human reproduction

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The current fertility preservation consultation model: are we adequately informing cancer patients of their options?[†]

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BACKGROUND: There is very limited information about the amount of information that cancer patients retain after a fertility preservation (FP) consultation (FPC). Our objective was to assess patients' knowledge following FPC and to examine predictors of increased knowledge.

METHODS: We conducted a multi-center, cross-sectional, web-based survey at academic IVF centers, including women aged 18–43 years seen for comprehensive FPC between April 2009 and December 2010. The primary outcome measure was a knowledge score designed to assess comprehension of FP options. Analysis was performed to assess which patient variables were associated with higher knowledge scores. A 13-item knowledge tool about FP was developed (Kuder–Richardson 20 = 0.64).

RESULT(S): Among 90 eligible subjects, 66 were successfully contacted and 52 completed the survey (79% response rate). Participant's median age was 30.7 (interquartile range (IQR) 24.9–36.9) years and most were Caucasian, college graduates, nulliparous and in a committed relationship. The median knowledge post-FPC score was 6 (IQR: 5–9). Higher knowledge scores were associated with a college education, higher income, a primary diagnosis of breast cancer, additional contact with the FP specialist following the initial FPC and use of specific reference websites such as www.fertilehope.org. Parity, marital status and completion of FP treatment were not associated with knowledge scores.

CONCLUSIONS: FP knowledge following comprehensive FPC remains limited. Modifications to the current single visit FPC, such as a standard follow-up visit or additional educational tools, may be needed to improve patient comprehension of complex FP treatment options. Further research is needed to validate the knowledge scale in broader populations of cancer patients receiving FPC.

Key words: assisted reproduction / counseling / cryopreservation / fertility preservation

Introduction

Advances in early detection and treatment for cancer offer reproductive-age women well-founded hope for survival. Consequently, issues relating to longer-term quality of life, notably future fertility, must become an integral part of comprehensive cancer care. Previous studies have demonstrated that young women with cancer have important concerns about the impact of their illness and treatment on their fertility (Dunn and Steginga, 2000; Fallowfield *et al.*, 2004; Connell *et al.*, 2006). The new field of fertility preservation (FP) has emerged to address the reproductive needs of patients with cancer and other illnesses requiring treatments posing a serious threat to future childbearing.

Several factors are involved when patients are attempting to make a high-quality medical decision, including acquisition of information, evaluation of one's values or attitudes, support from friends and

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family (Michie et al., 2002; Woolf et al., 2005). A thorough understanding of the disease and treatment options is essential to make high-quality decisions (Street et al., 1995). In medical disciplines apart from oncology, a patient's comprehension of their disease correlates closely with the disease outcome and satisfaction with treatment (Greenfield et al., 1988; Waljee et al., 2007; Wright et al., 2011). In women making decisions about breast cancer treatments, patients who were randomized to use a decision aid had improved knowledge about the options and improved satisfaction with decision-making (Whelan et al., 2003).

Unfortunately, surveys of breast cancer survivors indicate that up to 50% did not receive sufficient education, counseling or resources for making decisions relating to their reproductive health before treatment began (Thewes et al., 2003; Meneses et al., 2010). As might be anticipated, recent studies have demonstrated that knowledge about FP 'before' consultation with a fertility specialist is generally poor (Balthazar et al., 2011; Peate et al., 2011), but little is known about the level of patient knowledge 'after' consultation with a fertility specialist. Given that most patients make critical decisions about FP treatment options after a single FP consultation (FPC), the information provided must not only be accurate, but also be well understood and retained by the patients.

Accurate predictors of post-FPC knowledge may help to refine the FPC process to improve patients' comprehension of the complex treatment options. The aims of this current study were to measure the FP knowledge in women with cancer who received a comprehensive FPC and to identify the patient characteristics and components of the FP process that were associated with higher knowledge scores.

