

# Experiences of Living with Intestinal Ostomy: A Qualitative Meta-Synthesis

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## Abstract

**Aims and Objectives:** The aim and objective of the study was to identify, compare, and synthesize published qualitative evidence to have in-depth understanding of experiences of patients living with intestinal ostomy. **Background:** Over the past two decades, there have been numerous qualitative studies published depicting intense experiences of stoma patients brought about by the need to adapt with changing conditions following stoma creation. Synthesizing the findings of these studies can improve the understanding among health-care providers of needed support and care for ostomates. **Design:** This was a qualitative meta-synthesis. **Methods:** Published articles were identified from the Medline, CINAHL, SciELO, PsycINFO, PubMed, WOS, Google Scholar and a hand search through selected journals published since 2000, and from references lists. Thirteen articles were selected using the predefined criteria. **Results:** A total of 222 patients, aged between 14 and 83 years from 13 studies, were identified for data collection. Ninety-seven were male and the rest of them were female. The themes identified were physical problems, psychological issues, social relations, environmental impact, and coping and adaptation to stoma. **Conclusions:** The findings of the study identified numerous challenges and limitations in the life of patients with stoma. However, improving their skills of using problem-solving coping strategies and their interactions with other ostomates can help them to live a better and well-adjusted life.

**Keywords:** Challenges with stoma, intestinal stoma, living experiences, quality of life

## INTRODUCTION

The word “stoma” has come from the Greek word which means the mouth or opening. One well-known form of an artificial stoma is an intestinal ostomy, which is a surgically created opening in the large intestine or ileum that allows the removal of feces out of the body to drain into a pouch or other collection device.<sup>[1]</sup> Intestinal ostomy is a procedure that is implemented to treat several conditions, including acute diverticulitis, rectal cancer, trauma, or inflammatory bowel disease.<sup>[1,2]</sup> This therapeutic approach can be temporary or permanent and creates many challenges in terms of quality of life and functioning. Although ostomy is a life-saving surgery, there is immense evidence of maladjustment in ostomates throughout the world.<sup>[3]</sup>

The presence of a stoma enforces numerous changes and limitations in the life of the patient. These changes start, the moment the disease or condition is discovered, triggering different patient coping behaviors. People with a new ostomy generally pay more attention to the negative aspects of the stoma and its effect on his/her body image. At first, many

patients would rather like to die than living with the stoma. Over the days, they start to realize that having an ostomy means gaining the opportunity for a new life. In this sense, it is noticed that, after an ostomy, individuals thus treated experience moments of emotional or psychological change that, by affecting the quality of life, self-esteem, body image, and even their sexuality, can generate anxiety and even depression.<sup>[4-6]</sup>

When subjected to this surgery, these people start living a different experience where their standard of living and rhythm of life begin to change. Their desires and values are often not fulfilled nor respected; they feel rejected, seeking seclusion because of the odor and elimination of feces through the abdomen.<sup>[7]</sup>

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**Submitted:** 30-Jan-20 **Accepted:** 26-Mar-20  
**Published:** 19-Nov-20

### Access this article online

#### Quick Response Code:



**Website:**  
www.jpalliativecare.com

**DOI:**  
10.4103/IJPC.IJPC\_21\_20

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**How to cite this article:** Choudhary M, Kaur H. Experiences of living with intestinal ostomy: A qualitative meta-synthesis. *Indian J Palliat Care* 2020;26:421-7.

In view to complexity of the theme and intense experiences of stoma patients brought about by the need to adapt with changing condition, the meta-synthesis was done to explore the available evidence to have in-depth understanding of phenomenon.

### Objective

The objective of the study was to identify, compare, and synthesize published qualitative evidence to have in-depth understanding of experiences of living with intestinal ostomy.

## METHODS

A qualitative systematic review and meta-synthesis design was employed in the study. The process of meta-synthesis consisted of three steps: (a) identifying the published papers for inclusion and determination of their relevance, (b) quality appraisal of published papers and data extraction, and (c) summarizing and synthesis of findings.

