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Effect of Maternal Empowerment Program on Neonatal Colostomy Complications and Maternal Distress Tolerance

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Abstract

Background: Different complications of colostomy in neonates can lead to readmission, surgery, and even death. Therefore, prevention of colostomy complications highlights the empowerments of mother to care for the neonate and reduce maternal distress.

Aim: The present study aimed to determine the effect of maternal empowerment programs on neonatal colostomy complications and maternal distress tolerance.

Method: This randomized clinical trial was conducted on 60 mothers of newborns aged 1-90 days with colostomy referred to two specialized pediatric centers in northeastern Iran in 2019. The control group received a training session. The intervention group, in addition to one training session, participated in two sessions of maternal empowerment program regarding the care of neonates with a colostomy. The collected data were analyzed in SPSS software (version 21) using ANOVA, Friedman, and Mann-Whitney U tests.

Results: The two groups were homogeneous considering demographic variables ($P<0.05$). According to the results of the Mann-Whitney U test, the skin complication in the neonates was less in the intervention group than in the control group at all three stages of assessment ($P<0.001$). Moreover, the repeated measures ANOVA results demonstrated that the effect of group ($P=0.006$), effect of time ($P<0.001$), and interaction of group and time ($P<0.001$) were significant on the total score of distress tolerance.

Implications for Practice: Considering the positive effect of the maternal empowerment program on reducing maternal distress and skin complications of colostomy among neonates, it is recommended to use this program in surgical wards and neonatal intensive care unit.

Keywords: Colostomy, Distress, Empowerment, Mother, Neonate

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Introduction

Anorectal and colon abnormalities are the most common congenital malformations (1, 2). Reportedly, a range of 100-200 neonates undergo colostomy in Europe annually (2). The incidence of colostomy complications in children varies between 25.2 and 54.3% (3). Although colostomy plays a crucial role in the treatment of congenital anomalies of the colon and anus, it may cause some complications (1, 4). Colostomy complications include rupture, dermatitis, intestinal obstruction, adhesions, volvulus and internal hernia, infection, prolapse, retraction, stenosis, fistula, peptic ulcers, bleeding, and fluid and electrolyte disorders. In some cases, reoperation is even needed to repair the colostomy (1, 5).

Colostomy in newborns is usually formed in emergency situations and even in the early hours after birth. Parents may be shocked by the birth of such children, which may be associated with negative psychological consequences, such as depression, anxiety, aggression, fear, and guilt (4, 5) to the point that caring for such newborns causes stress throughout the family (6). The lives of parents, especially of mothers, are affected by the fear of fecal incontinence in the future and the need for long-term follow-ups (7). According to Hogan (2012), mothers experience high levels of stress and depression (8), which in turn can cause maternal distress and disruption in newborn care.

Mothers need to be informed about taking special care of colostomy in neonates and reducing short-term and long-term complications (9). They are also required to be aware of the emerging conditions for their child to be able to take care of him/her at home, without being dependent on a nurse. Therefore, they prevent repeated medical visits due to complications and readmission of neonates (6, 11).

Hosseinpour et al. reported that the training of the care principles that parents, especially mothers, receive at the hospital, along with taking care of neonates, gives them the ability to care for their newborn child at home with a greater sense of empowerment after discharge (11). Nurses can effectively help mothers by providing the necessary information and explaining the conditions for the mother's participation in taking care of the neonate and dealing with the new situation (11, 12). Nurses can greatly alleviate maternal distress, which is a source of stress, anxiety, and depression, by informing mothers about the future condition of the disease as well as emphasizing the parental role (13). The family-centered care in the neonatal intensive care unit (NICU), which is now prevalent (14), have policies that include respect, information exchange, and partnerships with families. The nurse should have more of an educational role than a teacher since the maternal empowerment program aims to make mothers independent in caring for the child (15), be the best supporter of themselves, and be more efficient and worthy (12, 14).

The effectiveness of educating parents and caregivers of children with colostomy has not been fully evaluated in most developing countries. Moreover, the parental empowerment to care for colostomy is poor in developing countries and some parents find it impractical and difficult (16). Previous Iranian studies have merely focused on the level of parents' knowledge of pediatric colostomy (17). In addition, ostomy care programs in the self-care clinics of the studied hospitals are dedicated to the period after the onset of side effects. Therefore, they are unable to cover all children with colostomy and only a limited number of people can benefit from these facilities. Regarding this, the current study was conducted to determine the effect of maternal empowerment programs on neonatal colostomy complications and maternal distress tolerance.

