to dignity in LTC, it would be strengthened by citing specific research studies or real-world examples to support the points being made. Incorporating concrete evidence can enhance the credibility of the arguments presented.

3. **Language and Style**: The language used in the article is generally clear and professional. However, some sentences could be made more concise and easier to understand. Additionally, some of the language might be considered technical, so providing clear explanations for specialized terms or concepts would make the article more accessible to a broader readership.

4. **Practical Recommendations**: While the article discusses the importance of person-centred care and dignity-conserving practices, it could benefit from offering more practical recommendations or case studies demonstrating how these strategies can be implemented effectively in real-world LTC settings. This would provide readers with actionable insights.

5. **Global Perspective**: The article briefly discusses the differences in LTC policies between high-income and low- to middle-income countries. Expanding on this topic and providing a more in-depth analysis of the challenges and potential solutions in various global contexts would add depth to the discussion.

6. **Conclusion**: The conclusion does a good job of summarizing the key points discussed in the article. However, it could be strengthened by emphasizing the urgency of addressing these issues and providing a clear call to action for policymakers, healthcare providers, and researchers.

7. **Terminology and grammatical suggestions**: Please use person-centred care instead of "person-centered care" throughout the manuscript because it is appropriate terminology from the field of person-centred care.

In conclusion, the article provides a valuable exploration of the importance of dignity in LTC and the challenges older adults face in such settings. The article could benefit from clearer structure, more concrete evidence, and practical recommendations for improving the dignity of care in LTC facilities to enhance its impact. Nevertheless, it significantly contributes to the ongoing discourse on this critical issue and encourages further research and action.

**Is the topic of the opinion article discussed accurately in the context of the current literature?**

Yes

**Are all factual statements correct and adequately supported by citations?**
Yes

**Are arguments sufficiently supported by evidence from the published literature?**
Partly

**Are the conclusions drawn balanced and justified on the basis of the presented arguments?**
Partly

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Nursing, Person-centred care, Palliative care, Care of older people, Dementia, Systematic review, Quantitative, Qualitative and Mixed method research

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.**

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**Author Response 22 Oct 2023**

**Patrick Wachholz**

**Reply to the reviewer.**

The authors agree with the reviewer's comments and consider that the proposed changes provide greater robustness and clarity to the description of this opinion article.

In the introduction, the authors included, after the objectives, a description of the key points to be discussed, helping readers understand the manuscript's structure and record its main messages.

Practical recommendations were added to the final comments, allowing readers to consider gaps in the literature when developing new investigations and applying models and practices that strengthen care with dignity in LTC homes. We include mentions of international, observational, qualitative, and intervention studies in end-of-life care, highlighting strategies effectively adopted in the real world.

We revised the language and style of the entire manuscript, correcting dubious sentences and making them more precise and concise.

Finally, we adopted the recommendation to use the term 'person-centered care,' as suggested.

**Competing Interests:** None competing interest to declare

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**Reviewer Report 27 February 2023**

https://doi.org/10.5256/f1000research.144106.r163874
Neil H. Chadborn
School of Medicine, University of Nottingham, Nottingham, UK

The authors have made amendments and have addressed concerns raised. This is now revised article is now suitable for publication and I hope achieves an international readership.

Is the topic of the opinion article discussed accurately in the context of the current literature?
Partly

Are all factual statements correct and adequately supported by citations?
Partly

Are arguments sufficiently supported by evidence from the published literature?
Partly

Are the conclusions drawn balanced and justified on the basis of the presented arguments?
Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Public health research and health and social care services research.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 15 November 2022

https://doi.org/10.5256/f1000research.138524.r154087

Neil H. Chadborn
School of Medicine, University of Nottingham, Nottingham, UK

This article discusses dignity, an important topic in health and social care, which can be
overlooked in health research literature. This is partly because it is difficult to quantify but also
because it may not be seen as a 'health outcome'. However, similar to person-centred care, dignity
is a crucial element of care as expressed by residents and family.

The introduction, following the abstract, starts from an ambiguous point, with dignity potentially
being different to different people and between different groups of people. This appears at odds
with the quote about dignity and rights as being universal concepts. While, clearly there may be
different attitudes or priorities with respect to dignity. The next paragraph develops the approach
that there is a ‘core concept’ (at least) for the meaning of dignity, so I wonder whether this could
be incorporated into the first paragraph so the article does not start with such an open definition.

“Of note, the increased demand for care by the older population occurs concomitantly with
changes in its provision” – clarity could be improved by stating what scale of change is being
discussed – it appears that demographic shift is being discussed, however it could be read as the
care of a cohort of people changes as they age. Further, this demographic change may relate to
USA and is different other countries? Also, I question the term ‘informal sector’ – if this mainly
means family members, I would argue that this group is not a 'sector' in an economic sense. My
point is that if someone is not receiving a service, then they may be supported by family members;
I don't believe they would be described as ‘receiving long-term care provided by the informal
sector’.

