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Is perceived patient involvement in mental health care associated with satisfaction and empowerment?

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Abstract

Background Patients increasingly assume active roles in their mental health care. While there is a growing interest in patient involvement and patient-reported outcomes, there is insufficient research on the outcomes of patient involvement.

Objective The research questions in this study are as follows: 'To what extent is perceived patient involvement associated with satisfaction and empowerment?'; 'What is the nature of the relationship between satisfaction and empowerment?'; and 'To what extent are background variables associated with satisfaction and empowerment?'. We assumed that a higher degree of patient involvement is associated with higher satisfaction and empowerment scores and that satisfaction and empowerment are positively associated.

Design, setting and participants Data were gathered using surveys of 111 patients of 36 multidisciplinary care networks for persons with serious and persistent mental illness.

Main variables studied and main outcome measures Demographic characteristics, patient involvement and satisfaction were measured using a new questionnaire. Empowerment was assessed using the Dutch Empowerment Scale. Descriptive, univariate (Pearson's r and independent-samples *t*-tests), multivariate (hierarchical forced entry regression) and mixed-model analyses were conducted.

Results The hypotheses of positive associations between patient involvement, satisfaction and empowerment are confirmed. The demographics are not significantly related to satisfaction or empowerment, except for gender. Men reported higher empowerment scores than did women.

Discussion and conclusions Making patient involvement a reality is more than just an ethical imperative. It provides an opportunity to enhance patient-reported outcomes such as satisfaction and empowerment. Future research should focus on the nature of the association between satisfaction and empowerment.

Introduction

Patients[a] increasingly take up active roles in their own care as well as in policy decisions. Furthermore, there is a growing range of studies conducted by patients themselves. Such 'service user or survivor research' enhances the reliability and quality of the study results.[1,2] Service user research has often been criticized as being biased.[3] Although protagonists of this type of research acknowledge that their standpoints are influenced by their experiences, this may also be the case for the so-called neutral researchers.[4]

This growing active involvement is the result of a range of scientific and societal evolutions including deinstitutionalization, consumerism, patient-centredness and democratization.[5–8] The main reasons for patient involvement are that it is considered to be ethically right, to enhance the quality of mental health care (MHC),[9–11] ultimately leading to more positive outcomes. A more comprehensive overview of the concept of patient involvement is given elsewhere[12]: 'Patient involvement in MHC means involvement in decision making and active participation in a range of activities (e.g. planning, evaluation, care, research, training, recruitment) starting from the expertise by experience of the person, in collaboration with and as equal partners of professionals'. While this definition is fairly broad, the scope of the current study is patients' involvement in their own care, rather than their involvement in broader practice and policy development.

There has been insufficient research establishing evidence for the outcomes of patient involvement. This is surprising in view of the growing interest in effectiveness and outcome management in MHC.[13]

Different outcome measures are relevant depending on the objectives and background of the research.[5,14–16] Policy makers, researchers, patients and politicians all possibly have different views on this. Traditionally, outcomes mostly regard clinical symptoms, duration of hospitalization and functioning, as assessed by clinicians.[17,18] A second range of outcomes concerns accessibility of services[19] and responsiveness to the patients' needs,[20] and a recent set of outcomes pertains to the costs and cost-effectiveness of health care.[17,21] A fourth series increasingly receives attention: *patient-reported* outcomes. These outcomes take into account patients' preferences and needs. A long-term example is quality of life,[22] and more short-term examples are the patients' satisfaction with the care they receive,[23] their recovery and empowerment.[24–28]

The current study investigates associations between patients' perceived involvement and two patient-reported outcomes: patient satisfaction and empowerment. *Patient satisfaction* has long been identified as a key element of outcome measurement within the patient perspective.[29] However, measuring satisfaction presents a challenge, because it may involve an element of coercion[30]; that is, patients may feel compelled to report high satisfaction when fearing that their answers may affect the way they are treated. It is thus important that the data collection is conducted by researchers who are not involved in the patients' treatment. Satisfaction is increasingly promoted as a quality-of-care indicator.[31] It can be considered as an outcome in itself as well as a factor promoting other outcomes such as quality of life.[32] Research on the relationship between satisfaction and other variables has provided mixed results. Some studies suggest that satisfaction increases as a consequence of involvement.[23,33] Concerning the role of age, there are both studies in favour of[31] and studies contradicting[34] a positive association with satisfaction. Most studies have failed to find a relationship between gender and satisfaction.[33–35] Psychotic symptoms do not seem to influence satisfaction,[35] while depressive symptoms might negatively impact satisfaction scores.[36] Quality of life may be of influence,[31,37] although this relationship has not always been confirmed.[38]