### Identifying the published papers for inclusion and determination of their relevance

Published articles were identified from the Medline, CINAHL, SciELO, PsychINFO, PubMed, WOS, Google scholar and a hand search through selected journals published since 2000, and from references lists. The keywords used for search were “Quality of Life,” Intestinal Stoma, “Living experiences,” and “challenges with stoma.” The suitability of the study for inclusion was determined by the following screening questions: (1) Do the report findings of paper involve qualitative methods for data collection and analysis? and (2) Is the focus of paper relevant to the synthesis topic?

### Inclusion criteria

- Qualitative studies with phenomenological, grounded, ethnographic, and descriptive research design
- Studies with adult patients having intestinal stoma as participants.

### Exclusion criteria

- Studies including patients with significant language impairment, cognitive impairment, other major comorbid medical difficulties, or with a past history of psychiatric problems
- The studies reporting focus from the perspectives of caregivers of ostomates
- Studies reporting use of mixed method approach, quantitative approach, or case studies.

### Quality appraisal and data extraction

Two main criteria were used in the evaluation and quality appraisal of qualitative research, i.e., credibility and relevance. Studies meeting inclusion and exclusion criteria were subjected to further scrutiny using the following series of seven questions.

### Credibility

- Were sampling strategies and data collection methods explained?

- Was method of data analysis discussed and enough data provided to allow the reader to determine support of the data to the interpretations (auditability)
- Did the authors acknowledge the influence of the research process and the presence of researcher including the role of prior biases, assumptions and experience, on the collected data (reflexivity)?
- Has appropriate attention given to negative cases and to contradictory data?
- Had the author explored alternative, plausible explanations for the data collected and incorporate a range of different perspectives (fair dealing).

### Relevance

- Was information regarding participants, settings, and context provided (transferability)?
- Did the author broadly discuss the findings and proposed generalization of findings and/or suggest the scope of future research (analytic generalization)?

### Summarizing and synthesis

Condensing labels were used to summarize and list down the perspectives of various studies. Themes identified by researchers were noted and cross-checked against their cited data. After summarization of data in each paper by labels, these were charted under unifying headings. Concepts were developed that synthesized the findings of all the papers included in the meta-synthesis.

## RESULTS

### Identifying the published papers for inclusion and determination of their relevance

The search identified 282 papers, of which 13 papers<sup>[8-20]</sup> had potential relevance to the review question [Figure 1].

### Quality appraisal and data extraction

All 13 included studies satisfied the criteria for quality appraisal and data extraction [Table 1].

