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Family members' experience of involvement in the patient care process on an interprofessional training ward: A qualitative interview study

Sofia Hemle Jerntorp *, Jenny Jakobsson, Malin Axelsson, Elisabeth Carlson, Anna Carin Aho

Department of Care Science, Malmö University, SE-205 06, Malmö, Sweden

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ABSTRACT

Background: Involving family members in the care process leads to higher-quality patient care. However, this requires collaboration among various healthcare professionals. At interprofessional training wards, healthcare students learn to work together across different disciplines. However, there is limited knowledge about family member's involvement in the patient care process during interprofessional education in clinical settings.
Aim: This study aimed to explore family members' experience of involvement in the patient care process on an interprofessional training ward.
Method: An inductive content analysis was applied on data from individual interviews with 19 family members of patients admitted to an interprofessional training ward.
Results: Family members experienced that they had to be involved in the patient care process to bridge knowledge between the patient and the interprofessional student team in order to influence healthcare and have control over the situation. Moreover, they wanted to be acknowledged as family members and needed transparency in the patient care process. Family members' involvement was governed by the patient's needs and influenced by the degree of trust in the interprofessional student team.
Conclusion: Interprofessional education activities should focus more on family members' involvement in the interprofessional training ward.

1. Introduction

Previous research shows that patients receive better quality of care when healthcare professionals involve family members in care planning and decision-making.[1,2] Involving family members reduces the duration of patients' hospital stay and frequency of rehospitalisation as family members have a unique knowledge of the patient's health needs.[2] Interprofessional collaboration (IPC) is central to utilising all professional resources needed in patient care to ensure patient safety and facilitate patient and family members' involvement in the care process.[3–5] However, to practise IPC, healthcare professionals need to acknowledge each other and have the skills to collaborate. Therefore, interprofessional education (IPE) has been implemented into healthcare educational programmes to equip forthcoming healthcare professionals for IPC.[6,7] Nevertheless, recent reviews highlight insufficient evidence to draw any conclusions about how IPE influences family members' involvement in the care process.[7,8] Thus, research is needed to explore this aspect in IPE.

The term *family member* used in the current study refers to Hanson's[9(p34)] definition of family: "Family refers to two or more individuals who depend on one another for emotional, physical, and economic support. The members of the family are self-defined." The World Health Organization[10] promotes person- and family-centred care, emphasising that patients and their families should be at the centre of all care.[11] Previous studies have also emphasised the benefits of family members' involvement in the patient care process.[12,13] Further, in a recent study by van Dongen et al.[14] patients emphasised the importance of involving themselves and their family members in the patient care process. However, results from another recent study indicate that patients perceive that their family members lack opportunities to be involved in care planning and decision-making.[2]

Including family members in patient care requires that healthcare professionals and patients allow them to be involved in discussions, treatment plans, and decisions.[12,13] Healthcare professionals play an

* Corresponding author.
E-mail address: sofia.hemle-jerntorp@mau.se (S. Hemle Jerntorp).

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important role in facilitating communication with family members and promoting their involvement.[14,15] Furthermore, family member involvement requires collaboration between different professions in healthcare. Therefore, the inclusion of family members has certain prerequisites, for example, training healthcare students at Interprofessional Training Wards (ITW) to adopt an inclusive approach to family members' involvement in the care process. In Sweden, several healthcare programmes offer training at ITWs, where students from diverse healthcare professions learn in interprofessional student teams to improve patient- and family-centred IPC.[15,16] In hospital settings, the general structure of ITWs in Sweden and globally is that students from at least two different healthcare educational programs collaborate. Furthermore, students often have a high level of clinical independence in patient care activities, such as care planning and ward rounds. However, to ensure patient safety, students receive continuous support from supervisors, who guide their work and encourage reflection among the students.[16,17] That is, the ITW is an arena where healthcare students can practice collaboration, increase interprofessional competence, and correspondingly practice involving patients and family members in the interprofessional teamwork.[17]

Previous research has emphasised the benefits of involving family members in care.[12,13] However, recent studies have shown that patients expressed concerns regarding the limited opportunities for such involvement.[2,18] Interprofessional education at ITWs should focus on the practical application of involving family members in care. Therefore, research is needed to explore family members' experiences of involvement in the care process on an ITW.