Walsh *et al.*[35] assert that the use of satisfaction as a sole outcome indicator is insufficient to provide reliable information. It is known

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[a] We use the term 'patient' for reader-friendliness. This does *not* imply that we view the patient as taking a passive role.

that involvement has an empowering effect and this concept fits in with the strengths-based approach of patient involvement.[39] Thus, it seemed important to include *empowerment* as an additional measure. According to the World Health Organization, 'empowerment refers to the level of choice, influence and control that users of mental health services can exercise over events in their lives'.[40] Previous research shows that almost every kind of involvement was shown to be empowering,[24–27,41] although Alegría[42] did not find a strong association. Income and quality of life were found to be related to empowerment,[43,44] while age, gender, ethnicity, marital status, education and employment status seem unassociated with empowerment.[44,45] However, one study found a non-significant difference between men and women,[43] as well as an inverse relation between severity of MH problems and empowerment.

Research about the relationship between patient satisfaction and empowerment is scant. Some studies report a positive relationship between satisfaction and empowerment rates,[41,46,47] but the causal direction of this relationship remains unclear.

The purpose of this study is to assess the relationship between perceived patient involvement, patient satisfaction and empowerment, using surveys. We report patients' *perceptions* of involvement, rather than their actual involvement level. The nature of the relationships between the actual involvement level and the two variables patient satisfaction and empowerment, combined with the perceived involvement level, is very complex, but is beyond the scope of the current study. Our research questions are as follows: 'To what extent is perceived patient involvement associated with patient satisfaction and empowerment?'; 'What is the nature of the relationship between patient satisfaction and empowerment?'; and 'To what extent are background variables associated with patient satisfaction and empowerment?'. We hypothesize that a higher degree of perceived patient involvement is associated with higher satisfaction and empowerment scores. We also expect a positive association between patient satisfaction and empowerment.

Methods

Setting

Questionnaires were filled in by patients of multidisciplinary care networks for people with serious and persistent mental illness (SPMI). The multidisciplinary care networks are consultation structures that gather all relevant caregivers (formal as well as informal) to coordinate the care for individual patients. The networks include caregivers from different professions (e.g. psychologists, nurses, psychiatrists, social workers) and sectors (e.g. MHC, welfare, education, vocational services). The networks are targeted at three age groups (minors, adults and elderly persons) and at a variety of psychiatric disabilities. They are pilot projects organized by the Belgian government aimed at implementing the principles of care networks, needs-based care, rehabilitation in society and continuity of care. These care networks are particularly relevant settings for the current research because they were stimulated to apply innovations in their functioning, and in the current Belgian MHC, patient involvement is a real innovation. The government enables patient involvement among others by involving patient representatives in the steering groups of the networks.

The data presented in this study were part of a larger study gathering the views of patients, family and MHC professionals on indicators of patient and family involvement. Families' and professionals' views are presented elsewhere[48,49] (the authors, 2 papers under review).

Procedure

The study objective was to obtain the views of patients for whom involvement would be desirable and feasible at the time of the study.[b]

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[b] Possible limitations of involvement are discussed in a previous paper.[12]

Patients were included if they were (a) aged 14 and above; (b) willing to participate; (c) able to comprehend and fill out the survey autonomously; (d) had at least one patient-centred care consultation; and (e) not hampered in their therapeutic process by survey participation. The selection of respondents was made by the project coordinators as they knew the patients personally. Additionally, the researchers did not have access to personal information of the patients due to privacy and anonymity regulations. The authors were not involved in the selection, but did provide the abovementioned selection criteria. Respondents completed the questionnaire autonomously, most often in the presence of the researcher to assist if necessary. Health-care providers were not involved in the administration of the questionnaire. The research took place in the spring (Dutch-speaking respondents) and fall and winter (French-speaking respondents) of 2009. The administration of the questionnaire took approximately 30 min. Approval of the study was granted by the ethics committee of the Medical Faculty of the University Hospital of Louvain (Belgium).