Methods

Design

The 'Preserving Reproductive Opportunity After Cancer Treatment' (PROACT) survey is a multi-center, cross-sectional study designed to evaluate patients' experience with the FPC process. This is a post-consultation, web-based survey which included a knowledge index measure, developed via a multistage validation process. A FPC was 45–60 minute visit, conducted by board-certified reproductive endocrinologists who discussed pregnancy after cancer and FP options. This included a discussion of the possible psychological implications of losing fertility potential after a cancer diagnosis. FP treatment options were also discussed, including ovarian suppression during treatment, emergency in vitro fertilization cycle either with oocyte or embryo cryopreservation, ovarian tissue cryopreservation, conservative surgical treatment for the early-stage ovarian or cervical gynecologic malignancies, surrogacy and oocyte donation. The study was approved by the Institutional Review Boards at the University of North Carolina at Chapel Hill and at the University of Pennsylvania, and consent was obtained from all participants.

Study population and recruitment

Female patients seen at the University of North Carolina and the University of Pennsylvania for FPC between April 2009 and December 2010 were approached for participation 3–12 months following their FPC. Patients were included if they met the following criteria: (i) age 18–43 years, (ii) plans to receive medical treatment posing a threat to future fertility, (iii) having received a FPC with a full range of FP options discussed and (iv) the ability to read English. The upper age limit was used because we do not routinely offer FP treatments to women aged above

42 at our centers. Women were excluded if they had received previous treatments that may have adversely affected ovarian function.

We attempted to contact all eligible subjects for enrollment. After expressing interest in the study, participants were sent a secure link to the web-based PROACT survey for completion. Patients reviewed and signed an electronic consent form prior to completing the PROACT survey.

Survey development and validation

Measures, knowledge item generation and piloting
The PROACT survey collected the demographic data, knowledge about FP and information related to the decision-making process such as social support, elements of the FPC process and the use of additional resources in the FP treatment decision. The primary outcome of our study was the 'knowledge score', which was designed to assess comprehension of FP options. A knowledge score was generated for each subject, with one point allotted for each correct answer. Any incorrect responses or 'don't know' responses received zero points.

To develop a knowledge instrument that had content validity, reproductive specialists familiar with FP first identified important content included routinely in the initial FPC, such as the FP treatment options, success rates, risks of procedures and the investigational protocols. Items of varying difficulty were subsequently generated and each item was written in the form of a true/false or a multiple-choice statement with a 'don't know' option to eliminate guessing. Members of our research team and additional reproductive specialists reviewed the questions for content validity to ensure all attributes of FP knowledge relevant for making treatment decisions are measured in the scale. In addition, non-physician staff with minimal FP experience commented on the preliminary draft of the questionnaire for clarity and face validity. Survey experts adjusted the language of the questions and instructions to an eighth grade reading level.

The PROACT survey, including the revised set of knowledge items, was then evaluated with five respondents from the target population. Following completion of the web-based survey, subjects participated in an in-depth telephone cognitive interview with a survey expert to identify any problematic items. Results from this pilot telephone survey were used to modify the tool for clarity, difficulty level and time needed to complete the questionnaire. Ambiguous or confusing knowledge items were reworded or removed for the final version of the PROACT survey.

Final knowledge scale construction
To determine which questions to include in the final FP knowledge scale, item analysis (discrimination index and item difficulty score) and item-rest correlations were utilized, as has been used in other studies that develop knowledge scales in other disciplines (Radosevich et al., 2004; Carpenter et al., 2009; Wright et al., 2011). Discrimination indices compare the proportion of correct responses of respondents having total scores in the upper 25th with those having scores in the lower 25th percentile and are intended to eliminate items that are the least effective at discriminating between high and low scorers on the overall scale. In general, D-values $<$ 0.15 are considered inadequate for discrimination (Ebel, 1971; Ebel and Frisbie, 1991; DeVellis, 2003). Item difficulty evaluated what percentage of subjects respond correctly to a question—if $\leq$5% of subjects answered a question correctly, we discarded the question, assuming that it provides little useful information about FP knowledge. We also calculated item-rest correlations, which demonstrate how correlated each item is with the overall scale. Items with negative item-rest correlations were removed (Wiermsa and SG, 1990).

