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The meaning of dignity in nursing home care as seen by relatives
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Abstract:	Abstract Background As part of an on-going Scandinavian project on the dignity of elderly care, this study is based on "clinical caring science" as a scientific discipline. Clinical caring science examines how ground concepts, axioms, and theories are expressed in different clinical contexts. Central notions are caring culture, dignity, at-home-ness, the little extra, non-caring cultures versus caring cultures and ethical context –and climate. Aim and assumptions This study investigates the individual variations of caring cultures in relation to dignity and how it is expressed in caring acts and ethical contexts. Three assumtions are formulated: 1. The caring culture of nursing homes influences whether dignified care is provided. 2. An ethos that is reflected on and appropriated by the caregiver mirrors itself in ethical caring acts and as artful caring in an ethical context. 3. Caring culture is assumed to be a more ontological or universal concept than, for example, an ethical context or ethical person-to-person acts. Research design The methodological approach is hermeneutic. The data consist of 28 interviews with relatives of older persons from Norway, Denmark, and Sweden. Ethical considerations The principles of voluntariness, confidentiality and anonymity were respected during the whole research process. Findings Three patterns were revealed: dignity as at-home-ness; dignity as the little extra; and non-dignifying ethical context. Discussion Caring communion, invitation, at-home-ness, and "the little extra" are expressions of ethical contexts and caring acts in a caring culture. A non-caring culture may not consider the dignity of its residents and may be represented by routinized care that values organizational efficiency and instrumentalism rather than an individual's dignity and self-worth. Conclusion An ethos must be integrated in both the organization and in the individual caregiver in order to be expressed in caring acts and in an ethical context that supports these caring acts.

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Abstract

Background

As part of an on-going Scandinavian project on the dignity of elderly care, this study is based on "clinical caring science" as a scientific discipline. Clinical caring science examines how ground concepts, axioms, and theories are expressed in different clinical contexts. Central notions are caring culture, dignity, at-home-ness, the little extra, non-caring cultures versus caring cultures and ethical context—and climate.

Aim and assumptions

This study investigates the individual variations of caring cultures in relation to dignity and how it is expressed in caring acts and ethical contexts. Three assumtions are formulated: 1. The caring culture of nursing homes influences whether dignified care is provided. 2. An ethos that is reflected on and appropriated by the caregiver mirrors itself in ethical caring acts and as artful caring in an ethical context. 3. Caring culture is assumed to be a more ontological or universal concept than, for example, an ethical context or ethical person-to-person acts.

Research design

The methodological approach is hermeneutic. The data consist of 28 interviews with relatives of older persons from Norway, Denmark, and Sweden.

Ethical considerations

The principles of voluntariness, confidentiality and anonymity were respected during the whole research process.

Findings

Three patterns were revealed: dignity as at-home-ness; dignity as the little extra; and non-dignifying ethical context.

Discussion

Caring communion, invitation, at-home-ness, and "the little extra" are expressions of ethical contexts and caring acts in a caring culture. A non-caring culture may not consider the dignity of its residents and may be represented by routinized care that values organizational efficiency and instrumentalism rather than an individual's dignity and self-worth.

Conclusion

An ethos must be integrated in both the organization and in the individual caregiver in order to be expressed in caring acts and in an ethical context that supports these caring acts.

Key words: dignity, nursing home, relatives, caring culture, caring, ethical context, clinical caring science.

Introduction

In an on-going Scandinavian project on dignity of elderly care, we ask whether the care given to older people is performed with dignity and how the older persons, their relatives, and their caregivers understand and experience dignity. To obtain data that addresses these questions, we interviewed older recipients of care, relatives of these older persons, and the staff who cared for the older persons. All the participants lived in Norway, Sweden, and Denmark. This study seeks the individual variations of caring cultures in relation to dignity and how it is expressed in caring acts and ethical contexts using a hermeneutical methodology. From this perspective, we formulated our theoretical and empirical pre-understandings. We *assume* that the caring culture of nursing homes influences whether dignified care is provided. This assumption, in part, is formulated from the theory of caritative care. Seen from this theoretical perspective, the essence of caring is compassion and love, and dignity that arises out of a caring communion with others (1). We also *assume* that an ethos that is reflected on and appropriated by the caregiver mirrors itself in ethical caring acts and as artful caring in an

ethical context. Abusive or neglecting acts of care reflect an ethos that ignores the dignity of the individual. An ethical context that allows abusiveness and neglect may also mirror and ethos of nihilism respective disregard. Such neglect could reflect a culture of common values that unconsciously ignores or abuses the dignity of patients, in this case, older patients in a nursing home (2).