Sample

Each care network invited five patients to complete a survey. Five family carers and five mental health professionals were also invited, but these results are beyond the scope of the current study. This relatively small number was chosen because the study was a pilot study with limited resources and time. Following the eligibility criteria, patients of nine networks were excluded from the study. The aim was thus to obtain questionnaires of 260 patients (5*52 networks). The study sample consisted of 111 patients, resulting in a response rate of 43% of the intended number ($N = 260$). Respondents ranged in age from 15 to 78; 60% were female ($N = 67$) and 81% ($N = 90$) were Dutch-speaking (19% French; $N = 21$). All patients suffered from SPMI, and about 35% of patients ($N = 39$) were part of a network providing care for a diverse range of psychiatric disabilities. Fourteen percentage of patients ($N = 16$) were part of a network regarding personality disorders, 14% for substance dependence ($N = 15$), 13% for depressive disorders ($N = 14$), 9% for psychosis ($N = 10$), 9% for comorbid disorders ($N = 10$), 5% for psychiatric disability and a forensic statute ($N = 6$) and 1% for conduct disorder ($N = 1$). After complete description of the study to the participants, written informed consent was obtained. In the case of minors, consent was obtained both from the teenager and from a parent or guardian.

Instruments

Involvement indicators scale

A questionnaire was constructed by the researchers to optimally fit the research questions and changing context. It was designed to correspond to the particularly relevant Belgian law regarding patients' rights which was adopted in 2002. The questionnaire was furthermore informed by a literature review on patient involvement[12] and was inspired by existing instruments such as the Consumer Participation Questionnaire[50] and the Care Perception Questionnaire.[51] The questionnaire consists of 27 items and was pre-tested and adapted after consultation with a patient association and two MHC professionals. It assesses several aspects, but in this study, the focus lies on aspects of patient involvement. An exploratory factor analysis with VARIMAX rotation yielded a factor that could be described as the 'Involvement Indicators Scale'. It has good internal consistency ($\alpha = 0.846$) and consists of 7 indicators of patient involvement: 'Decisions about my treatment are taken in collaboration with me', 'Providers actively create chances for patient involvement', 'I am treated as an equal conversation partner', 'I receive tailored information', 'My opinion is considered important in the care network', 'The end decision about my treatment is taken by me' and 'My strengths and weaknesses are considered equally'. Patients were asked about their opinion on the way they are involved in consultations about their treatment. For each item, they were asked to what degree it was realized. Answering possibilities ranged from 'never' to 'always' on a 5-point Likert scale. We furthermore included a dichotomous item regarding patients' presence at care meetings (yes/no).

Patient satisfaction scale

This scale consists of four questions assessing patients' satisfaction concerning the care they receive, providers' expertise, the type of care and the support of their family. Answering possibilities range from 1 (very unsatisfied) to 10 (very satisfied). The internal consistency of the scale is excellent ($\alpha = 0.913$).

Empowerment scale

The Dutch Empowerment Scale (Nederlandse Empowermentvragenlijst)[43] was used integrally, with some minor language adaptations to fit the Belgian context. For the Walloon[c] respondents, the scale was translated in French. The scale is divided into seven subscales with mostly good internal consistency: (a) *Professional help* (4 items; $\alpha = 684$); (b) *Social support* (7 items; $\alpha = 0.846$); (c) *Own wisdom* (12 items; $\alpha = 0.909$); (d) *Sense of belonging* (6 items; $\alpha = 0.219$); (e) *Self-management* (5 items; $\alpha = 0.759$); (f) *Community inclusion* (6 items; $\alpha = 0.723$); and (g) the entire scale (40 items; $\alpha = 0.899$). All 40 questions have five answering possibilities, ranging from 'strongly disagree' to 'strongly agree'.

