



## Self Management

## Self-management support: A qualitative study of ethical dilemmas experienced by nurses

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## ABSTRACT

**Objective:** Policymakers increasingly focus their attention on stimulating patients' self-management. Critical reflection on this trend is often limited. A focus on self-management does not only change nurses' activities, but also the values underlying the nurse–patient relationship. The latter can result in ethical dilemmas.

**Methods:** In order to identify possible dilemmas a qualitative study consisting of semi-structured interviews was conducted. Six experts on self-management and medical ethics and 15 nurses participated.

**Results:** Nurses providing self-management support were at risk of facing three types of ethical dilemmas: respecting patient autonomy versus reaching optimal health outcomes, respecting patient autonomy versus stimulating patient involvement, and a holistic approach to self-management support versus safeguarding professional boundaries.

**Conclusion:** The ethical dilemmas experienced by nurses rest on different views about what constitutes good care provision and good self-management. Interviewed nurses had a tendency to steer patients in a certain direction. They put great effort into convincing patients to follow their suggestions, be it making the 'right choice' according to medical norms or becoming actively involved patients.

**Practice implications:** Because self-management support may result in clashing values, the development and implementation of self-management support requires deliberation about the values underlying the relationship between professionals and patients.

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## 1. Introduction

Self-management has become an important paradigm in healthcare. Policy-makers have high expectations of what it can achieve. It is believed to improve quality of life while respecting patient autonomy. In addition, self-management is expected to cut public spending [1]. Because of the singular emphasis on these positive effects self-management can be considered a 'hurrah word' [2]; it is difficult to argue against. The problem with concepts like these is that they are not often subject to critical reflection. In this paper, we argue that such reflection is important, since self-management implies important changes in the values underlying the professional–patient relationship.

Although the term self-management is commonly used in both academic and political debates, it does not denote a clear-cut concept [3,4]. The common denominator among existing definitions is that it implies involvement of patients in their own care process. However, the extent of this involvement differs between definitions. Healthcare professionals tend to define adequate self-management as compliance with the medical regimen [5–8]. There are more holistic definitions, too, which include health promotion activities, interaction with healthcare providers, compliance to recommendations, monitoring of physical and emotional status, making autonomous decisions and the management of self-esteem, role function and relationships [3,9,10].

The introduction of self-management brings about a change in healthcare professionals' tasks, as they are expected to support patient self-management. The values underlying the professional–patient relationship are also subject to change. For instance, self-management strongly focuses on patient autonomy and active patient involvement, implying a less dominant role for healthcare professionals [10]. These changing values can result in ethical dilemmas. Ethical dilemmas are a specific type of moral conflict in

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which two or more ethical principles apply but support mutually inconsistent courses of action [11]. In case of self-management support, the focus on patient autonomy and individual patient responsibility may clash with other values such as promoting health and medical outcomes, which could confront professionals with a dilemma on what action to take [12].

Literature on self-management mentions certain ethical tensions arising from a focus on self-management. Firstly, self-management might become a duty in which freedom is imposed on individuals [1,13–16]. Secondly, tensions can occur when professionals have trouble with relinquishing professional control and accepting choices that may enhance quality of life at the expense of medical outcomes [5,17–19]. Thirdly, self-management may be wrongly understood as patients having to manage their illness on their own, which can lead to patient abandonment [20–22]. Thus, literature already provides some insight into the potential dilemmas associated with self-management support (SMS). However, ethical dilemmas are mostly mentioned in passing, and are rarely backed up by empirical data. Since SMS has become such an important aspect of healthcare, it is essential to gain insight into these dilemmas encountered in daily practice. Ignoring these dilemmas might adversely influence the partnership needed between patients and professionals, and consequently, the effectiveness of self-management interventions. In this paper, we aim to gain insight into the ethical dilemmas encountered by nurses when providing SMS to patients with chronic conditions and into the ways they deal with these. The focus on nurses is a logical choice, as SMS is most often attributed to this group of professionals [18].

## 2. Methods

### 2.1. Sampling

In order to explore the understudied subject of ethical dilemmas in SMS, a qualitative study was conducted in the Netherlands [23]. In the Netherlands, self-management figures prominently on the agenda of healthcare providers, patient organizations and policy makers alike. Recently, self-management has also become a core element of the new Dutch general nursing competency framework [24].