2. Aim

This study aimed to explore how family members experience involvement in the care process on an Interprofessional Training Ward.

3. Method

The study used a descriptive qualitative approach to analyse data collected through semi-structured individual interviews with family members of patients admitted to an ITW. The interviews were recorded, transcribed, and analysed using content analysis as described by Elo and Kyngnäs.[19]

3.1. Setting

The study was performed on an interprofessional training ward in southern Sweden. The patients at the ITW are commonly elderly and in need of general medical, nursing, and rehabilitation care. At the ward, medical, nursing, physiotherapy, and occupational therapy students in their final year participate in a two-week clinical placement, learning together as interprofessional healthcare teams. Students share all basic patient care in addition to their profession-specific duties. The ITW's focus is to create the opportunity for students to practice interprofessional collaboration with patients and their family members. Senior supervisors from each profession supervise the interprofessional student teams during the day shifts. On evenings and weekend shifts, one registered nurse supervises the whole interprofessional student team.[18]

3.2. Sample

Data were collected between February and December 2022. During this period, all admitted patients received written information about the study to share with their family members. The written information was handed out by the healthcare professionals working at the ward. To be able to ask family members to participate, the patient needed to give their consent and reveal who their closest family member was. To be included, the family members had to be able to express themselves verbally and understand Swedish. Eligible family members were then approached by the first author with support from the healthcare professionals at the ITW. This kind of purposive sampling is appropriate when searching for informants who have the most knowledge of the topic.[20,21] A total of 40 family members were asked to participate, 17 of which directly declined participation and four initially accepted but withdrew their consent before data collection. The main reason for withdrawing participation was stated to be a lack of time as their family member had returned home from the ward. Finally, the study included 19 family members, eight women and 11 men, aged between 40 and 82 years. Their relation to the patient was mainly sons, daughters and wives. Other relations were being a close friend or a nephew. The related patients had been admitted to the ward between five and 14 days, and the interviews were performed in close connection to the patient's discharge. All participating family members received written and verbal information about the aim of the study, and they were given the chance to ask questions before giving informed consent; they were also informed that participation was voluntary.

3.3. Data collection

All interviews were conducted over the telephone as per the family members' wishes. Before each interview, there was a brief conversation and gathering of background data regarding age and relation to the patient.

A semi-structured interview guide was used to ensure that all issues of interest were covered. The interviews started with an open-ended question: "Can you describe how you have been involved in the care process of your family member at this interprofessional training ward?" Probing questions were posed during the interviews to gain a deeper understanding of the family members' statements. All interviews were conducted by the first author, who had no relation to the family member or clinical context. The interviews lasted between 14 and 29 min, with a mean time of 19 min. They were all digitally recorded and transcribed verbatim by the first author. (See Supplementary File 1 for additional data).

3.4. Analysis

The interviews were analysed using inductive content analysis according to Elo and Kyngäs's approach.[19] The organisation phase began with reading the transcribed interviews several times to get well acquainted with the dataset. This was followed by a systematic data coding to identify important features relevant to the research question. Open coding was performed to identify patterns in the data by writing notes on a semantic level in the text while reading it.[19] Next, the text was reread, and labels were written in the margins to categorise various aspects of the content. Code sheets were made to organise and manage the data, as recommended by Elo et al.,.[19] Thereafter, all codes from the whole dataset were sorted, and the process of creating sub-categories began. All coded data relevant to the aim were systematically and inductively sorted under preliminary sub-categories. The preliminary analysis was discussed with the co-authors for further abstraction. In the next step, the sub-categories were named with content-representative vocabulary. Subcategories with related occurrences and similar descriptions were grouped under generated generic categories. The generic category's purpose is to reflect the result of the analysis, and the subcategories represent the variations of the result.[19] In this study, the variations are demonstrated within the generic categories. The generic categories were further abstracted and finally generated one main category. All categories were checked by going back to the original data transcriptions to ensure that the result had a solid association with the analysed data.[19,20]