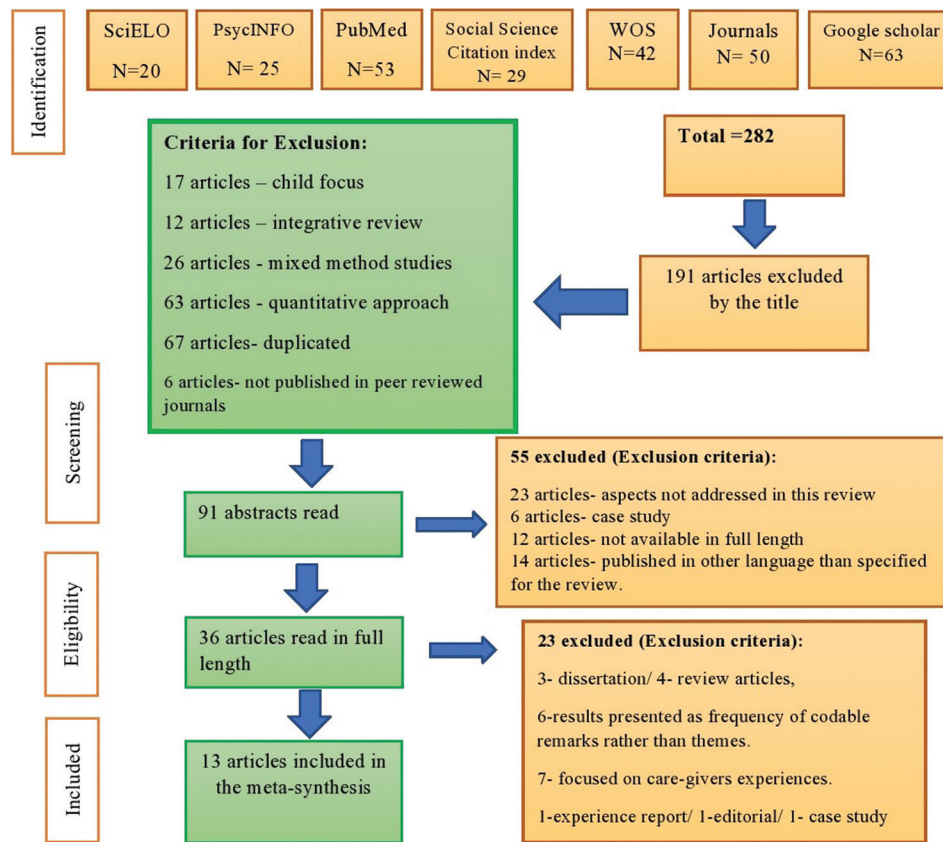
### Summarizing and synthesis

A total of 222 patients, aged between 14 and 83 years, from 13 studies were included in the study. Ninety-seven were male and the rest of them were female. Studies from 2000 to 2020 were included in the meta-synthesis.<sup>[8-20]</sup> There were 11 phenomenological studies and 2 exploratory ethnographic studies. The method of data collection in the included studies was self-report technique, interviews using semi-structured questionnaire, open-ended questions, focused group interviews, and in-depth interview technique. The themes identified were physical problems, psychological issues, social relations, environmental impact, and coping and adaptation [Table 2].

### Physical problems

#### Limitation in physical and recreational activities

Majority of the patients experienced lack of energy leading to a reduction in their usual activities. It affected their person's life style, ability of self-care, and care of family members. Patients also reported limitation in lifting heavy objects due to



**Figure 1:** Flow diagram of the selection process of articles of the meta-synthesis according to the preferred reporting items for systematic reviews and meta-analyses

weakness and site of stoma.<sup>[8,9,14,15]</sup> Stoma was also perceived as an obstacle in various recreational activities such as visiting to theater or cinema, opting for swimming, or just to have a day outing for shopping, as it is difficult to find public convenience for bag emptying.<sup>[9-12,16,18,20]</sup>

### Alteration in body image

Stoma, stoma appliance, and abdominal wounds changed perceived appearance of ostomates. Patients reported feeling of shame and horror while having first sight of stoma. They viewed their body image as deeply unattractive and avoided looking at stoma. Temporary or permanent changes in abdominal shape were also reported to be disheartening.<sup>[10,16,18,20]</sup>

### Issues in travelling

Difficulty in cleaning, emptying, or changing the stoma bag during long travels was the main issue hindering ostomates to plan for long journeys. Fear of passing of flatus in public transport further reported to restrict the travel.<sup>[8,10,14-16]</sup>

### Sleep disturbance

Patients explained an increased need for resting as they never feel free while sleeping and often have to be awake in the event of leaking of stoma bag. They had to avoid few sleeping positions as per the site of stoma further adding to sleep disturbances.<sup>[8,9,12,14,16]</sup>

### Nutritional issues

One major problem reported was a need to change diet to avoid obstruction and lack of proper information about needed dietary changes. Patients reported to have discomfort and problems such as belching, nausea, or gas formation after consuming some of the food items. The need to leave their favorite dishes to manage the stoma functioning was described as distressing.<sup>[9,14-16]</sup>

### Alteration in clothing style

Ostomates mentioned impaired self-identity, as they could not dress like before, nicely and fashionably. They were forced to avoid tight fitting clothes as it reveals their stoma bag. Few positions of stoma made it compulsory to wear loose and baggy clothes to cover stoma site so that no one can see it. Furthermore, ostomy placed at the site of waistband added to problem of scraping and irritation, necessitating change in clothing style.<sup>[10,13,14,16]</sup>

### Complications of stoma

Frequent irritation, itching, and rash around the ostomy site were common reported complication by the ostomates. Patients were severely discommoded by the problem of passing flatus and with the fear of passing it in the public.<sup>[10,14,16,17,20]</sup>

### Psychological issues

#### Impaired psychological well-being

Patients mentioned to suffer from some degree of cognitive and mental problems following stoma creation. Feeling of