In view of the lack of knowledge on the subject, the first step of the study was to identify potential dilemmas by means of a literature scan and expert interviews ( $n=6$ ). Experts were purposively sampled based on their expertise on SMS and medical ethics [25]. Subsequently, nurses providing SMS ( $n=15$ ) were interviewed. Nurses were purposively sampled based on the following criteria: (1) variation across chronic conditions; (2) variation across healthcare settings (outpatient hospital care, home care); and (3) working with adults and with children. A description of respondents can be found in Table 1. Maximum variation was chosen because the explorative nature of our study required a broad approach to the subject. All nurses working in chronic care who focus on SMS are expected to change their role and therefore are likely to come across ethical dilemmas. At the same time however, the dilemmas encountered are likely to vary between different conditions and settings, and it is imperative, therefore, to take the diversity in chronic care into account.

### 2.2. Interviews and study procedure

The expert interviews were open interviews in which we asked the respondent to reflect on the concept of self-management and the potential dilemmas they expected nurses to encounter. The interviews with nurses were semi-structured and guided by

**Table 1**

Overview respondents' characteristics.

Nurse	Setting	Sex	Chronic condition	Adults/children
N1	Hospital	F	Kidney diseases	Adults
N2	Hospital	F	Diabetes	Adults
N3	Hospital	F	Radiotherapy	Adults
N4	Hospital	F	Cystic Fibrosis	Children
N5	Hospital	F	Gastroenterological diseases	Children
N6	Hospital	F	Endocrinal diseases	Adults
N7	Hospital	F	Cancer	Adults
N8	Hospital	F	Rheumatology	Adults
N9	Hospital	M	HIV/AIDS	Adults
N10	Hospital	F	Hematology	Adults
N11	Hospital	F	Sickle-cell anemia	Children
N12	Homecare	F	Various conditions	Adults
N13	Homecare	F	Various conditions	Adults
N14	Homecare	F	Various conditions	Adults
N15	Community service	F	Tuberculosis	Adults
Expert	Role	Sex	Expertise	
E1	Researcher and teacher	F	Nursing, ethics and self-management	
E2	Researcher	F	Patient participation, healthcare policy	
E3	Researcher and teacher	F	Ethics and self-management	
E4	Ethics advisor of national nursing organization	F	Nursing, ethics	
E5	Advisor patient organization	F	Patient participation	
E6	Researcher	F	Health and self-management	

a self-developed interview guide based on the outcomes of the literature scan of ethical dilemmas of SMS, the expert interviews, and interviews with nurses conducted in another study on SMS [26]. Both authors (in most cases jointly) conducted the interviews at the workplace of the nurses. The interviews lasted 60 min on average. The interviews started by asking the nurse to talk freely about their ideas on and experiences with SMS, and on any difficult situations they had encountered. We did so because we wanted to avoid steering the nurse directly to the dilemmas deduced from the expert interviews and the literature. Next, we asked them to reflect on the dilemmas deduced from the literature and previous interviews. The interview guide is provided in Box 1. The interviews were audio-recorded and transcribed verbatim.

#### Box 1. Interview guide.

- Respondent's background
- Definition of self-management in own work setting
- Most important principles of self-management
- Self-management support activities in own work setting
- Good examples of self-management support
- Examples of difficult situations in self-management support and how to deal with these situations
- Exploring dilemmas identified from expert interviews and literature
  - o Patient autonomy vs do not harm principle
  - o Responsibility patient vs responsibility professional
  - o Privacy patient vs holistic view on self-management
  - o Patient interest vs solidarity (family and society level)
- Differences between nurses in dealing with dilemmas
- Differences between patients groups and healthcare setting with respect to dilemmas
- Self-management interventions that counteract respondent's ideas about good care