4. Trustworthiness

To ensure the trustworthiness of the result a purposive sampling

technique was used to recruit family members as it was the most appropriate sample strategy to address the research question.[20] The participants varied in age and biological sex, which strengthens the credibility of the study. Reflexivity was used amongst all authors to discuss the influence of the first author on the interview situation. The authors also reflected on the participants' social context, which might have influenced their responses.[21–23] Nevertheless, research shows that informants are more likely to participate and feel more comfortable doing interviews over the telephone.[24] Furthermore, telephone interviews as a research tool have been evaluated and recognised as an effective way to generate high-quality research.[24,25] To avoid misinterpretation, the first author summarised and reiterated the participants' responses throughout the interview.[24,25] To ensure confirmability, the first and last authors worked together on the analytical process; however, all authors were involved in reading and making contributions to the analysis.[21] The transcribed interviews were also reread after the analysis was finalised to make sure that the results were generated from original data as recommended by Elo et al.[19,20] In addition, every step of the research process was described both to enhance transferability and to strengthen the trustworthiness of the study results.[20] With regards to preunderstanding, all authors are registered nurses and have years of clinical experience. However, none of them had the experience of working at an interprofessional training ward.

5. Ethical approval

Ethical approval was received from the Swedish Ethical Review Authority (No 2019–03761).

6. Results

The analysis generated one main category and four generic categories to describe how family members were involved in the care process, as visualised in Fig. 1.

7. Bridging knowledge between the patient and the interprofessional student team

Family members' involvement in the care process was governed by the patient's needs, often taking the form of bridging knowledge between the patient and the interprofessional student teams. Family members expressed that they were involved in the care process mainly because they perceived that the patient needed their support to assimilate information. Furthermore, they argued that they could fill in the information gaps that the interprofessional student teams had and inform them of changes in the patient's health condition. Their involvement was considered even more important if the patient had memory problems or a diagnosed cognitive impairment that made it difficult for the patient to convey their wishes to the interprofessional student teams.

> It means a lot to her that I understand the plan and what's going on. She feels old and has trouble remembering, she values my involvement and awareness of what is happening. (Family member number 19, a son)

However, to be able to bridge knowledge and be involved in the care process, family members sought transparency in the care process and requested to be acknowledged as a valuable part of patient care. Family members sometimes worried because they had witnessed that the interprofessional student teams did not always observe the patient's needs, were not responsive to the patient's physical or cognitive abilities, nor seemed familiar with the patient's health and social situation. The degree of trust in the interprofessional student teams influenced how the family members bridged the knowledge between them and the patient. Family members wanted to be a resource for both the interprofessional student teams and the patient as they possessed a unique knowledge important for patient care and discharge.

7.1. *Requesting to be acknowledged as a family member*

All 19 family members who participated in the study described the importance of being acknowledged as an important part of patient care and being allowed to be involved in care planning and decision-making. For instance, family members argued that it was important to feel involved, to be heard, and to feel seen as a family member.

> So that I would have felt acknowledged as a person who is important to [patient name] so that I would be informed. (Family member number 10, a wife)

Only a few family members expressed that they had been contacted by the interprofessional student teams and were involved in treatment and care planning. However, most family members expressed that the interprofessional student teams did not acknowledge their close relationship with the patient, and they were disappointed at being excluded from discussions of important care decisions. Two family members felt like the interprofessional student teams did not involve them even though they were physically present. They argued that if the interprofessional student teams had been more open, they could have contributed with valuable input.

> It would have been great if they had asked me. I've known him for a long time. I have some background information about him. If they're interested in it. (Family member number 18, a close friend)

Not having a dialogue with the interprofessional student teams was frustrating, particularly when the family members knew they could have made a difference. A few even pointed out that the interprofessional student teams were making wrong decisions due to a lack of information.

Moreover, all 19 family members expressed a need to stay informed for their own sake. They wanted to know that the patient was being well taken care of and argued that it was their responsibility as a family member to be actively involved in the patient's care.