Statistical analysis

Descriptive statistics were calculated as frequency and percentage for the categorical data, and median and interquartile range (IQR) for the continuous data. We used Wilcoxon rank-sum tests to evaluate the differences in the total knowledge score based on various patient characteristics, such as demographics, elements of the FP process, use of social support and reference to the additional resources. A value of $P < 0.05$ was considered statistically significant. Multivariable linear regression models were used to explore the association of certain factors with knowledge scores when controlling for other factors. Specifically, three models were fit with two to three variables at a time since the sample size was only 52. The first included demographic variables significantly or borderline significantly associated ($P < 0.1$) with the outcome of knowledge score in the univariable setting (college education, BMI and household income). Since college education retained its significant association with knowledge, the second model included only two significant FP process and social support variables (discussing FP with someone after FPC and additional contact with a fertility specialist after the consultation), controlling for college education. Finally, the third model evaluated the association of use of websites after controlling for education (the only significant resource variable). Reliability (internal consistency) of the scale was assessed using Kuder–Richardson 20 (KR-20) with the standard of 0.70 being desirable for group-level comparisons. Statistical analyses were conducted using SAS statistical software v9.2 (Cary, NC).

Results

Participant characteristics

Among 90 eligible patients, 66 were successfully contacted by telephone and 52 of 66 women completed the web-based *PROACT* survey (79% response rate). There were no significant differences in socio-demographic data between responders and non-responders. The median interval between FPC and survey completion was 7 (IQR: 5–10) months.

Overall, the median age of participants was 30.7 (IQR: 24.9–36.9) years at the time of FPC (Table I). Most participants were white (82.7%), college graduates (84.6%), nulliparous (78.8%) and in a committed relationship (67.3%). Approximately one-half of the subjects had a primary diagnosis of breast cancer (51.9%), with the remainder having hematologic, gynecologic, brain, colon and skin cancers. Thirty-seven percent elected FP treatments, which included embryo, oocyte or ovarian tissue cryopreservation. A single provider performed all of the FPC at the University of Pennsylvania, and at the University of North Carolina, one provider performed the majority (83%) of consultations, while 17% were performed by a different provider who used essentially the same FPC model.

Knowledge index results

The item response characteristics for all 20 items originally considered for our knowledge index in *PROACT* survey are presented in Table II, including the item difficulty (proportion of correct responses), item-rest correlation and discrimination index (*D*) for each. Seven items were removed from the final knowledge scale because they failed to meet the minimum selection criteria; two items had an item difficulty $\geq 95\%$, one item had a negative item-rest correlation and the remaining four items had a discrimination index ≤ 0.15. The

Table I Baseline characteristics of patients seen for fertility preservation consultation.

Variable	Median (range) or *n* (%) *n* = 52
Age (y)	30.7 (14.4–43.1)
Knowledge score (max = 13)	6 (1–12)
BMI (kg/m²)	25.8 (15.3–53.9)
Ethnicity	
White	43 (82.6)
Black	7 (13.5)
Hispanic	1 (1.9)
Asian	1 (1.9)
Education	
College graduate	44 (84.6)
High school graduate	8 (15.4)
Relationship status	
Single	17 (32.7)
Partnered	35 (67.3)
Household income (US$)	
>40 000/year	35 (68.7)
<40 000/year	16 (31.4)
Previous live birth	
Yes	11 (21.2)
No	41 (78.8)
Received FP treatment	
Yes	19 (36.5)
No	33 (63.5)
Type of cancer	
Breast	27 (51.9)
Hematologic	6 (11.5)
Gynecologic	11 (21.2)
Other	8 (15.4)
Distance from clinic (miles)	35 (2–506)
Interval between FPC and survey completion (months)	7 (3–12)

FP, fertility preservation; FPC, fertility preservation consultation.

final knowledge scale included 13 items, for which the KR-20 = 0.64, just slightly below the suggested internal consistency (0.70) for group comparisons.

The median knowledge score after FPC was 6 out of 13 possible points (IQR: 5–9). Three general FP topics were answered correctly by >90% of the cohort (Q14, Q15 and Q16). A majority of patients also understood that, whereas IVF is an established treatment (Q2), ovarian tissue cryopreservation is an investigational treatment strategy (Q4). Questions focusing on risks of cancer and FP (Q6, Q9) and procedures and timing for FP treatments (Q7, Q8) were answered correctly by only ~50% of the cohort. Less than 10% of the cohort knew that the chances of pregnancy remain unchanged if embryos or oocytes were frozen for more than 5 years (Q19, Q20).

Table II Validated knowledge tool and discarded questions.