### 2.3. Data analysis

Data collection and analysis was an iterative and reflexive process [27]. The analysis was conducted in several steps. First, an overview of the characteristics of each respondent was prepared (e.g. gender, years of experience as a nurse, level of education, care setting, and the type of patients cared for). The possible impact of these differences was addressed throughout the subsequent analysis. Secondly, the data were coded in an inductive way. Third, a thematic framework was constructed [25] including the following elements: (1) the definition of self-management; (2) SMS activities; (3) values in the patient–nurse relationship (e.g. autonomy, active patient involvement, medical standards, professional boundaries, the role of family members and privacy); (4) tensions between these values encountered when providing SMS; and (5) ways in which these tensions were dealt with in practice. Ongoing analysis refined the specifics of each theme. To ensure reliability, in each phase themes were discussed between the two authors until consensus was reached. During the last phase (reporting the data), the analysis was further refined by the selection of quotations. To enhance the validity of the analysis, preliminary findings were presented to and discussed at four symposiums for healthcare professionals and with the advisory board of our study. These audiences confirmed our findings and provided additional examples of the ethical dilemmas we identified, which helped us to refine our analysis.

### 2.4. Ethical considerations

In the Netherlands, this type of research among professionals does not require consent from an ethics committee. All respondents gave their informed consent to participate and provided permission to use quotations from the interviews anonymously.

## 3. Results

In the first part of this section, the importance nurses attach to self-management is described. Then, we present three ethical dilemmas derived from the data: (1) patient autonomy versus optimal health outcomes; (2) patient autonomy versus stimulating patient involvement; and (3) a holistic approach to SMS versus respecting professional boundaries.

### 3.1. The importance of self-management

Respondents generally recognize self-management as an indispensable element of healthcare. As one of the experts stated: *'self-management is not an ideal; it is daily practice'* (E1). Patients are the ones who have to live with their illness and have to perform activities such as taking medication and adjusting one's lifestyle. In the end, respondents argued, the patient is responsible for his or her condition, because *'he's the one who has to perform all these tasks'* (N2) and as a nurse *'you cannot monitor someone continuously'* (N9). In addition, nurses refer to values such as equality, patient choice and patient control in relation to the importance of self-management. Even though they transfer the end responsibility to patients, they also note that this does not imply that patients are solely responsible for their care; patients share this responsibility with professionals. It is the nurse's job to provide patients with information enabling them to make an informed choice. Apart from similarities, there are also differences in the way self-management is conceptualized. Some nurses conceptualize self-management as medical adherence. Others stress the importance of patients performing daily activities themselves. Lastly, some respondents have a more holistic approach in which all aspects of

the life of the patient are considered to fall under self-management. We will go into these differences in more detail below, where we also show that the ethical dilemmas nurses experience have much to do with the way they define self-management.

### 3.2. Dilemma 1: patient autonomy versus optimal medical outcomes

When asked about their experiences with SMS, nurses in hospital care tend to adhere to a narrow definition of self-management and often conflate it with compliance to the medical regimen. This poses them with difficulties in practice, since patient autonomy can get in the way of compliance. Nurses adhering to such a narrow definition consider non-compliance as the most challenging situation in daily practice. They do not easily accept unhealthy behavior from their patients and try to convince them to make the 'right' choice according to their own professional norms. Non-compliance conflicts with their perception of good quality care, which are focused on medical outcomes. A nurse who worked with kidney transplantation patients said that she repeated information about a healthy lifestyle over and over, because she *'wants people to live a long and healthy life.'* (N1) Experts also recognize that nurses tend to conceptualize self-management as compliance.

*Nurses think that is their duty and task to ensure patient compliance to the medical regimen.* (E1)

The nurses we talked to use a range of strategies to convince patients to make the right choice. They repeatedly provide information, discuss consequences of non-compliance and lab results, and increase the frequency of consultations or phone patients who missed a consultation. They continue to provide information to patients to ensure that patients are aware of the implications of unhealthy behavior. At the same time, nurses also withhold certain information about treatment options as a strategy to increase compliance, as is illustrated by this quote from a nurse in child care.

*You know, if parents have a limited IQ, if they just don't understand it, then I don't think it is fair to offer them a choice [between treatment at home and in the hospital in case of cystic fibrosis].*<sup>1</sup> (N4)

Nurses' perceptions of medical risks of non-compliance are important for the way in which they perceive and deal with the dilemma of accepting patient autonomy while simultaneously focusing on optimal medical outcomes. One of the experts also points to this issue.