**Table 1: Studies included in the meta-synthesis**

Author's name	Year of publication	Title of the study	Subjects	Themes
Alwi F <i>et al.</i>	2018	Quality of life of persons with permanent colostomy: a phenomenological study	12 patients with permanent colostomy having end stoma	Limitation in daily living activities, limitations in marital relations and social relationship with others, negative feelings about having the colostomy, financial difficulties, increasing demands of living with colostomy, changes in the needs of rest, physical and expectation of complications, and hoping to live a normal life after colostomy
Ceylan H, Vural F	2017	Living with stoma - A phenomenological study	19 patients having a stoma for at least 3 months	First encounter, challenges, and coping
Thorpe G <i>et al.</i>	2016	Adjusting to bodily change following stoma formation: A phenomenological study	12 participants who had undergone stoma creation surgery	Changes in bodily appearance, disruption in bodily function, altered bodily sensation
Shaffy <i>et al.</i>	2014	Psychosocial experiences of the patients with colostomy/ileostomy: A qualitative study	40 patients with colostomy/ileostomy with minimum time period of 6 weeks after surgery	Embarrassment with the ostomy appliance, feeling of disgust and alienation towards the body and feelings of uncleanliness with the ostomy appliance
Danielsen A K <i>et al.</i>	2013	Learning to Live with a Permanent Intestinal Ostomy: Impact on Everyday Life and Educational Needs	15 patients with permanent colostomy or ileostomy	Being different, training in living a life with a stoma
Danielsen AK <i>et al.</i>	2012	Impact of a temporary stoma on patients' everyday lives	7 patients with temporary stoma	Life before and after creation of the "stoma," "uncertainty" and "mastery and personality," putting life on hold
Shaffy <i>et al.</i>	2012	Physical, nutritional and sexual problems experienced by the patients with colostomy/ileostomy: A qualitative study	40 patients with colostomy/ileostomy with minimum time period of 6 weeks after surgery	Physical problems, psychological problems, sexual problems
Dabirian A <i>et al.</i>	2010	Quality of life in ostomy patients: A qualitative study	14 patients having had an ostomy in place for at least 6 months	Physical problems related to colostomy, impact of colostomy on psychological functioning, social and family relationships, travel, nutrition, physical activity, and sexual function, as well as religious and economic issues
Honkala S <i>et al.</i>	2009	Living with an ostomy: Women's long term experiences	Seventeen women with stoma	Bodily restraints, I as a woman, reconciliation to a changed life, adaptation to daily life
Barnabe NC <i>et al.</i>	2008	Coping strategies of ostomized individuals	11 ostomized subjects	I did not choose it; I had to accept it and I have to live with the ostomy
Nicholas DB <i>et al.</i>	2008	Struggles, strengths, and strategies: an ethnographic study exploring the experiences of adolescents living with an ostomy	20 adolescents with an ostomy	Body intrusion and body image challenges, decreased independence and control, secrecy: Considerations in deciding whether to tell others about the ostomy, adjustment over time, challenges for the family, Sources of strength: Family and friends, benefits and growth
Annell M	2006	The experience of flatus incontinence from a bowel ostomy: A hermeneutic phenomenology	Six people with a bowel ostomy from a city in Australia	I am undignified, I am a secret, I am always with gas, I am not myself alone, I am without choice, I am a seeker of control, I am the smell, I am not normal, and I am living a life-sort of
Persson E., Hellstrom AL	2002	Experiences of Swedish Men and Women 6-12 Weeks after Ostomy Surgery	Nine patients with stoma for at least 6 months	Alienation from the body, altered body image, influences on sexual life, uncertainty, influences on social life, influences on sports and leisure activities, and physical problems

uncertainty of future further added to mental distress. Patients reported negative feelings about themselves and stoma creation such as guilt, feeling afraid, feeling alone, shame, getting upset easily, and remarked feeling of inferiority.<sup>[8,10,12,19]</sup> They often felt lack of confidence; few revealed events of mental break down and receiving psychiatric therapy for major depression.<sup>[10-13,15,19]</sup>

### Comparison with normal people

The limitations imposed by the stoma enhanced comparison with normal persons in surroundings such as family members and friends adding to feeling of jealousy, feeling of

incompleteness, and inferiority, leading to mental distress and social isolation. Dependency on others for self-care further contributed to this comparison.<sup>[11,14,16]</sup>

### Social relations

#### Marital and sexual relationship

Majority of the patients described limited or no sexual intercourse following stoma creation, which added to the fear getting separated or divorced. Although many felt their partner to be supportive and helpful, but still they perceived changes in relationship with their partners.<sup>[8,9,15,20]</sup> Problems with erection in males and fear of looking unattractive with stoma among