Culture is related to meaning and meaning-making (3) through a perspective of horizon and tradition. The horizon reflects the individual's interpretation of the tradition. (4). If caring is seen as based on a value order from ethos as an ontological entity to ethics, caring culture is assumed to be a more ontological or universal concept than, for example, an ethical context or ethical person-to-person acts. Caring culture expresses the ethos of caring, whereas ethical context expresses the ethical interpretation or meaning making of the ethos by the members of an organization.

These views are related to the theory of science perspective of this study: "clinical caring science" as a scientific discipline based on its ontology and ground concepts, that define the discipline. Clinical caring science examines how ground concepts, axioms, and theories are expressed in different clinical contexts. This approach can be seen as deductive although the data collection is inductive. That is, the ground concepts set the sight for clinical research. This approach requires looking at the knowledge and research in clinical caring science to expand the understanding of the founding principles of caring, the art and act of caring, caring's individual variations, as well as the contextual prerequisites of caring (5). Furthermore, praxis or contextual conditions help refine the theory by highlighting individual variations. The discipline creates the pre-understanding from which questions to the clinical field or praxis emanate. These questions could be seen as qualitative hypotheses or assumptions.

Background

Caring culture

The concept caring culture, as defined by Eriksson, rests on an ethos as a basic value order. An example of the value order of an ethos is when, due to the ethos, communion appears. When this communion appears, the culture is characterized as being inviting. The goal of communion in a caring culture is to preserve the dignity of the other. A caring culture can prevail if dimensions such as cultivating, tending, caring, and reverence are present and encouraged. Referring to Lévinas, Eriksson defines a caring communion as acts that present and encourage possibilities for others in a sustained manner (6, 7). In this light, an invitation from the caregiver to the patient to explore his or her possibilities, is characterized by creating room for authentic hospitality where the human being or patient is allowed to rest and respond to this charitable appeal (7). In other words authentic hospitality gives room for rest but also to look for one's possibilities in a charitable atmosphere.

An ethos gives an inner sight to ethics. If this value order is absent, ethics may become empty, caught by outer rules and principles. On the other hand, an ontological ethical identity can grow if an ontological ethos is related to experience-based knowledge, for example, on compassion and caring presence. A caring culture is central to preventing nihilism and detachment. In the original ethos of a caring culture, honouring the dignity of the other is characterised by an open and inviting community sustained by the ethos of the culture (8).

Dignity

Although the research on dignity and caring culture in nursing homes is scant, some precepts have been formulated. Dignity can be expressed as absolute dignity (in the merit of) being a human being, or relative dignity that depends on contextual respective personal factors (9). This understanding of dignity can also be understood through the use of the two concepts

"human dignity" and "social dignity". Human dignity has the same meaning as absolute dignity mentioned above. Social dignity means "dignity-of-self" and "dignity-in-relation". The former is about self-worth and self-respect, and the latter is how worth and respect is conveyed by others' behaviour (10). For example, a study on suicide in older people concluded that dignity-preserving care both by single caregivers and by the (health care) system (i.e., dignity-in-relation) could have prevented these suicides. In this case, dignity-in-relation would have entailed effective communication with the older people by appealing to their autonomy and needs and not by degrading the already vulnerable older persons even more (11). When healthy older persons were asked how they would like to be cared for in the future, they often replied that they wanted to be cared for with dignity – seen as a human being with meaningful relations and not seen as a "nobody" (12). Eriksson relates the right to be seen or met as a unique human being to absolute dignity (7).

At-home-ness

The concepts of at-home-ness and dignity are related to each other. When a flexible culture reflects an ethos that prioritises the dignity of older persons, a home-like atmosphere can be created (13). In adddition, to be cared for in a dignified way means that the staff has a proper education and is acquantied with the life-history of the older persons under their care and knows them well (12). At-home-ness can also be seen as an existential experience and environments that are therapeutic can maintain this at-home-ness as an existential experience for older people (14). From a history of ideas perspective home can be described as a sacred area, where one is protected from the surrounding world (15).