Final knowledge score items (*n* = 52)

Question	Correct answer	Item difficulty (% correct)	Item-rest correlation	Discrimination index (D)
Q1. A doctor can accurately predict the effect that cancer treatment will have on someone's chance of becoming pregnant in the future	False	86.5	0.2265	0.18
Q2. IVF with embryo freezing is an established treatment used for people with infertility	True	82.7	0.4248	0.24
Q3. Frozen embryos have more than a 90% chance of resulting in pregnancy in the future	False	65.4	0.2610	0.30
Q4. Ovarian tissue cryopreservation is a FP specific treatment	Yes	59.6	0.3366	0.42
Q5. Egg freezing has the same chance of future pregnancy as embryo freezing	False	57.8	0.4487	0.67
Q6. Chemotherapy increases the risk that future children will have birth defects	False	53.9	0.3051	0.42
Q7. Egg freezing can be done in less than 1 week	False	53.9	0.4269	0.55
Q8. Embryo freezing requires ovarian stimulation	True	50	0.3826	0.48
Q9. Women who have fertility treatments before cancer treatment are at increased risk for recurrence of their cancer in the future	False	48.1	0.2106	0.36
Q10. Frozen eggs have more than a 50% chance of resulting in pregnancy in the future	False	48.1	0.2116	0.30
Q11. More than 100 babies have been born to women who had ovarian tissue freezing	False	25	0.2399	0.30
Q12. A patient who experiences ovarian failure after cancer treatment can become pregnant in the future	True	26.9	0.4833	0.61
Q13. A patient who has had an ovary removed is less likely to become pregnant in the future	False	25	0.1234	0.18
Discarded Questions				
Q14. A patient does not have to have a partner to make use of fertility preservation treatment	True	100	0.4375	0.00
Q15. Some fertility preservation options have a much better chance than others of achieving pregnancy	True	98	0.4079	−0.06
Q16. All cancer leads to infertility	False	92.3	0.4631	0.06
Q17. A woman who freezes her eggs will have them available in the future when she is ready to use them	True	92.3	0.2468	−0.06
Q18. For women who freeze their embryos before cancer treatment, what are their chances of becoming pregnant in the future	Depends on age	19.6	−0.0442	0.06
Q19. The chance of future pregnancy decreases if eggs are stored longer than 5 years	False	7.7	0.0419	0.12
Q20. The chance of future pregnancy decreases if embryos are stored longer than 5 years	False	5.8	0.1166	0.06

Knowledge score associations

Univariate analysis of sociodemographic categorical variables revealed that knowledge scores were higher in patients with a college education ($P < 0.01$), income greater than $40,000 ($P = 0.08$) and those with BMI under 30 ($P = 0.03$) (Table III). Race, parity, marital status, institution and consulting physician were not significantly associated with knowledge scores. Time between FPC and survey completion was not associated with knowledge scores ($\rho = 0.04$, $P = 0.8$). Although not statistically significant, those with breast cancer scored slightly better than those without ($P = 0.1$). We also analyzed the association between knowledge scores and the FPC process, the use of social support and the use of additional resources. Additional contact with the FP specialist following the initial FPC ($P = 0.03$) and discussing FP treatment options with someone after the visit ($P < 0.01$) were both significantly associated with increased knowledge scores. Interestingly, completion of FP treatment was not associated with knowledge scores. In addition, the use of specific websites such as www. fertilehope.org (2010) was associated with higher knowledge scores

($P = 0.01$), while other resources including general internet searches and handouts provided at the visit were not associated with knowledge scores.

Exploratory multivariable linear regression analysis including predictors with at least a borderline association ($P < 0.1$) with the outcome of knowledge score showed that college education was still associated with higher knowledge scores after controlling for BMI and income ($P = 0.01$, 0.06, 0.65, respectively). A regression model with only college education resulted in an adjusted R^2 of 0.14. Building on this, an exploratory model including discussing FP with someone after FPC and additional contact with a fertility specialist after the consultation, and controlling for college education, showed that only discussion retained its significant association with increased knowledge ($P = 0.02$, 0.09, 0.01). Adding discussion to the model including only college education improved the fit (adjusted $R^2 = 0.24$). Finally, to look at the association of additional resources with knowledge score, a model including the use of FP-specific websites, and controlling for college education, showed that the use of FP-specific websites

Table III FP knowledge score associations.