**Table 2: Summary of themes and subthemes identified from the studies**

Major themes	Studies	Subthemes
Physical Problems	Alwi F <i>et al.</i> (2018), Ceylan H, Vural F (2017), Thorpe G <i>et al.</i> (2016), Shaffy <i>et al.</i> (2014), Danielsen A K <i>et al.</i> (2013), Danielsen A K <i>et al.</i> (2013), Dabirian A <i>et al.</i> (2010), Honkala S <i>et al.</i> (2009), Nicholas DB <i>et al.</i> (2008), Annells M (2006), Persson E., Hellstrom AL (2002)	Limitation in physical and recreational activities Alteration in body image Issues in travelling Sleep disturbance Nutritional issues Alteration in clothing style Complications of stoma
Psychological Issues	Alwi F <i>et al.</i> (2018), Thorpe G <i>et al.</i> (2016), Danielsen A K <i>et al.</i> (2013), Shaffy <i>et al.</i> (2014), Dabirian A <i>et al.</i> (2010), Honkala S <i>et al.</i> (2009), Annells M (2006)	Impaired psychological wellbeing Comparison with normal people
Social Relations	Alwi F <i>et al.</i> (2018), Ceylan H, Vural F (2017), Thorpe G <i>et al.</i> (2016), Shaffy <i>et al.</i> (2014), Danielsen AK <i>et al.</i> (2013), Dabirian A <i>et al.</i> (2010), Annells M (2006), Nicholas DB <i>et al.</i> (2008), Persson E., Hellstrom AL (2002)	Marital and sexual relationship Relationship with family friends and others
Environmental Impact	Alwi F <i>et al.</i> (2018), Ceylan H, Vural F (2017), Thorpe G <i>et al.</i> (2016), Shaffy <i>et al.</i> (2014), Danielsen AK <i>et al.</i> (2013), Dabirian A <i>et al.</i> (2010), Honkala S <i>et al.</i> (2009)	Financial burden Lack of tailored counselling services
Coping and adaptation	Alwi F <i>et al.</i> (2018), Ceylan H, Vural F (2017) Danielsen A K <i>et al.</i> (2013), Dabirian A <i>et al.</i> (2010), Honkala S <i>et al.</i> (2009), Barnabe NC <i>et al.</i> (2008), Nicholas DB <i>et al.</i> (2008), Annells M (2006)	Use of problem-solving coping strategies Learning in group

females were common factors contributing to the avoidance of sexual activities.<sup>[8,9,14,15,20]</sup>

### Relationship with family, friends, and others

Some of the patients mentioned that their family and friends accepted the stoma and tried to cooperate; however, others felt that they tried to maintain distance and avoid the ostomates. Patients felt more comfortable and less depressed when they received support of family and friends. Ostomates reported preference to avoid family or social gatherings because of fear of offensive gas emission.<sup>[8-10,15,16,19]</sup> Further dilemma of disclosing about stoma and self-imposed limits about disclosures to the gathering restricted their participation. Feeling of getting nervous and upset easily, feeling of inferiority, and shame made public interaction very difficult for the patients, further adding to social isolation.<sup>[9-11,13,18,20]</sup>

### Environmental impact

#### Financial burden

Patients reported that they had to either change or leave their job following stoma creation, which affected their income. Various complications of stoma hindered working hours and increased need of sick leaves, further decreasing income. Moreover, disease-related costs, for example, buying bags, gloves, and stoma care kits, enhanced financial burden.<sup>[8-10,14-16]</sup>

#### Lack of tailored counseling services

Patients experienced that follow-up counseling services were not tailored to their specific needs related to stoma care and complication management. Lack of regular meetings and failure of coordinator to address personal questions were major concerns of patients.<sup>[12,16,18]</sup>

### Coping and adaptation

#### Use of problem-solving coping strategies

Patients reported to focus on problem-solving strategies to deal with various limitations, to establish relationship with family members and significant others, and to have continuity

of daily activity performance. The personal competence of being positive and experimenting with different ways to resolve limitations had a great influence on adaptation process.<sup>[8,9,13,15-17]</sup>