*You will recognize general dilemmas. However, the moral considerations will depend partly on the specific context and consequences of inadequate self-management. That differs across chronic conditions.* (E3)

For example, not taking pain medication is acceptable for nurses, whereas stopping radiation treatment is not. According to a nurse working with neck cancer patients, a patient who is considering stopping radiation treatment because of the adverse side-effects should be convinced to continue treatment. Still, this nurse recognizes that this pressure can become too forceful:

*We present the whole package [radiation treatment for specific periods of time at regular intervals] to the patient. We think this is a good thing. (...) Nine out of ten people draw the right conclusion: 'I have no alternative, I am up against the wall.' (...) Sometimes we*

<sup>1</sup> In order to ensure the readability of the citations we omitted some words which are indicated with ellipses (...). Explanatory text is marked by square brackets [...].

*almost cross the line. (...) Once, six professionals together repeated the same message [to the patient], over and over again. (N3)*

In some cases, nurses seem to prioritize patient autonomy over optimal medical outcomes. For instance, if a patient is able to articulate her wishes eloquently and shows awareness of the consequences of her behavior, nurses accept choices that go against their medical norms. When nurses accept non-compliance, however, this is usually not based on the value they attribute to patient autonomy. Nurses repeatedly explain that this is simply a matter of being 'the lesser of two evils'.

*And you will say: 'you can't stop' [taking your medication for inflammatory bowel disease], but then there are people who do it anyway. So it's better to do it [stop taking medication] in a controlled manner. That makes it possible to monitor the consequences. (N5)*

Some nurses argue that patients' unhealthy choices sometimes need to be accepted, lest one may lose sight of the patient altogether. Acknowledging patient choice as an expression of autonomy that should be valued for itself and 'allowing patients to define their own values of a good life' (E4), seems to be difficult for nurses. Although one of the experts provided an example of nurses doing just that:

*The ultimate example of self-management is a young adult, 25 years old I believe, who is treated with one more dialysis so he is able to drink too much beer. (E5)*

The respondents consider respecting patient autonomy as an indispensable part of self-management. However, most nurses seem to find it hard to accept that some patients make choices at odds with optimal medical outcomes.

### 3.3. Dilemma 2: respecting patient autonomy versus stimulating patient involvement

In this dilemma, nurses identify patient involvement as an important value. According to the homecare nurses we interviewed, patients are good self-managers when they perform as many tasks as possible. Nurses should not take over activities that patients can carry out themselves. At the same time, the respondents emphasize that patient autonomy is important and can be increased by encouraging patients to make decisions about everyday issues, such as choosing the preferred time and method of being washed. Therefore, they argue that one has to adjust professional care to the patient's daily routine. Every now and then, however, the values of active patient involvement and patient autonomy clash. This can happen when patients wish to be cared for rather than performing all kinds of activities themselves. The home care nurses we interviewed maintain, however, that a patient's choice to remain passive is not an expression of autonomy that can be taken for granted. Homecare nurses should not respond to questions from patients that nurses do not consider to be necessary.

*We could have chosen the easy way. Just doing what the client asked us to do. Like, let's say, 'your wish is our command'. But is this what you want as a healthcare organization? (N14)*

This dilemma is intensified when colleagues have different ideas about good care: this increases the difficulty of activating patients.

*Some colleagues [from homecare] say: "It's so sad she has to do it on her own [e.g., washing or eating]". My reply would be: "It's sad to make them dependent. You are not providing care, you are smothering someone." (N12)*

Stimulating active patient involvement versus patient autonomy is also an important dilemma in the care for adolescents and young adults. In the interviews nurses state that adolescents should become independent of their parents. They feel that it is important to speak to adolescents alone, even when they come to the hospital with their parents. From experience they know that adolescents will then talk more easily about certain issues (e.g. sexuality). This may also stimulate young patients to become more actively involved in their own care, which is considered a developmental task for reaching adulthood.

*Some teenagers do not tell their story easily. That's difficult. (...) They should be autonomous. That's how we think about it. Growing up implies that you have to become independent. (N5)*

At the same time, respondents note that being ready to go into the consultation room alone depends on the individual's development. One of the experts also raises the question of whether nurses should 'force' patients to become independent and whether patients have 'the right to stick to their mothers' (E3). One nurse report the case of a 38-year-old patient with blood clotting disease whose mother is still strongly involved in his care. The mother calls the nurse to order medication for her son or to ask questions about medication adjustment.