Methods

This randomized clinical trial with two parallel groups was carried out on the research units referred to surgical and NICU wards of two specialized pediatric centers in northeastern Iran in 2019. According to the quantitative dependent variables in this study, the sample size was estimated using the formula "estimation of sample size based on comparing the mean and standard deviation of the dependent variable in the two communities."

The findings of the pilot study on 20 samples were used for colostomy complications (S1=1.2, S2=1.5, M1=0.9, M2=2.2) based on which the sample size was estimated to be 17 people in each group. The findings of a study performed by Reyhani et al. (18) were used regarding the distress tolerance variable (S1=7.0, S2=6.7, M1=33.7, M2=41.9) based on which the sample size was estimated to be 11 people. The minimum sample size was calculated taking into account the 95% confidence interval and 80% test power. Finally, data analysis was performed on 60 cases (n=30 in each group) to increase the generalizability of the results.

The inclusion criteria for neonates were being a candidate for colostomy, having chronological age of 1-90 days, having stable clinical status (including heart rate and respiration rate in the normal range), and lacking other abnormalities affecting colostomy complications (including metabolic diseases, immune system deficiency, and chemotherapy). The inclusion criteria for the mothers included the willingness to participate in the study, no history of mental disorders (based on self-expression and/or confession of spouse or caregiver), no history of physical disability or debilitating illness affecting newborn care based on self-declaration, no history of addiction based on self-declaration, minimal literacy, and having a smartphone. On the other hand, the exclusion criteria for mothers and infants were maternal physical and mental disorders affecting the care of the neonate during the study according to the physician, mother's unwillingness to continue cooperation, not attending one of the program sessions, neonate death, diagnosis of a neonate with one of the metabolic diseases, immune system deficiency, and chemotherapy during the study affecting the incidence of colostomy complications.

The following tools were used to collect the data and perform the study: Research Unit Selection Form, Demographic Information Form, Informed Consent Form, Ostomy Skin Tool (OST), Distress Tolerance Scale (DTS), and a form to record other complications leading to newborn readmission. The OST is a standard tool developed in 2008 to assess the peristomal skin. The total score of this scale is obtained between 0 and 15. Its validity has been confirmed in several studies, including the studies carried out by Martins et al. in 2010 (19) and Ghasemi Rad et al. in 2017 (20). The reliability of this tool was evaluated by Ghasemi Rad et al. in 2017, in which the peristomal skin of 10 children was scored at the same time by two nursing experts. The reliability of this instrument was estimated at 0.90 using the kappa correlation coefficient (20).

The Distress Tolerance Scale is a distress tolerance self-assessment index consisting of 15 items and four subscales including tolerance (emotional distress tolerance), absorption (absorbed by negative emotions), evaluation (subjective estimation of disturbance), and adjustment (effort to relieve disturbance). The items of this questionnaire are scored on a five-point Likert scale (strongly agree=1 to strongly disagree=5). One of the items (item 6) is reverse-scored. A score of 45 is considered the cut-off point of the questionnaire so that the scores greater than 45 indicate a high-stress tolerance level in the individual. Simons and Gaher (2005) reported that this questionnaire has an acceptable criterion and convergent validity (21). They also evaluated the reliability of the whole scale by the Cronbach alpha coefficient method (α=0.82). Alavi et al. (2011) calculated the internal consistency of the instrument as 0.71 (22).

The form which was used to record other complications leading to newborn readmission examined the following complications: dehydration, prolapse, hernia, retraction, scarring and stenosis, fistula, obstruction, ischemia, ulcer, and stoma bleeding. The answers to this form were measured at a Yes/No scale.