In a concept analysis of "home" no comprehensive definition was detected, but experience, relationship, and place were important components of the concept. A home is a place where one lives, is secure, and is comfortable (16). According to Rytterström et al., a caring ethos can be reflected in activities if the caregiver feels "at home" and is confident,

protected, and feels no need to play a role ((4). A concept analysis of autonomy in elderly care highlights that autonomy of the cared for requires that beliefs and values of the staff are non-paternalistic, but rather person-centred. A person-centred approach requires the care giver to be flexibile, developing a culture from which emmanates an ethos that priortises dignity above all else. This type of environment results in a home-like atmosphere. Contextually, to create such an atmosphere both physically and existentially, requires a shift from a ritual or routinised based care (often a characterisitic of most nursing care facilities) towards a more person-centred care (13).

The little extra

To preserve the dignity of another person by meeting her or him as a unique human being (7) is the ethos of experiencing the little extra. The little extra means that a caregiver goes "beyond" what is normally expected. A little extra could be seen as a caregiver who gives a patient a violet dress because she likes the colour violet, or someone who sits down to talk with a person (17). Seen from the perspective of the "ethics of understanding of life" that set focus of the utmost intention of a caring act (18), these seemingly insignificant acts of caring may improve the existence of the patient and make him or her feel as "being seen as a human being". On an ontological level, "being seen" can be understood as belonging to humanity. Therefore, to give the patient a violet dress is a dignity-preserving act of caring. The "little extra" may be a sign of good caring. If care givers provide a little extra, something unexpected and spontaneous, patients' dignity can be re-inforced. The small acts of the little extra are interpreted as bridges between the universal aspects of life and the individual ones. The acts of the little extra may, for example, be seen as ethical signs of ontological or universal interdependence. These ethical signs express "spontaneous utterances of life" such as openness of speech and compassion (19). If the caregiver is open to these spontaneous utterances of life, it may express itself in doing the little extra in order to ease suffering (17).

To see the needs of the older person can be seen as sign of the little extra even if, as Rytterström et al. note, there exists a social culture that is medical oriented where patient care is task oriented. This kind of culture may lack caring if the residents are not seen as human beings and individuals within their subjective lifeworlds (2). The attitudes reflected in the caring acts of 'the little extra' could, for example, from a beneficence or a virtue ethics perspective be seen as normal things to do, and thereby nothing 'extra'.

Non-caring cultures versus caring cultures

If a ward's care culture is non-caring as experienced by nurses, the nurses may rationalize this by ignoring it. A defence strategy is to do only what duty urges one to do and this can be described as professionalism. The opposite of this are wards that are described with the metaphor of "home" where one feels relaxed, confident, protected, restful, strength promoting, and a place where there is no need to play a role. One can be true to oneself in a way that mirrors one's "caring ethos" (4).

Jakobsen and Sørli believe working culture should be more open, especially when collegues are concerned. They found that the ability to work under daily pressure was enhanced if the environment was open. Many participants in Jakobsen & Sørli's study said that they were "forced into 'assembly- line care'" (2010, 294) meaning that when they spoke out about something nothing was done to improve it. Also when patients complained about being "forced into assembly-line care" (2010, 294), little was done to develop it. In a case where "forced assembly-line care" was not changed, the staff stopped asking questions and did things that opposed their own cultural values. One adapts to others behaviour even if activities are not good for the patient, so care providers tend to reproduce their culture irrespective of the needs of the patients. When ethical violations are accepted in a working culture, ethical dilemmas could be connected to why some care providers do not consider the dignity of the older person. Hence, in an organization where efficency is demanded and

personal competence ignored, there is a great risk of colonizing the lifeworlds of the caregivers (20).

Ethical context - and climate

Ethical climate theory, according to Victor and Cullen (20), says that within any organisation there exists specific ethical climates. Victor and Cullen have presented five ethical climates based on studies in health care and industry: law, rules, caring, instrumental, and independence. The climate that is caring stresses the welfare of individuals or the whole organisation. When one relies on moral values and beliefs of each person, the context is based on independence. The rule and law ethical climate depends on standard rules and laws such as conduct codes. To priviledge the interests of the organisation regardless of personal benefits or pitfalls is named the instrumental ethical climate.