*At a certain moment you begin to think: well it's their way of life. He still lives there happily with his mother. (N10)*

We can conclude that nurses question whether patients have the right to remain passive and let others (nurses, parents) do the work. They struggle with accepting such choices, as these conflict with their ideals of active patient involvement and independence.

### 3.4. Dilemma 3: holistic approach to SMS versus safeguarding professional boundaries

Some nurses interpret SMS in a holistic way. Next to helping patients adjust their lives to the medical regimen, they focus their support on the social impact of the medical condition. For example, the HIV-nurse discusses stigma with patients and pays attention to social participation. A nurse working with patients with tuberculosis claims that this more holistic view is something that separates them from doctors. As a nurse, she tries to adjust the treatment to the daily lives of patients.

*[The question is] how to make adjustments [to the treatment regimen] (...) and how to decide on this together [with the patient and the doctor]? What other options exist besides the options doctors' think of behind their computers and who just see the little creatures that need to be cured. (N15)*

Nonetheless, taking such a holistic approach may conflict with nurses' perception of professional boundaries. One nurse relates that she would like to tell patients they cannot travel to certain countries, because the medication they take decreases their resistance to dangerous viruses. On the other hand, however, she worries about being too intrusive. Another example of this dilemma concerns patients who do not wish to work even if they could, as a nurse working with patients who underwent a kidney transplantation put in words as follows.

*A lot of people like to have a job. However, there also people who just don't want to, while their medical condition doesn't hinder participation. That's difficult (N1).*

The question respondents are struggling with is whether it is acceptable to discuss these patient choices, and if so, to what extent. They worry about crossing professional boundaries and intruding in a patient's privacy. Some respondents are involved in

many aspects of certain patients' lives, such as helping them to apply for funds, to build structure in their lives or their housing situation. A nurse working with children with sickle cell disease has a holistic conceptualization of SMS. For example, she contacts the housing association in case a child's bad housing circumstances may worsen disease symptoms (N11). However, this nurse sometimes feels uncomfortable with discussing private matters, since she feels limited in the action she can take as a healthcare professional.

*Then these people start to tell their shocking story saying they didn't know how to arrange things. You can't just say: OK, best of luck. You have to do something about it. (N11)*

Adopting a holistic approach to SMS challenges the professional boundaries of nurses. As a nurse, it is difficult to decide to what extent you can and should be involved in non-medical issues.

## 4. Discussion and conclusion

### 4.1. Discussion

This study is among the first to address everyday ethical dilemmas that may arise as a result of the increased focus on self-management in healthcare. We identified three ethical dilemmas that nurses are confronted with when providing SMS. The first dilemma, patient autonomy versus optimal health outcomes, shows that, similarly to other professionals, nurses find it difficult to let go of their professional control [5,10,17,18]. They often focus on optimal medical outcomes at the expense of patient autonomy. Although nurses claim to value patient choice and self-management, in practice their support is much less focused on increasing the freedom of the patient to make their own well-informed decisions [7]. The second dilemma, respecting patient autonomy versus stimulating patient involvement, relates to the question of whether active involvement can be imposed on patients, even when patients like to remain passive; a question which previously has been raised in the literature [1,13,14,16]. The third dilemma, a holistic approach to SMS versus safeguarding professional boundaries, refers to the conflict that arises when nurses interpret self-management in a broad way. Doing so implies that SMS should be directed at all aspects of the patient's life, while one may feel uncomfortable with invading in the patients' private lives, and feel limited in helping patients with issues outside the medical domain.

The study shows that the ethical dilemmas nurses encounter and the ways to deal with them partly depend on their definition of self-management (e.g. defined as compliance to treatment or in a more holistic way) and their definition of values such as patient autonomy (e.g. does this include the right to abstain or remain passive) [28]. For example, nurses who highly value compliance to professional norms do not experience a dilemma when confronted with patients who do not wish to or cannot take full responsibility for their medical regimen themselves. They do not consider it problematic when a patient is less actively involved in the treatment, as long as the patient adheres to the treatment and lifestyle prescriptions. A different perspective is the one in which nurses perceive patients who become active in their own care to be good self-managers. In this perspective, one should prevent a patient from opting to remain passive. The context in which nurses work also seems to be of influence on the types of dilemmas experienced. Home care nurses in this study were less worried about invading a patient's private life, while nurses working in the hospital setting seemed to experience more difficulties in broadening their support beyond medical management. We can conclude that the ethical dilemmas experienced by nurses rest on different views about what constitutes good care provision and what is considered good self-management. What becomes