Analyses

Analyses were conducted using SPPS, version 16.0.2 (SPSS Inc., Chicago, IL, USA). We performed descriptive analyses for all included variables. The assumption of normality held for age and the empowerment scale. The Involvement Indicators and satisfaction scales were negatively skewed, which theoretically makes sense.[32] The latter two were transformed using their square roots, and extreme outliers were removed where necessary, resulting in normally distributed scales. Language, gender and presence at meetings are categorical variables. To investigate bivariate correlations, we used Pearson's *r*, and independent-samples *t*-tests were used to investigate group differences. Sample sizes of the groups were mostly unequal, but Levene's test for homogeneity of variance proved all variances to be equal. Effect sizes were calculated using the formula $\surd\ (t^2/t^2 + \mathrm{df})$.[52]

Hierarchical forced entry regression models[52] were conducted and the choice of the predictors depended on the results of the univariate analyses and on our hypotheses. For each model, the assumption of heterogeneous errors was checked using the Durbin–Watson statistic and multicollinearity was assessed. None of the applied models revealed problems in this regard. As we assess the relationships between patient involvement, satisfaction and empowerment in different care networks, the nature of our data is inherently hierarchical. This means that characteristics of the care networks may influence the results. To correct for possible influences of this hierarchical nature of the study design, the same models were tested using linear mixed modelling. Practically, the linear mixed-models procedure of SPSS[52] was used, incorporating a random intercept for 'care network'.

Finally, a mediation analysis was performed following Preacher and Hayes's guidelines.[53]

Results

Patients' involvement, satisfaction and empowerment scores

The majority of patients (78%; $N = 86$) are present at care meetings. Patients generally feel involved in their care (mean, $M = 4.04$; standard deviation $\mathrm{SD} = 0.68$; range, 1–5) and report high average satisfaction scores for the care network in which they participate ($M = 7.4$; $\mathrm{SD} = 1.7$; range, 1–10). Satisfaction regarding family support is the lowest and has the largest variability ($M = 7.06$; $\mathrm{SD} = 2.70$; range, 1–10). Respondents attain fairly high

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[c] Belgium's two largest language communities were included in this study: (i) the Flemish (Dutch-speaking) community and (ii) the Walloon (French-speaking) community.

empowerment scores ($M = 3.55$; SD = 0.67; range, 1–5).

Relationships between demographics, involvement, satisfaction and empowerment

Satisfaction

Univariate analyses reveal significant positive correlations between satisfaction and perceived involvement (Pearson's correlation $r = 0.65$; $P < 0.001$), presence at care meetings ($r = 0.21$; $P < 0.01$) and empowerment ($r = 0.28$; $P < 0.05$) (Table 1). No significant associations were found between satisfaction and age, gender and language. Independent-samples *t*-tests were conducted to evaluate the hypothesis that more involvement is associated with greater satisfaction. On average, satisfaction scores were higher among participants who reported more involvement ($M = 1.36$, standard error SE = 0.06) than among those who reported low involvement rates ($M = 0.52$, SE = 0.21). This difference was significant ($t = -4.35$, df = 54, $P < 0.001$) and presents a large sized effect $r = 0.51$. There were no significant differences in satisfaction based on gender, age, language and presence at meetings; neither did we find a substantial effect size.

In multivariate analyses (Table 2), only involvement significantly predicted satisfaction scores, explaining more than 30% of its variance. Presence at meetings did not contribute significantly; neither did empowerment. The demographic characteristics were not included

Table 1 Bivariate correlations using Pearson's *r* (N)

	Age	Gender	Language	Involvement indicators	Presence at meetings	Patient satisfaction	Empowerment
Age	1.00 (109)	−0.11 (110)	0.00 (110)	0.04 (86)	−0.01 (109)	0.17(69)	0.06 (84)
Gender†		1.00 (111)	0.13 (111)	−0.07 (87)	−0.02 (110)	−0.14 (70)	0.27 (85)*
Language‡			1.00 (111)	0.04 (87)	0.09 (110)	−0.01 (70)	−0.03 (85)
Involvement indicators				1.00 (87)	0.27 (87)*	0.65 (56)***	0.31 (70)*
Presence at meetings§					1.00 (110)	0.21 (69)**	0.02 (85)
Patient satisfaction						1.00 (70)	0.28 (55)*
Empowerment							1.00 (85)

$^{*}P < 0.05$; $^{**}P < 0.01$; $^{***}p < 0.001$.

†Female = 0, Male = 1.