As noted above, the ethical climate describes the context, in which expressions of the ethos can be detected. One way of expressing an individual variation of the ethos of the caring cultural aspect is to use the word ethical context. If the context is "non-ethical" it can make older people feel undervalued and disempowered (21). To be infantilized and thereby violated is one way elderly describe how they are disrespected, their dignity diminished (22).

Aim

This study investigates the individual variations of caring cultures in relation to dignity and how it is expressed in caring acts and ethical contexts.

Methodology and method

The methodological approach is based on a hermeneutic epistemology where the preunderstanding is expressed as assumptions and a thorough concept review is performed. Data were interpreted hermeneutically where the pre-understandings were merged with data to a fusion of horizons (23). By understanding individual variations of the chosen fundamental concepts and theoretical perspectives, an understanding of the phenomenon (caring culture and dignity) can grow in accordance with clinical caring science as a scientific discipline (5). When preunderstanding and data are merged together in a fusion of horizons, a new understanding appears of both the ground concepts and the clinical context. As a result, both the understanding of the theoretical perspective and the phenomenon in a clinical context grows simultaneously. Therefore, when using clinical caring science, it is important to make the fundamental concepts, theoretical perspectives and empirical data as clear as possible. Based on this reasoning, the theoretical part in the study is given greater space than in ordinary qualitative studies as it represents the preunderstanding. An example on how data were interpreted can be seen in Figure 1.

What is said	Interpretation	Sub-theme	Theme
"There are some of	By doing the little	The little extra and	Dignified caring is
them who do the little	extra it is pronounced	dignity	expressed by the
extra –makes an	in what spirit caring	10	"little extra"
omelette or makes	is given.	1	
some decorating,			
food and drinks,			<i>y</i>
something a bit more			
extra".			

Figure 1. Interpretation matrix

In this study in-depth interviews were used with 28 family caregivers in Denmark, Norway and Sweden from January to February 2010. All the interviews were tape recorded and typed

verbatim. Each interview lasted between from 45 minutes to 1 hour. Most of the interviews were conducted in the nursing homes except for some being conducted at the university college or at the workplace of the family caregiver.

All these data were interpreted together by the Scandinavian research team.

Ethical considerations

Along with informational updates, forms were signed by the participants in order to provide written consent. The principle of voluntariness was respected for participation in the study. The duty of confidentiality and the anonymity of the participants were respected during the whole research process.

The research persons were informed about the possibility to withdraw from participation without giving arguments for that.

Only statements that could not be identified are used when the result is presented in the article.

The project was approved by one of The Research Ethics Committees in Norway, and authorized by the privacy protection ombudsman of NSD (Norwegian Social Science Data Services).

Also respective countries' ethical committees approved the project, wherever relevant.

Results

Dignity as "at-home-ness"

The first time the next of kin meets the staff is very important for creating a good dignifying "at-home-ness" start. The first meeting with the resident is also important, as noted by one next of kin:

"It felt warm directly; as soon as she came here she had a value".

Another expression for at-home-ness caring is when relatives stress the importance of caregivers being close to the residents. To have reports on what is going on, both negatively and positively, is a very important part of care. In addition, the resident's room is very important, and it has something to do with dignity in the home as when someone takes care of

the flowers and cleans the table. The ethos grounding the home can also be expressed as feeling safe, as expressed by this relative:

"In my experience of older persons it is more important that they feel safe than to be in a fancy surrounding. That they are cared for. When they come to a stage in life when they no longer can take care of themselves, they really have enough with themselves".

Clearly, part of being safe is more about being surrounded by people who are familiar than, for example, changing floors in order to get a single room. When the caregivers do not know the resident, the resident's dignity is violated, as the resident is seen not as an individual person, but as a thing that belongs to a group of persons.

Dignity as the little extra

Small acts (such as shaking hands with the resident every day) are highly valued. Similarly, when a caregiver kneels in front of a patient to establish an intimate contact, this signals to the resident that the caregiver is genuinely interested in their welfare. In other words, to see the needs of the resident acknowledges the dignity of the resident, as explained by the two following remarks:

"Dignity is upheld when the staff's respects the resident as an individual person where her needs and wishes are considered".