> Obviously, when you live together, you want to know what's going on – how he experiences it, what treatment he gets, and things like

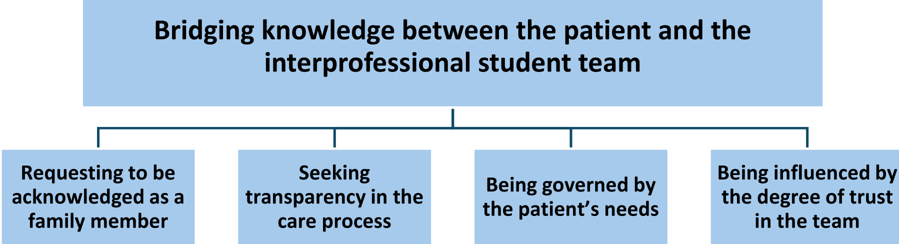

Fig. 1. Main category and related generic categories visualising how family members experience involvement in the care process on an Interprofessional Training Ward.

that. So I'm quite involved in this, actually. (Family member number 8, a wife)

7.2. Seeking transparency in the care process

All the interviewed family members expressed the need for transparency in the care process to facilitate their involvement and enable them to bridge knowledge between the interprofessional student teams and the patient. Family members expressed that they wanted to be involved to influence the patient's healthcare and be in control of the situation. Namely, they stressed the need for transparency in healthcare to be able to plan for the patient's return home and their care after discharge. Family members argued that, above all, receiving information from the interprofessional team was necessary to facilitate their involvement.

> I think it's really important because there may be details he [the patient] has missed, either things that are going to happen or things that he's going to think about when he gets home or something. I think it's very important that a relative has been involved and listened. (Family member number 17, a son)

Moreover, family members expressed that seeking transparency in the care process was not just about receiving information; they had to be given the chance to ask questions as well, for instance, regarding the causes behind the patient's condition and hospitalisation.

> You kind of want to know what's going on and why they think he's being readmitted all the time. (Family member number 3, a daughter)

When actively seeking information about the patients' care planning, family members said that it felt natural to ask the interprofessional student teams, and the students were always available. Family members described how the calm environment at the ward promoted their involvement, as they did not hesitate to interrupt the interprofessional student teams to ask them questions. This way they could bridge knowledge between the patient and the interprofessional student teams.

However, nearly all family members explained that their involvement in the patient's care was through dialogue with the patient, not with the interprofessional student teams. It was often the patient who conveyed all the details and kept family members informed. In addition, family members did not feel sufficiently informed and often had some unanswered questions. For instance, they complained that the decision to send the patient home came suddenly, with short notice, and it was made without dialogue or their involvement in the decision-making. Not being included in the discharge process was difficult in practical terms because they were not prepared.

> It would have been helpful to know that he was going home, so to speak. This is partly because he is old and fragile, and he has difficulty walking, so he needs assistance to get home. If I had known, I could have offered to help him. (Family member number 6, a son)

7.3. Being governed by the patient's needs

The interviewed family members described their involvement as being governed by the patients' needs. They argued that since the patients did not always know what they needed or had difficulty conveying themselves, they had to be involved in the care process to bridge knowledge between the patients and the interprofessional student teams. Furthermore, they wanted to provide support when the patients did not have the energy to be involved or had difficulty keeping track of what was said. They did not believe that the patients could communicate and discuss decisions with the interprofessional student teams without their support.

> Mother is old and has bad hearing, and there is too much information. So it's incredibly important as a family member to listen, and to be allowed to get involved in the care. (Family member number 15, a son)

The family members described their involvement as a security for the patient, as both practical and mental support. According to them, a lot of responsibility seemed to be placed on the patient despite having difficulties making informed decisions about their health. Therefore, the family wanted to be available for the patient since they were aware of the patient's vulnerable situation.

> My involvement in her care is very important, both for me and for her. Always will be. (Family member number 1, a daughter)

> I think it's surely quite positive that I get a little involved. (Family member number 8, wife)

All the interviewed family members expressed that they wanted to respect the patient's will. However, a few were afraid that the interprofessional student teams may have misinterpreted the patient's signals and that the patient did not receive the necessary care and treatment because of it. Nevertheless, when the family members tried to advocate for the patient, they sometimes experienced that the interprofessional student teams did not want them to interfere.

> My only interest is to receive information about what is happening, not to interfere with the care being given. (Family member number 14, a son)

7.4. Being influenced by the degree of trust in the team

The degree of trust in the interprofessional student teams influenced the family members' involvement in bridging their knowledge. On the one hand, most family members described the interprofessional student teams as helpful and service-minded, and they gave adequate information about care plans. For instance, the interprofessional student team were described as making eye contact during conversations or when just passing by in the corridor. This conduct promoted the family members' involvement; it encouraged them to trust that the patient received accurate care. It allowed them to be involved and focus on the overall care process and support the patient.