After obtaining approval from the Ethics Committee of the Mashhad University of Medical Sciences, Mashhad, Iran, and obtaining a written recommendation letter from this university to enter the research environment, the researcher referred to the selected hospitals. Upon being informed of the neonate's hospitalization, the researcher, who was present at the patient's bedside at the earliest opportunity, completed the research unit selection form to review the inclusion criteria and coordinated with the parents, especially the neonate's mother, to attend. The parents were free to complete and sign the informed consent form. Eventually, 60 mothers of eligible 1-90-day-old newborns with colostomy were selected using convenience sampling method and randomly assigned to intervention and control groups. In the allocation of participants to the intervention and control groups, the block randomization method with four blocks (AAAA and BBBB) was applied to prevent the dissemination of information and create a balance in the number of samples assigned to each group. The first and second blocks were randomly categorized as the control and intervention groups, respectively. Subsequent groups were sampled in every other block; therefore, the conditions were almost homogeneous for the groups during the sampling time. To prevent the dissemination of information, sampling was started in the next block after the discharge of the last research unit of the previous block.

Initially, the demographic data questionnaire was completed after the neonate's admission. Due to the necessity of informing the neonatal colostomy complications by the mother to the medical center, a training session was held by the researcher before colostomy implantation for mothers of both groups

in the hospital ward (Table 1). In addition, the importance of informing the researcher about the complications was emphasized. Afterward, the control group received routine ward care. The researcher's knowledge and skills for teaching ostomy care were confirmed by a pediatric surgeon. The intervention in the experimental group included the implementation of a maternal empowerment program by the researcher. The axes of the maternal empowerment program included self-regulation (providing real and tangible information about the stressful event, reducing the distance between expected and happened events, and increasing the ability to understand and interpret what happened) and control (comparing the current situation and the ideal situation, motivating the parent, and moving towards the ideal goal) (9). This program was held individually and face to face for the mothers of the intervention group on the first and second days after the colostomy (Table 1). Moreover, the educational booklet compiled by the research team was given to the mothers in the intervention group. Subsequently, the parents of the two intervention and control groups were joined by the researcher in two separate virtual networks. The mothers of the intervention group, in case of having any questions or problems, communicated with the researcher in the virtual network. Additionally, they received

Table 1. Content of sessions held for mothers to care for neonates with a colostomy

Sessions	Duration	Educational content	Methods	Expected outcomes
Training session (Before colostomy implantation)	Overview of background information (10 minutes)	Digestive system colostomy caring for a neonate with a colostomy, possible complications of colostomy, and colostomy care problems	Verbal and face-to-face for both groups	Identifying maternal educational needs
	Introducing gastrointestinal tract, colostomy, complications, and importance of reporting to the physician (35minutes)	Gastrointestinal tract (5 minutes), necessity of colostomy for infants (5 minutes), possible complications of colostomy and the need for medical visits (10 minutes), images of colostomy complications (5 minutes), answering mother's questions and educational evaluation (10 minutes), and determining the time of subsequent visits for the assessment of colostomy	Verbal and face-to-face for both groups	Obtaining the necessary information about colostomy and the resulting complications
The first empowerment session (First day after colostomy implantation)	Assessing mother's knowledge and ability in practical care of the neonate (15 minutes)	Communicating with mother, examining the mother's feelings towards the neonate with a colostomy, explaining how to change and use diapers for the baby, applying the colostomy bag, taking care of the peristomal skin, and controlling the infection	Practical and theoretical questions and answers for the intervention group	Determining the mother's knowledge and practical skills in caring for a neonate with a colostomy
	Empowering mother in child care according to the mother's needs (30 minutes)	Training on how to wash hands and wrapping diapers (5 minutes), caring for peristomal skin and preventing bleeding (5 minutes), teaching neonate feeding method, neonate dehydration symptoms, stool consistency, and infection symptoms (5 minutes), replacing the colostomy bag/diaper/clothing on the model and monitoring the neonate's growth (10 minutes), and answering the mother's questions (5 minutes)	Practical and theoretical delivery of an educational booklet for the intervention group	The mother's gaining the ability to provide proper care for the infant with a colostomy

Table 2 Continued.