"Only after a short while my mother went to concerts, bingo, church ceremonies, hobby days, digital book days and reading loud days. Everything that was going on she participated in. She became a new human being, became healthier. Now she appreciates life".

Being offered a cup of coffee when visiting the ward;

"may have something to do with dignity for my mother when also relatives are taken care of". If the caregiver thinks it is important that the resident is dressed well, it; "says something about how you look upon one another".

In addition, the spirit in which caring is given influences the way patients and their relatives see the little extra:

"There are some of them who do the little extra – makes an omelette or makes some decoration, food and drinks, something a bit more extra".

So, to be "really seen", as an individual with dignity by the staff, is an expression of the staff's attitude. In addition, a commitment from the caregiver to look for common interests with the resident can be interpreted as creating a caring communion.

The relatives stressed the importance of who provides care. Some staff members are just there for a job, not interested in providing the little extra. If the "wrong" person gives care, the resident can be ignored. As one of the relatives noted, to do the little extra is when the residents are really seen by caregivers who are suited for their jobs and can see "the beauty in the faces of the old persons".

Non-dignifying ethical context

An example of non-dignifying ethical context where a feeling of disempowerness, violation by infantilization, and undervaluation can appear is when a mentally alert resident is served meals with persons with dementia who cannot eat by themselves and in a proper manner:

"Also you cannot speak to them and all this is violating to her dignity".

An attitude that says that although the resident has full intellectual capacity, the resident does not have the strength to make all decisions and is deadly tired of doing so. If the ideal is autonomy without considering the person's capacity or strength for this, this could end up violating a patient's dignity:

"You decide, was a mantra. It almost killed my mother. My mother is completely clear".

Another way to express a negative ethical context is not being seen by others:

"When you work night time you can do a lot of bad things for a patient without it being detected".

"[During daytime] all done by an individual person is seen by others".

Not to dare to take things up that have happened is another expression for the ethical context of a ward. It gets even worse when a patient is promised a change and nothing happens, i.e., when promises are not kept. For some, a positive interaction with staff requires good dialogue and it is from this dialogue that promises are voiced and kept. In addition, to focus on the next of kin although the older person is present could be a non-dignifying act of care:

"It is a question of dignity and respect not to ignore the older person even when I as a relative am present in the room".

Interpretation

Different individual variations of caring cultures in relation to dignity are detected in data as ethical contexts and individual ethical acts. If a caring culture is seen as a caritative ethos, its value order can be mirrored in purely ethical and artful caring activities. This reflects the idea that the particular reflects the universal. At-home-ness seems to reflect directly the ethos of a caring culture as an ontological entity, seen as the room or space where the residents can be invited into a caring communion. Doing the little extra is an ethical act and attitude that reflects truly person-centred care and demonstrates ways the caregivers encourage inviting attitudes towards the residents. We have seen in our interviews that what the relatives say is mostly related to a meaning-making or an interpretation of a caring culture. For example, to meet a resident for the first time does not happen in a vacuum, but is an interpretation of the caring culture of the institution reflected by the prevailing ethical context at the institution.

Both surprisingly and not surprisingly we have seen different individual variations of caring cultures expressed by caring and non-caring in ethical non-ethical acts and contexts as interpreted by the relatives, where they seem to sometimes exist side-by-side. Rytterström, Cedersund et al. believe that caring values are often diffuse but connote the phenomenon of caring itself. Therefore, maybe the patients or residents are best suited to judge the caring quality by the concrete caring activities they are exposed to (4). If the field is open for independent interpretation of the caring culture, it is not surprising that different caring cultures expressed as ethical and non-ethical contexts and acts of caring can exist side-by-side. Hopefully, the patients receive dignified care if the caregivers are well educated (12) and therefore can bridge non-caring cultures that reflects itself in an ignorant ethical context and non-caring acts.