> Now I feel that I can both practically and tangibly take part in and simply access information. (Family member number 7, a daughter)

Most family members had experienced that the students did their best and contributed with good ideas in patient care. This made them trust that the patient was in good hands.

> I need to know that she's okay and that she's not in pain. That's what's important to me. (Family member number 15, a daughter)

On the other hand, not every family member felt confident with the interprofessional student teams. Instead, they stated that although there seemed to be numerous persons in the interprofessional student teams, it was sometimes unclear and difficult to find who was responsible for the patient. Several family members reported that they had had minimal contact with the interprofessional student teams and that they also had difficulty reaching them via telephone. Having to put so much effort to be updated on the care process was burdensome. For instance, they were managing their daily job or taking care of their children, but they had to put the patient's needs above their own. One family member argued that it was challenging to be involved when they were not physically present at the ward. However, it was difficult to visit often because of ward routines and visiting hours, which hindered their involvement.

> So, no, I don't feel like I'm on board with any decision. I'm just a receiver. (Family member number 10, a wife)

Not being able to contribute to and influence the care was

frustrating, and several family members were concerned that the patient was not receiving adequate care.

8. Discussion

Our main finding illustrates that family members perceive that they carry specific knowledge that can bridge the information gap that may be present between patients and the interprofessional healthcare student team. Nevertheless, our results also show that family members' valuable contribution to patient care is not always acknowledged by the interprofessional student teams. This is particularly noteworthy as the patients were admitted to an ITW with a focus on IPC. Previous research within other clinical settings[14,26] has suggested that family member's involvement in the care process requires collaboration between different healthcare professions and inadequate IPC has been recognised as a barrier to patient and family involvement in care.[8,14,26] This may indicate that the pedagogical approach at the ITW in this study did not sufficiently facilitate the family members' involvement. The reason for this could be that family members' contribution to patient care during IPE is not that well known yet.[18,27] However, family members' role has been highlighted in several other settings.[2,26] For example, Mackie et al.[2] explored patients' and family members' experiences of involvement in acute care wards and revealed that family members were important for supporting the patient by sharing information with healthcare professionals. In addition, the current study's results are concordant with previous research within a primary care context,[28] emphasising that family members are indeed important for patient care. Therefore, students at interprofessional training wards might need more active supervision and guidance to recognise the benefits of involving family members. This implies that the ITWs might need a pedagogic strategy to implement a routine for family member involvement in the patient care process. For example, a framework for interprofessional competency in patient- and family-centred care could help to guide and organise IPE activities.[29] The Core Competencies for Interprofessional Collaborative Practice framework[30] has a clear patient- and family-centred approach and might be beneficial when implementing and developing IPE activities to promote family involvement at ITWs. This framework can be used to give structure to ward rounds and reflection sessions, providing valuable opportunities for interprofessional student teams to discuss with family members and reflect on their involvement in the care process.

A previous study on family members' involvement and interprofessional teams in a primary care setting concluded that organising educational sessions for family members about the patient's treatment plans could be beneficial.[28] Implementing educational sessions for family members on ITWs could be a feasible IPC activity. In these sessions, students can share information about the patient's condition, treatment, and care planning to encourage family involvement. Additionally, it creates valuable pedagogical benefits for the healthcare students' interprofessional and professional development.

Moreover, participants in this study expressed that they wanted to be acknowledged as family members. When acknowledged, they could easily contribute to care planning. Additionally, family members described that friendly and straightforward communication with the interprofessional student teams reduced their concerns. Previous studies[15,16] have shown that healthcare professionals play a substantial role in facilitating communication with family members and supporting their involvement. Xyrichis et al.'s study[8] on interventions to promote family involvement found that including family members in decision-making led to high satisfaction with care. In this study, family members felt that the interprofessional student teams did not always acknowledge their important role. Additionally, family members expressed frustration when patients were discharged from the hospital without their involvement. This lack of involvement made the discharge process stressful and problematic, as patients often required support from their family members when returning home. To resolve these issues, educators at ITWs could adopt an educational strategy that involves structured IPE activities that focus on including family members in the care process. For example, Jensen et al.[31] described IPE activities where the patients gave students feedback on their experiences of different kinds of situations in the care process. This feedback could also be provided by family members, preferably during ward rounds and when planning for the patient's discharge. By receiving feedback, students' ability to engage and recognise family members' valuable contributions to the care process could be enhanced.