Patient characteristic	Characteristic present, *n* (%) *n* = 52	Median (IQR) knowledge scores (max = 13)		
		Characteristic present[a]	Characteristic absent[a]	*P*-value[b]
Socio-demographic variables				
Age >30 years	28 (53.9)	6.0 (5−9)	6.5 (4.5−8.5)	0.66
BMI >30	15 (28.9)	5.0 (4−7)	8.0 (5−9)	0.03
Caucasian	43 (82.7)	7.0 (5−9)	5.0 (4−8)	0.18
College education	44 (84.6)	7.0 (5−9.5)	4.5 (3−5.5)	<0.01
Income >40K	35 (68.6)	7.0 (5−10)	5.5 (4−8)	0.08
Parity ≥1	11 (21.2)	6.0 (5−9)	7.0 (5−9)	0.46
In a relationship	35 (67.3)	7.0 (5−9)	5.0 (4−9)	0.19
Breast cancer	27 (51.9)	8.0 (5−10)	6.0 (4−8)	0.10
FP process				
Researched FP before FPC	24 (46.2)	6.5 (5−10)	6.0 (5−8)	0.23
Oncologist supported interest in FPC	39 (95.1)[c]	7.0 (5−10)	7.0 (6−8)	0.95
Discussed FP with oncologist after FPC	41 (78.8)	7.0 (5−10)	5.0 (4−8)	0.11
Additional contact with fertility specialist after FP visit	25 (48.1)	8.0 (5−10)	6.0 (5−8)	0.03
FP treatment	19 (36.5)	8.0 (5−10)	6.0 (5−9)	0.43
After visit, felt understood FP options	47 (90.4)	7.0 (5−9)	5.0 (5−6)	0.48
Before visit, had decided about FP treatment	5 (9.6)	8.0 (8−9)	6.0 (5−9)	0.09
Social support				
Brought someone to FP appointment	37 (71.2)	7.0 (5−9)	5.0 (4−8)	0.10
Discussed FP with someone after appointment	44 (84.6)	7.0 (5−9.5)	5.0 (3−5)	<0.01
Found additional resources helpful				
FP-specific websites (e.g. www.fertilehope.org)	33 (63.4)	8.0 (5−10)	5.0 (5−7)	0.01
General internet searches about FP	31 (59.6)	7.0 (5−10)	6.0 (5−8)	0.35
Handouts given at visit	42 (80.8)	6.5 (5−10)	6.0 (5−8)	0.58

FP, fertility preservation; FPC, fertility preservation consultation.
[a]Data are presented as median and interquartile ranges (IQR) for knowledge scores with maximum score = 13.
[b]Wilcoxon rank-sum test.
[c]41 subjects completed this question.

remained positively associated with the level of knowledge (*P* = 0.01, 0.03, adjusted R^2 = 0.21).

Discussion

Our study represents the first published report on patients' knowledge about FP in the relevant population *following* the FPC. Using a systematic method of survey design, we created a valid instrument to quantitatively measure post-FPC knowledge. Women from two large university centers completed this novel tool as a part of the web-based *PROACT* survey to further evaluate and develop the continually evolving model of the FP experience.

This study finds that overall *post-visit* knowledge scores are generally poor, with an average score of ~50% correct. Knowledge and understanding of disease and treatment is closely linked to patient outcomes and quality of life (Street *et al.*, 1995; Waljee *et al.*, 2007; Peate *et al.*, 2009; Tschudin and Bitzer, 2009). In addition, women have reported that concerns about fertility have an impact on their overall cancer

treatment decisions (Partridge *et al.*, 2004). Our findings suggest that even after the FPC with a trained fertility specialist, many women may not understand the information well enough to make a fully informed FP treatment decision. Poor comprehension of FP-related information may falsely influence patients' ultimate decisions about participation in some form of FP treatment.