apparent from our study is that nurses have a strong tendency to steer patients in a certain direction, and that they put great effort into convincing patients to follow their suggestions; be it making the 'right choice' according to medical norms or becoming actively involved patients. They are not inclined to 'let go' and leave patients to sort out their own lives. This approach is likely to be a reason why we did not find examples of patient abandonment, which due to the focus on patient autonomy and responsibility is identified as a hazard of self-management [20].

### 4.2. Study limitations

Ethical dilemmas that arise due to an increased focus on self-management have been scarcely investigated. Our study is therefore an exploratory one that offers first insights into possible differences across healthcare settings. The maximum variation in setting fitted this exploratory character; our research was aimed at getting a first overview of the ethical dilemmas caused by a stronger focus on self-management. Studying several different settings, we had to limit ourselves to interviewing only few respondents in each setting. Thus, we could not exhaustively explore the influence of the chronic condition and sector specific context nurses are working in when providing SMS. Since the results seem to indicate that different work settings (e.g. hospital care or home care) and certain characteristics of the chronic conditions (e.g. the consequences of non-adherence) are related to different dilemmas, this deserves further study.

A further limitation of our study is that it does not incorporate the patients' perspective. It is crucial to understand if patients perceive similar dilemmas, and if so, how patients perceive these dilemmas and how they deal with these. Patients may experience the dilemmas identified in this article differently. Moreover, patients may have other ethical dilemmas (e.g. patient involvement versus patient abandonment, as is suggested in the literature [20–22]) or propose other ways to solve them. Future research should therefore focus on the perspective of the other side of the professional–patient relationship.

### 4.3. Conclusions

Three types of ethical dilemmas that nurses providing SMS may experience were identified: (1) respecting patient autonomy versus reaching optimal health outcomes, (2) respecting patient autonomy versus stimulating patient involvement, and (3) a holistic approach to SMS versus safeguarding professional boundaries. Nurses we interviewed often focus on optimal medical outcomes at the expense of patient autonomy when providing SMS. Acknowledging patient choice as an expression of autonomy that should be valued for itself seems to be difficult for nurses. Respondents also struggle with the question whether they can impose active involvement on patients who prefer to remain passive. Furthermore, the results indicate that nurses seem to feel uncomfortable with interfering in the private lives of their patients and also feel limited in their options to support patients in dealing with issues outside the medical domain. The ethical dilemmas that nurses experience have much to do with the way they define self-management and patient autonomy.

### 4.4. Practice implications

We do not aim to make normative judgments about the way nurses give meaning to SMS and the way nurses solve their ethical dilemmas in practice. We aim to show that the dilemmas rest on different views about what constitutes providing good care and what is considered good self-management; views that often remain implicit. The implication of this is that nurses and patients



should discuss ideas about good SMS and the ethical dilemmas this may involve.

Such ethical deliberation is especially important because the respondents, despite the fact that they feel burdened by the ethical dilemmas described, do not always reflect on these dilemmas nor on the decisions made to solve them. Respondents did not always seem to be aware that alternative decisions, based on other ethical values, could have been made in certain cases. Nurses often implicitly opted for certain values. This underlines that it is important to reflect on everyday ethical issues in healthcare practices [29]. The ethical dilemmas uncovered in this article can provide input for such ethical debates. These are highly relevant at this moment, since self-management is likely to become even more important in the future. As an illustration, Huber et al. have even proposed to redefine health itself as ‘the ability to adapt and self-manage’ [30].

Deliberation is also important because different parties can emphasize different values or attribute different weight to certain values. Deliberation therefore should also include these other parties, especially patients. For instance, patients may value quality of life in the short term over medical compliance that might (but also might not) prevent complications in the future [31]. This again relates to the way self-management is conceptualized; in this view, ‘strategic’ non-compliance, in which patients monitor symptoms and change the medical regimen in order to live a good life, could also be seen as an expression of self-management [32].

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## Conflict of interest

The authors declare that there is no conflict of interest.

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