The second empowerment session (Second day after colostomy implantation)	Empowering mother in recognizing and controlling colostomy complications (45 minutes)	Evaluating the mother's caring performance and communicating with the baby (10 minutes), resolving existing problems with a practical display (5 minutes), examining the mother's information about colostomy complications by showing pictures and description to the mother, explaining how and when to visit a doctor, and completing the mother's information form (10 minutes), expressing the need to visit the self-care clinic at the appointed times (5 minutes), and answering mother's questions (15 minutes)	Practical and theoretical methods for the intervention group	Identifying the mother's weaknesses and retraining

guidance on the need for follow-up or special action so that they could manage the problem well in case of any problems. The researcher was available to the mothers of the intervention group at least four times a day on a virtual network and answered the questions. If necessary, the researcher made a phone call to a specialist physician to respond more quickly to the problem raised by the mother. The mothers in the control group, in case of complications in colostomy, took a photo of the site of the complication and sent it to the researcher for receiving guidance on whether or not the neonate needed to be hospitalized.

The complications of colostomy during the newborn's referral to the center were evaluated three times (i.e., 1, 2, and 3 months after the intervention) by the lead researcher using two instruments, including OST and stomal complication assessment instrument, leading to the hospitalization. Maternal distress tolerance was assessed by completing the DTS instrument four times (before the intervention, and immediately after, 1, and 2 months after the intervention) during the mother's face-to-face visit in two groups.

This research received the code of ethics of IR.MUMS.NURSE.REC.1398.003 from Mashhad University of Medical Sciences. All ethical considerations on human samples were considered and the information of all participants was analyzed anonymously. The collected and coded data were analyzed in SPSS software (version 21) using descriptive statistics, included mean, standard deviation, and frequency distribution. In analytical statistics, first, the normal distribution of quantitative variables was determined by Kolmogorov-Smirnov and Shapiro–Wilk tests. Chi-square test, Fisher's exact test, independent t-test, and Mann-Whitney U tests were also performed to evaluate the homogeneity of the two groups. Repeated measures analysis of variance (ANOVA) and Friedman tests were applied to analyze dependent variables. Two-way ANOVA was used to determine the extent of the effect of contextual and intervention variables on the dependent variables. In this study, a significance level of 5% was considered in all tests.

Results

Demographic and contextual variables of research units in the two groups of intervention and control were compared with each other. According to the results, 66.7% and 73.3% cases respectively in the intervention and control groups were hospitalized in Akbar Hospital, Mashhad, Iran. In addition, 90% and 100% of the neonates in the intervention and control groups had insurance, respectively. Moreover, 51.9% of newborns in the intervention group and 56.7% of neonates in the control group had rural insurance (P=0.23). However, 100% of newborns in the intervention group and 93.3% of newborns in the control group had no supplemental insurance (P=0.492). The results of statistical tests on other demographic variables indicated that the two groups were homogeneous regarding demographic and contextual variables (Table 2).

It was observed that one month after the intervention, 81.7% and 54% of neonates in the control and intervention groups had skin complications, respectively. Furthermore, 2 months after the intervention, 66.6% and 29.7% of cases and 3 months after the intervention, 49.8% and 19.8% of these subjects respectively in the control and intervention groups developed skin complications. Based

Table 2. Demographic information of mothers and neonates in intervention and control groups

Variables	Groups		Test results (P-value)
	Intervention (n=30)	Control (n=30)	
	Frequency (percentage)	Frequency (percentage)	
Maternal educational level			
<High school	19 (63.3)	20 (66.7)	0.88*
High school	8 (26.7)	6 (20.0)	
Academic	3 (10.0)	4 (13.3)	
Maternal occupation status			
Housekeeper	30(100.0)	28 (93.3)	0.49**
Employee	0 (0.0)	2 (6.7)	
Neonate gender			
Girl	14(36.7)	16 (63.3)	0.66***
Boy	16 (63.3)	14 (36.7)	
Type of infant feeding			
Breastfeeding	28 (93.3)	30 (100.0)	0.49**
Mixed	2 (6.7)	0 (0.0)	
Cause of ostomy			
Imperforate anus	23 (76.7)	20 (63.3)	
Hirschsprung's disease	6 (23.3)	7 (16.7)	0.13***
Intestinal atresia	1 (0.0)	2 (6.7)	
Intestinal obstruction	0 (0.0)	1 (6.7)	
Concurrent anomaly			
Yes	3 (10.0)	3 (10.0)	>0.99**
No	27 (90.0)	27 (90.0)	
Type of anomaly			
Down's syndrome	2 (66.7)	1 (33.3)	1.000**
Esophageal atresia	1 (33.3)	2 (66.7)	
Neonate age (day)	9.2±3.5	8.5±2.4	0.11*
Neonate birth weight (g)	3072.5±429.2	3035.3±716.8	0.54*
Maternal age (year)	28.0±5.2	28.7±5.3	0.67*

*Mann–Whitney U test
**Fisher's exact test
***Chi-square

on the findings, the mean score of skin complication in the studied newborn was lower in the intervention group than in the control group in all three stages. Considering the intragroup comparison, the Friedman test results showed that the difference between the stages in terms of skin complication score was significant in both intervention (P<0.01) and control (P<0.01) groups (Table 3).