Our examination of individual knowledge index items allowed us to investigate patients' comprehension of specific topics included in the FP consultation. Because patients have a poor understanding of FP options 'before' their FPC (Balthazar *et al.*, 2011; Peate *et al.*, 2011), the fertility specialist must explain a large amount of information during the FPC. Whereas patients appeared to gain an overall understanding of general FP-related topics, we found they assimilate limited information relating to specific FP treatment options, including time requirements and pregnancy rates. Knowledge about risks associated with FP and future pregnancy after cancer also was limited. Although concerning, this observation highlights a specific area that must be addressed effectively in the consultation process. A patient's misperception that there may be significant increased risks relating to

FP treatments or to birth defects may falsely influence not only FP treatment decisions, but also her ultimate decision to pursue future pregnancy at all.

We found that higher knowledge scores were associated with: (i) additional contact with the fertility specialist ($P = 0.03$) and (ii) discussing FP options with someone else after the FP consult ($P < 0.01$). Considering that patients must process a large amount of complex medical information in the context of a new cancer diagnosis, it is not surprising that additional contact with the FP specialist increases overall knowledge scores. Interestingly, patients who accessed specific websites such as www.fertilehope.org also had significantly higher knowledge scores, compared with those who used only general internet searches. This latter observation indicates the importance of ensuring that patients are made aware of educational resources specifically dedicated to FP. Among patient characteristics, college education was associated with higher knowledge scores. Although this characteristic is not modifiable, providers may need to adjust the consultation to the education level of the patient to improve comprehension of complex FP information.

A breast cancer diagnosis showed a borderline significant association with increased patient knowledge ($P = 0.1$). There are several possible explanations for this association. Oncologists who specialize in breast cancer mostly treat women, and therefore may be more familiar with the importance of fertility-related issues for women and concerns relating to FP treatment. In addition, the majority of published literature about FP has focused on women with breast cancer (Thewes et al., 2003; Partridge et al., 2004; Peate et al., 2009; Meneses et al., 2010). This may signal the need to further educate providers in other oncologic specialties on fertility-related concerns and the availability of FP treatment options (Forman et al., 2010).

The current FPC model employed by the majority of FP providers is a single consultation. Our study demonstrates that this model might benefit from modifications. Given that additional contact with the fertility specialist increases patient knowledge, patients might be scheduled to receive a follow-up visit, telephone call or email message to provide a structured format for answering further questions. Because time often is limited, early referral for FPC is essential to afford patients the additional time needed for further contact with the fertility specialist (Lee et al., 2010). Patients could also be referred to websites such as www.fertilehope.org when their initial visit is scheduled, to provide accurate introductory information in advance of their FPC.

Our study has several limitations. Only patients seen at two academic medical centers were surveyed, and it is possible that knowledge could vary by region or by the type of practice (academic vs. private). Our results may reflect some degree of reporting bias, because knowledge levels may be higher in patients who enrolled in the study than in those who chose not to participate. This is a cross-sectional study of women 3–12 months after their FPC and, although it is possible that knowledge scores are highest immediately after the FPC and decrease progressively with time, we found no relationship between knowledge scores and time from FPC to survey completion. Due to the study design, we do not have information about improvement in the FP knowledge as a result of the actual consultation—however, regardless of whether knowledge improved as a result of the FPC or not, it is concerning that the post-FPC knowledge is so poor, with only 50% of the questions answered correctly. Finally, further research is needed to improve generalizability by validating the knowledge scale in other populations receiving FPC.

In conclusion, our survey provides novel data revealing that FP knowledge after a comprehensive, personalized FPC remains limited. Results obtained using our 13-item knowledge scale indicate that the additional contact with the fertility specialist and the use of specific websites such as www.fertilehope.org improved the overall patient knowledge scores. The current single-visit FPC should be modified to improve patient comprehension of complex FP treatment options and, potentially, the overall FPC experience. Further research will be required to validate our knowledge scale in other populations of patients receiving FPC. Also, studies in many disciplines have found that the use of decision aids can improve decisional satisfaction, by improving knowledge, clarifying individual values and improving support systems (O'Connor et al., 2009). Future studies in the field of FP may assess how knowledge and outcomes could be improved through targeted interventions such as decision aids.

Authors' roles

U.B.: study design, execution, data analysis, manuscript drafting. A.M.D.: study design, data analysis, manuscript revising, M.A.F.: study design and manuscript revising. L.A.K.: patient recruitment and manuscript revising. J.K.: data analysis, manuscript drafting. J.E.M.: study design, execution, data analysis, manuscript drafting, and corresponding author.

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Conflict of interest

None declared.

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