Furthermore, all the family members in the current study wanted to be involved to be able to influence the patient's care and have control of the situation. Their ambition was to provide support to the patient and be fully prepared for their discharge and return home. However, they reported that a lot of responsibility seemed to be placed on the patients themselves. This aligns with the study by Mackie et al.,[2] which underscored the stress patients experienced when they had to handle information themselves without their family members' presence. Despite the patients being too ill to handle the situation, family members were not actively invited by the interprofessional student team. Moreover, in the current study, a few family members said they had witnessed how the interprofessional student teams sometimes misinterpreted the patient's signals, and they expressed worry that the interprofessional student teams have consequently made the wrong decisions. Thus, the current study results and previous studies within other clinical settings,[2,14,26] indicate that family members' involvement is important in preventing misunderstandings and alleviating family members' concerns.

Therefore, in line with recent research,[32] we argue that educational activities, such as ward rounds and reflection sessions, in IPE can provide an opportunity for the interprofessional student teams to reflect on family member's involvement in the care process. Previous research[33,34] has shown that IPE is an ongoing process, and learning IPC is dependent on the students' experience of working together; furthermore, identity and identification within the group are essential for the interprofessional learning process. Therefore, the ITW has thus far focused more on collaboration between the students as they needed to get to know each other, which might explain why collaboration with family members appears to be deprioritised. Looking at learning from a sociocultural perspective, extending the clinical placement at ITW can offer advantages. Students can gain more experience in working together, which can help in improving IPC.[33,34] Additionally, they can also get sufficient time to work on involving family members in the care process.

9. Limitations

The results were based on a limited sample of family members in one ITW and the participants had to be able to understand and speak Swedish to be included in the study. In addition, the interviews were rather short and potentially lacked sufficient depth to explore the participant's experience fully. However, they all lasted for as long as the family members needed or were able to talk, and their descriptions were thorough enough to answer the research question. However, as communication through gestures and movements is lost via telephone, this method may have influenced how the participants responded and how the first author perceived their answers.[21,24] Furthermore, the exclusion of family members who do not speak Swedish may have led to the loss of valuable experiences and consequently reduced the trustworthiness and transferability of the result.[22]

10. Conclusion and educational implications

The result of this study can contribute to improving IPE. They indicate that IPE needs to place more focus on involving family members in the ITWs. For example, the Interprofessional Education Collaborative's Core Competencies framework[30] has a visible patient- and family-centred approach and might be useable when implementing IPE activities in ITWs. Since IPC is aimed at optimising the patient care

process through using all available resources and necessitating the involvement of all care professionals with the patient and each other, we need to consider family members as partners and make use of their potential contribution to the patient care process. Therefore, IPE activities need to be implemented within several courses and clinical placements throughout healthcare programmes to foster IPC and interprofessional habits in all patient care and treatment, including family members' involvement. However, more research is needed to develop IPE methods to improve family involvement in patient care at ITWs.

CRediT authorship contribution statement

Sofia Hemle Jerntorp: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Jenny Jakobsson:** Writing – review & editing, Supervision, Methodology, Data curation, Conceptualization. **Malin Axelsson:** Writing – review & editing, Supervision, Methodology, Data curation, Conceptualization. **Elisabeth Carlson:** Writing – review & editing, Supervision, Project administration, Methodology, Data curation, Conceptualization. **Anna Carin Aho:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Data curation, Conceptualization.

Author's contribution

The first author recruited and interviewed the family members, transcribed and analysed the interviews, and wrote the manuscript together with the last author. However, all authors contributed to the study plan, research design, ethical application, and analysis. Further, all authors made valuable intellectual contributions and critically revised the manuscript. All authors approved the final manuscript to be published, and they share responsibility for all aspects of the study.

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Conflict of interest

There is no conflict of interest.

Appendix A. Supplementary data

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