Also, I have same concerns with this para “In most of the countries, LTC provision involves a mix of
formal (state, local authority and nongovernment) and informal (primarily unpaid family) provision
– though there are wide differences in the balance between these sectors in the context of
national cultures and welfare traditions.” I would argue that family provided care should not be
included in the category of ‘receiving care service’. I would define the different sectors, then, as:
voluntary (third sector – informal or formal), for-profit, and state. The reason that I labour this
point is that individuals (particularly in 'Western' cultures) do express different views when they
are receiving care from family or friends compared to receiving ‘a service'; particularly for intimate
care, individuals may feel that this compromises their dignity, whereas receiving care from a
careworker or volunteer from an NGO is likely to be seen as protecting their dignity. This point
may be Western-centric and may not apply in different cultural contexts, but I believe the
distinction remains important. In fact maybe dignity cannot be described independently of familial
duty.

“Rigid or inflexible technical and organizational routines depersonalize care in LTC homes,
depriving residents of expressing their opinions and desires. Due to time constraints, resources,
and caregivers’ propensity for task-oriented care, the depersonalization of care often
compromises the resident’s dignity, who is forced to “obey” mealtimes, hygiene standards, and
continence, participation in social activities, and sometimes even control over one’s belongings”
For this paragraph, I think it would be helpful addition to quote the work of Tom Kitwood on
malignant social environments (Dementia Reconsidered, 1997).

I think it would help clarity of the article to state that discussion is focused on long term care
facilities – rather than care in own home (also included in the term long-term care).

While the authors emphasise protecting, promoting and conserving dignity, it may be worth
touching on where there may be exceptions or trade-offs; particularly for safety of the individual,
care staff or co-residents (including protection from outbreak of COVID-19).
Specific comments:
- Abstract: “long-term facilities” should be long-term care facilities
- Intro “Flagship value, dignity may involve, signify, and encompass different meanings” for readability amend to: Dignity, as a flagship value, may involve...

Check formatting of reference 4 – should be Mann, J. “Dignity and Health: The UDHR's Revolutionary First Article.” Health and Human Rights, vol. 3, no. 2, 1998, pp. 30–38. JSTOR, https://doi.org/10.2307/4065297. Accessed 14 Nov. 2022.

Is the topic of the opinion article discussed accurately in the context of the current literature?
Yes

Are all factual statements correct and adequately supported by citations?
Yes

Are arguments sufficiently supported by evidence from the published literature?
Yes

Are the conclusions drawn balanced and justified on the basis of the presented arguments?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Public health research and health and social care services research.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 06 Feb 2023
Patrick Wachholz

We very much appreciate the reviewer’s comments and recommendations. We have included your suggestions in this new version, corrected minor errors, and revised the bibliographic references.

We agreed with the reviewer that it was necessary to adapt the first paragraph to start the manuscript with a less open definition of dignity.

We agree that the term "informal sector" may convey the wrong message to the audience and have amended this paragraph accordingly.

We have included a mention of Tom Kitwood’s work on malign social psychology and its
impact on the attitudes and practices of caregivers in the formal sector.

Likewise, we corrected the title so that the manuscript focuses on long-term care facilities.

We agree that during the COVID-19 pandemic, adaptations and exceptions to practice were necessary to reduce the odds of outbreaks and ensure the safety of care homes, their workers, and residents.

**Competing Interests:** No competing interests were disclosed.

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**Comments on this article**

**Version 2**

**Author Response 22 Oct 2023**

**Patrick Wachholz**

In this new version, the authors changed the first paragraph to start the manuscript with a less open definition of dignity.

The term "informal sector" was removed, as it may convey the wrong message.

We have included a mention of Tom Kitwood's work on malign social psychology and its impact on the attitudes and practices of caregivers in the formal sector.

**Competing Interests:** No competing interests were disclosed.

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**Reader Comment 20 Feb 2023**

**M. Zaenul Muttaqin**, Cenderawasih University, Jayapura City, Papua, Indonesia

Long-term policies related to care in nursing homes require clear agenda setting. The author has marked this urgency in writing. This paper is interesting with the construction of ideas for the development of human-based policy models, as well as dignity care. Although, no matter how interesting, the sentence "and there are other threats, like their invisibility to the public sector and the prejudices about this service model" needs to be pursued further with a clear explanation from the author. The scope of the public sector is quite broad, and decision makers in many countries have promoted this design with effective implementation.

**Competing Interests:** Competing Interests: The reviewer declare there is no competing interests disclosed.
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