Regarding the complications of ostomy during the study period, the findings reported one case of prolapse and one case of colostomy site infection in the control group, as well as one case of fungal infection in the intervention group, which all underwent outpatient treatment as recommended by the physician. At the baseline, the mean of the total DTS score was obtained as 30.6±5.7 and 31.6±5.7 for the mothers in the intervention and control groups, respectively. The results of the repeated measures ANOVA in the pre-intervention stage, and immediately after, 1 month, and 2 months after the intervention stages showed that independent effect of group (P=0.006), the independent effect of time (P<0.001) and group-time interaction (P<0.001) were significant on the total DTS score (Table 4).

Table 3. Mean score of neonates' skin complication in different stages of the study in intervention and control groups

Skin complication score	Groups		Intergroup test results of Mann – Whitney U test
	Intervention (n=30)	Control (n=30)	
	Mean	Mean	
1 month after intervention	2.0±1.9	3.5±2.0	0.005
2 months after intervention	1.4±0.8	2.4±1.8	0.001
3 months after intervention	1.3±0.6	2.1±1.5	0.001
Nonparametric Friedman test result	P<0.01	P<0.01	

Table 4. Total score mean of maternal distress tolerance in different stages of the study in intervention and control groups

Total score of maternal distress tolerance	Group	
	Intervention (n=30)	Control (n=30)
	Mean	Mean
Before intervention	30.6±5.7	31.6±5.7
Immediately after intervention	42.1±4.2	33.7±5.2
1 month after intervention	46.2±2.1	36.2±5.3
2 months after intervention	53.2±3.2	39.2±5.9
Results of repeated measures analysis of variance test	Group	0.006*
	Time	<0.001*
	Group×Time	<0.001*

*P-value

The two-way ANOVA test was performed to evaluate the effect of contextual and confounding variables on the total DTS score (immediately after the intervention stage) in both groups. Accordingly, it was revealed that the independent effect of insurance (P=0.049), the independent effect of insurance type (P=0.019), the independent effect of neonate age (P=0.014), the independent effect of birth weight (P=0.043), the interaction of child rank (P=0.026), and the independent effect of ostomy reason (P<0.001) on the total DTS score were significant. The independent or interaction effects of other contextual and confounding variables on the total DTS score were not significant (P>0.05).

Discussion

This study aimed to evaluate the effect of maternal empowerment programs on neonatal colostomy complications and maternal distress tolerance. The results of the present study showed that the skin complication of the newborns in the intervention group was significantly less than that in the control group. Moreover, the intragroup comparison in the intervention and control groups demonstrated that the skin complications reduced in both groups after 1, 2, and 3 months; however, this decrease was greater in the intervention group than in the control group.

Sheikh et al. conducted a study in 2006 on 121 children with colostomy in Surgical Unit B, National Institute of Child Health, Karachi, Pakistan. The results of the mentioned research showed that 67.7% of children and newborns with colostomy suffered from its complications with skin complications as the most common type (55%) (5). These results were in line with the findings of the present study. According to the current study, 82% and 54% of neonates in the control and intervention groups, respectively, developed ostomy-related skin complications 1 month after a colostomy. The observance of fewer skin complications in the intervention group 1, 2, and 3 months after the intervention highlighted the importance of educating nurses about ostomy in pediatric hospitals. The reason for such significance lies in the fact that since nurses are actively present at the clinic of neonates with a colostomy, they can educate mothers with neonatal colostomy and follow them through a virtual group. In the present study, unlike the study of Sheikh et al., no other colostomy complications were observed other than skin complications. This discrepancy might be due to the difference in the study population in these two pieces of research. Accordingly, the study population in the study performed by Sheikh et al. included 110 neonates < 1 month, 1 month < 6 patients > 1 year, and 5 patients > 1 year, among which 4 cases underwent colostomy due to trauma and all had complications. Moreover, three patients underwent colostomy due to hemorrhagic cholecystitis and all had complications. Nonetheless, in the present study, the newborns were within 1-90 days old and were followed up for 3 months individually. In addition, rapid action treatments were performed in most neonates, including anorectoplasty and ostomy closure in a short time (3 months after colostomy). There was also inadequate time for colostomy complications leading to readmission (such as prolapse and stenosis) (5).