A caring culture is related to a value order from an ethos to an ethical context and individual ethical acts of care, and it is when this ethos is expressed in the ethical context and in the person-centred dignifying care that both the organization and individual caregivers become caring and dignity promoting, often expressed by doing the "little extra". An ethos must be integrated in both the organization and in the individual caregiver in order to be expressed in caring acts and in an ethical context that supports these caring acts. Maybe this integration process of the ethos (together with knowledge) is the way to overcome different meaning-makings of the caring culture. This does not mean that the ethos becomes a mantra that everyone repeats. On the contrary, the ethos must be so integrated that every caregiver can use himself or herself in performing it in concrete and unique caring activities based on the individual caregiver's attitudes (as an interpretation of the ethos), knowledge, and artful caring. It is insufficient to share routinized caring activities among the staff; true dignity-inspired caring requires sharing an ethos of caring that is knowledgeable and artistic.

The relatives' notions seem to reflect implicitly that a paradigm shift can never take place if caring is not grounded in an ethos of a caring culture. This means that particular ethical contexts and caring acts reflect an ontological ethos. This idea can be seen in the data as both caring and non-caring cultures seem to prevail side-by-side in different ethical and non-ethical contexts. If oppressive care of the residents takes place, this reflects a meaning-making of a caring culture that is non-caring, although unspoken.

A caring culture characterized by an invitation to an at-home-ness caring means to be cared for by someone who knows the residents well and therefore cares for them in a dignified way (12), and the caregivers feel relaxed and secure (4), is also reflected in our data. For example, when the caregiver is committed to looking for common interests with a resident, this resident feels dignified. This can even create a "caring communion" that goes deeper than just a relation because the commitment could be seen as related to an ethos. In this way, "to be at home" reflects existentially and ethically the ethos of a caring culture. So, when, for example, staff specifically care for a resident's flowers, it reflects the existential safety of a home, but it is also reflects an ethical caring act of caring communion where this little (extra) gesture reflects the willingness from the caregiver to, in accordance with Norberg et al., to share the sacred dimension of life with the resident as a dimension of communion (24).

To do the "little extra" marks dignified care, and can be connected to the ethos of the culture. The ground values are mirrored by the caring activities that are experienced as something that exceeds what can be expected. To experience the little extra is to be really seen (17). In our material, to do the little extra is when the residents are really seen by caregivers who are suited for their jobs or, as one relative noted, when caregivers see the beauty in the faces of the elderly persons.

What is described above can be seen as ethical attributes of a caring culture. Also attributes of a non-caring culture as an instrumental attitude (20) were found. In a non-ethical context, the residents can feel disempowered (21) or even abused if the older person's dignity is violated through, for example, verbal offences (25). An ethical context that is characterized by good intentions of preserving the autonomy of the elderly persons can be oppressive if it becomes a mantra and the resident is not fit enough to respond to the demands of such autonomy. This can in fact be seen as a sign of a routinized instrumental ethical context where a learned mantra becomes more important than an ethos of caring, especially when the mantra is not integrated in the caregiver. An example of an ethical context characterized by independence is when caregivers prefer night work in order not to be seen by others so they can act with less accountability, as interpreted by the relatives. The caregiver can also act from her or his individual preferences towards the residents.

Conclusive remarks

The idea of a value order from ethos as a caring culture to ethical context and individual ethical acts is the principle idea behind this research. Ethical context and individual ethical acts are seen as individual variations of the ethos of the caring culture. A caring communion, invitation, at-home-ness, person-centred care, and "the little extra" are ethical expressions of a caring culture. In a non-caring culture, these characteristics are not present and the care given may not consider the dignity of the residents. Routinized, instrumental care is designed for the organization, not the residents that may result in a non-caring culture expressed as a non-ethical context.

We believe our research has provided some substance to the assumptions mentioned in the introduction. We assumed that the caring culture of nursing homes has a decisive impact on whether dignified care is given to the older residents. We have not seen evidence of the caring culture per se, but we have detected clinical expressions of it. For example, we have seen in the ethical contexts and in individual acts of caring signs of invitation, caring communion, at-home-ness, and the little extra. If these entities are present, dignified care is presumably given to the older person – they are seen as unique persons, deserving of "dignity in relation".

We also assumed that there is an ontological difference between the concepts caring culture and ethical context. A context may not be ethical if invitation, caring communion, athome-ness, and the little extra are absent. To not provide these may indicate a non-caring or abusive ethical context.

One final remark on methodology and method is that only the views of relatives are presented here. That of course sets a limitation on the trustworthiness on the care that is really given to the residents as the care is interpreted by the relatives.

Declaration of Conflicting Interests

The authors declare that there is no conflict of interest

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