‡Dutch = 0, French = 1.

§No = 0, Yes = 1.

Table 2 Summary of forced entry multivariate regression analysis explaining patients' satisfaction scores

	Model 1		Model 2		Model 3	
	β†	Sig.	β	Sig.	β	Sig.
(Constant)		0.000		0.383		0.685
Presence at meetings (0 = no; 1 = yes)	0.27	0.067	0.11	0.366	0.12	0.307
Involvement Indicators Scale			0.64	0.000	0.61	0.000
Empowerment Scale					0.12	0.335
Adjusted R^2	0.05		0.43		0.43	
df1	1		1		1	
df2	44		43		42	
F Change (Sig.)	3.52 n.s.		30.52***		0.95 n.s.	

$^{*}p < 0.05$; $^{**}P < 0.01$; $^{***}P < 0.001$.

†Standardized regression coefficient.

because they were not significantly correlated to satisfaction. The linear mixed-model analyses did not yield significantly different results as compared to the hierarchical regression analyses and are consequently not reported.

Taken together, these findings confirm our hypothesis of a relationship between perceived involvement and patient satisfaction.

Empowerment

Empowerment is significantly positively correlated (Table 1) to perceived involvement ($r = 0.31$: $P < 0.05$), gender ($r = 0.27$: $P < 0.05$) and to patient satisfaction ($r = 0.28$; $P < 0.05$). Language, age and presence at meetings were not significantly associated with empowerment. Independent-samples *t*-tests confirmed our hypothesis of a relationship between perceived involvement and empowerment. Participants with high involvement scores ($M = 3.56$, SE = 0.08) were more likely to have higher empowerment scores than those with lower scores ($M = 3.08$, SE = 0.17). This difference was significant $t = -2.06$, df = 24, $P < 0.01$ and presents a small-sized effect $r = 0.24$. On average, men ($M = 3.76$, SE = 0.10) had higher empowerment scores than did women ($M = 3.40$, SE = 0.10), presenting a significant difference $t = -2.51$, df = 83, $P < 0.05$ with a small effect size $r = 0.27$. Finally, higher satisfaction scores ($M = 3.71$, SE = 0.09) were also significantly associated ($t = -2.63$, df = 58, $P < 0.01$, medium-sized effect $r = 0.33$) with higher empowerment rates as compared to lower satisfaction scores ($M = 2.99$, SE = 0.24).

In the multivariate analyses (Table 3), language, age and presence at meetings were not entered because they did not significantly correlate to empowerment. Gender and involvement together significantly predict empowerment scores and explain 14% of its variance. When satisfaction is brought in, perceived involvement is no longer significant; neither does satisfaction make a significant contribution. As was the case for satisfaction, the linear mixed-model analyses did not yield significantly different results as compared to the hierarchical regression analyses.

The results of the hierarchical regression analyses evoked the idea that satisfaction might mediate the relationship between perceived involvement and empowerment, and a mediation analysis was consequently performed. Baron and Kenny's[54] conditions for mediation are not met (Fig. 1). Involvement is significantly related to empowerment ($B = 0.21$; $P < 0.01$) and satisfaction ($B = 0.38$; $P < 0.001$), but satisfaction does not have a significant effect on empowerment ($B = 0.15$; $P > 0.05$). The effect of involvement on empowerment while controlling for satisfaction is not statistically different from zero ($B = 0.15$; $P > 0.05$), but the covariate gender remains of influence ($B = 0.49$; $P < 0.01$). The bootstrap approach confirms this conclusion: after 5000 bootstrap resamples, the 95% bias–corrected confidence interval (−3.28 to 7.70)

Table 3 Summary of forced entry multivariate regression analysis explaining patients' empowerment scores

	Model 1		Model 2		Model 3	
	$\beta^{\dagger}$	Sig.	β	Sig.	β	Sig.
(Constant)		0.000		0.000		0.000
Gender (0 = female; 1 = male)	0.27	0.050	0.29	0.026	0.31	0.020
Involvement Indicators Scale			0.33	0.013	0.21	0.208
Satisfaction scale					0.18	0.282
Adjusted R^2	0.05		0.14		0.15	
df1	1		1		1	
df2	44		43		42	
F Change (Sig.)	4.03 n.s.		6.65*		1.18 n.s.	