In the empowerment program of the present study, the information required by the parents was taught to the intervention group by the researcher face-to-face and practically, and the educational booklet was provided to the parents. The intervention group could communicate with the researcher during the

study by accessing the researcher's phone and membership in a separate social group and receive the necessary instructions. The main care strategies are establishing effective communication between the nurse and the client, being available, and responding to care needs (23). However, the relationship between the mother and the doctor or nurses is impossible in the routine situation due to the high workload in the NICU and pediatric surgery wards. Aite et al. (2006) conducted a study on the parents' informational needs at the birth of a baby with a surgically correctable anomaly (24). In the mentioned research, 100% of parents stated that they needed to receive sufficient information from the treatment and care staff about the anomaly and the survival rate of their child after surgery, the stage of recovery from the disease, and their child's quality of life after discharge.

According to the results of the current study, the mean DTS scores in different stages of post-intervention measurements were significantly higher in the intervention group than in the control group. In addition, the repeated measures ANOVA results showed that the time effect, group effect, and time-group interaction on maternal distress tolerance was significant. Regarding this, it can be concluded that time was able to increase maternal distress tolerance, which was higher in the intervention group than in the control group. The results of the present study indicated that the empowerment program and the mother's relationship with the stoma care nurse during the treatment implementation could increase the distress tolerance by increasing the information and abilities of parents. The empowerment intervention had a significant effect on all dimensions of maternal distress tolerance.

It was also revealed that in the control group, the DTS scores increased slightly over time, which was lower than that in the intervention group. Regarding this, it can be concluded that the time factor has affected maternal distress tolerance. The difference in the mean score of effort to relieve disturbance was significant between the intervention and control groups. Moreover, a decrease was observed in the score of this dimension in the control group, although other dimensions' scores stayed unchanged. This can be related to the fact that their efforts to relieve disturbance have not been effective due to the lack of expert advice from the stoma care nurse (i.e., researcher).

The results of the present research were in line with those of a study performed by Goudarzi et al. (2016), who examined the effect of empowerment programs on stress, anxiety, and depression among the mothers of neonates undergoing colostomy. They conducted an empowerment program for the mothers in the intervention group within three sessions; however, the mothers in the control group received only routine care of the ward. After the intervention, the results showed that the reduction of maternal stress levels was significantly greater in the intervention group than in the control group (2). The results of the present study were also in line with the results of research carried out by Reyhani et al. (2014) entitled "Investigating the effects of spiritual self-care training on psychological stress of mothers with preterm infants admitted in neonatal intensive care unit" (18). In the aforementioned study, the intervention group underwent awareness-raising training on neonatal conditions for 14 days and self-care training in 6 sessions for 45 min every other day. In the post-intervention stage, the results showed that the mean DTS score in the control group was lower than that in the intervention group.

One of the limitations of the present study was the mental and psychological states of mothers at the time of completing the questionnaires, which could affect the results of maternal distress tolerance.

Implications for Practice

It is recommended to adopt measures to reduce complications of colostomy, prevent the need for medical visits and readmission, and increase maternal distress tolerance. To fulfill such purposes, it is suggested to hold empowerment sessions in simple and understandable language for mothers and have non-face-to-face communication with the stoma care nurse who has enough information about infant care and can communicate with the patient's physician in emergencies. The results of this study can also provide a significant point for the managers of self-care clinics. Due to the existence of communication tools in most families, it is possible to form a virtual social group and parental membership. Therefore, virtual education can be considered a way to prevent patients from visiting clinics in person and spending time and money on referrals.

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Conflicts of Interest

The authors declare that there is no conflict of interest in this study.

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