### Learning in group

Learning in group with and from another person with stoma was mentioned as extreme helpful to enable individual to manage stoma. Patients reported to have improved mood and ability to relax when they got opportunity to interact with other ostomates. Experimenting and planning activities together was mentioned to solve many problems of every day's life with stoma.<sup>[12,16,18,20]</sup>

## DISCUSSION

The main focus of the meta-synthesis was to assess experiences of living with intestinal ostomy which were categorized in various themes as physical problems, psychological issues, social relations, environmental impact, and coping and adaptation. The findings of the meta-synthesis exhibited the complexity and diversity of experiences of individuals living with intestinal stoma. When it is concerned with physical problems, patients reported limitation in numerous aspects such as limitation in physical and recreational activities, inability to opt for long journeys, sleep disturbance causing increased felt need for rest, inability to consume various food items, imposed need to change the clothing style, and necessity to deal with frequent complication of stoma (Alwi F *et al.* [2018], Ceylan H, Vural F [2017], Thorpe G *et al.* [2016], Shaffy *et al.* [2014], Danielsen A K *et al.* [2013], Danielsen A K *et al.* [2012], Dabirian A *et al.* [2010], Honkala S *et al.* [2009], Nicholas DB *et al.* [2008], Annells M [2006], Persson E., Hellstrom AL [2002]). The fear of leakage, gas, and obstruction along with a lack of energy imposed various limitation in the life of ostomates.

Stoma was found to have devastating psychological impact on ostomates. Negative feelings about stoma creation and

themselves such as guilt, feeling afraid, feeling alone, shame, getting upset easily, and remarked feeling of inferiority impaired psychological well-being of patients (Alwi F *et al.* (2018), Thorpe G *et al.* (2016), Danielsen A K *et al.* (2013), Shaffy *et al.* (2012), Dabirian A *et al.* (2010), Honkala S *et al.* (2009), Annells M (2006).

Limitations caused by stoma imposed social isolation among ostomates. However, the support of family and friends was positively appreciated by patients. Concern about sexual life and relationship stability was more evident and emphasizes counseling needs in this area. (Dabirian A *et al.* (2010), Shaffy *et al.* (2012). Financial burden was other added concern because of inability to carry out routine job, need to either leave or change the job, and increased need of sick leaves. Bearing expenses of routine stoma care further adds to this stress. (Alwi F *et al.* (2018), Dabirian A *et al.* (2010), Honkala S *et al.* (2009).

However, most of the patients reported use of problem-solving coping strategies to deal with these limitations, adding to their personal competence of being positive and proactive, strongly influencing their rehabilitation process. (Barnabe NC *et al.* (2008), Nicholas DB *et al.* (2008), Annells M (2006). Various interventional studies enlightened innovative methods of such preoperative intensive education combined with traditional postoperative education (Chaudhri *et al.* 2005, Bryan and Dukes 2010),<sup>[21,22]</sup> use of multimedia in patients' teachings (Lo *et al.* 2011),<sup>[23]</sup> follow-up using telemedicine or telenursing services (Bohnenkamp *et al.* 2004)<sup>[24]</sup> to improve self-care capacities of ostomates. Individual-based follow-up counseling session can further enhance the patient's ability to combat imposed challenges by stoma.<sup>[25]</sup>

### Limitation and recommendations

The meta-synthesis focused on the qualitative evidence only. Although qualitative evidence provides better understanding and insight into experiences of patients with stoma, the addition of quantitative evidence can enhance the degree of certainty with the help of quantitative analysis. This study recommends and emphasizes the need for meta-analysis of quantitative evidence to have in-depth knowledge of consequences of having a stoma. Furthermore, the studies included in the meta-synthesis focused on the limitation related to stoma but lacked exploration on techniques to manage those limitations to improve health-related quality of life or to reduce cost. The study recommends an additional research to assess the effect of group learning on coping and adaptation to stoma among ostomates and to explore further techniques to ease the life of ostomates.

### CONCLUSIONS

The findings of the study identified a numerous challenges and limitations in life patients with stoma. However, improving their skills of using problem-solving coping strategies and their interactions with other ostomates can help them to live a better and well-adjusted life.

### Financial support and sponsorship

Nil.

### Conflict of interest

There are no conflict of interest.

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