$^{*}P < 0.05$; $^{**}P < 0.01$; $^{***}P < 0.001$.
†Standardized regression coefficient.

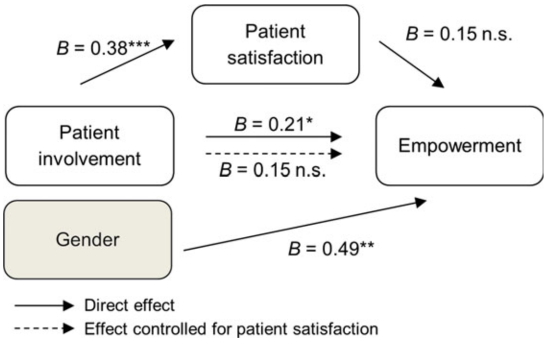

Figure 1 Mediation analysis of the relationship between perceived patient involvement, patient satisfaction and empowerment.

contains zero. There is consequently no evidence for mediation of the relationship between perceived involvement and empowerment, and the nature of the relationship between satisfaction and empowerment remains unclear.

Discussion

The hypotheses of a relationship between perceived patient involvement, satisfaction and empowerment are confirmed. In line with previous research,[23–27,33,41] univariate analyses revealed positive associations between the three concepts and regression analyses were able to replicate this. Linear mixed-model analyses did not alter the conclusions based on the hierarchical regression analyses. It can consequently be concluded that the relationship between perceived patient involvement, patient satisfaction and empowerment did not vary significantly across the different care networks.

In agreement with previous research,[33–35,44,45] the demographic characteristics were not significantly related to satisfaction or empowerment. However, there was a significant difference for gender. On average, men reported higher empowerment scores than women. Nevertheless, the size of this effect is small, and it may not be of practical relevance. It is unclear why our results reveal gender differences for empowerment, although the authors of the empowerment instrument also report (non-significant) higher scores of men on the subscale ‘own wisdom’.[43] This difference may be due to coping styles, for example men might be more inclined to use problem-centred coping styles than women,[55] which might more easily evoke feelings of being in control or being empowered. More research is needed to investigate both psychological and sociological explanations for this gender difference.

Consistent with earlier findings,[41,46,47] satisfaction and empowerment seem associated, but the nature of this association remains unclear. Our study assessed the possibility that satisfaction would mediate the relationship between involvement and empowerment, but this was not confirmed. This relationship requires more investigation by intervention studies that can identify the causal direction of this association.

Limitations of our research

Some limitations of our study should be addressed. Our study used a correlational design, and we are consequently not able to draw causal conclusions about the associations between perceived involvement, patient satisfaction and empowerment. Future studies should include interventions allowing for the identification of the causal direction of the relationships.

A second limitation is that the Involvement Indicators Scale we used is not yet fully validated. Further research should set out to conduct additional psychometric analyses, which were not possible in the current study given the budgetary and time constraints.

Because the researchers did not have access to personal information of the patients due to privacy regulations, the project coordinators selected the respondents. For this reason, our results might be susceptible to selection bias. It is not possible to exclude that the coordinators selected respondents who are more ‘conforming’ or satisfied. Furthermore, respondents may have been subject to a latent form of coercion[30] and may have felt compelled to report favourable views. However, they still reported aspects with low perceived realization, indicating that they did provide a balanced view.

Our study focused on patients who were approachable through survey research. To allow for generalization of our findings to the entire population of patients with SPMI, the associations we found between involvement, satisfaction and empowerment should be replicated in a broader sample.

Conclusions

We believe that our results add to the knowledge about the processes behind involvement and its linkages with satisfaction and empowerment. This study confirms the value that is placed on involvement. Making patient involvement a reality is more than just an ethical imperative; it may enhance patient-reported outcomes such as patient satisfaction and empowerment. Nevertheless, our results remain tentative, and the associations between involvement, satisfaction and empowerment should be replicated and assessed in more depth. Our findings do, however, indicate directions for further research. Ideally, an intervention study would measure several patient-reported outcomes. The concept of quality of life could be included because this can be considered the ultimate goal of MHC and patient involvement initiatives.

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Conflicts of interest

No conflicts of interest have been declared.

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