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Novel Use of a Social-Media-Based Survey to Detect Regional Differences in Management of Monochorionic–Diamniotic Twins

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Abstract

Objective This study aims to evaluate the utility of social media to distribute a patient survey on differences in management and outcomes of monochorionic–diamniotic (MCDA) pregnancies.

Study Design A cross-sectional survey was posted to an English-language MCDA twins patient-centered support group within the social media site, Facebook from April 2, 2018 to June 26, 2018. Subjects were recruited through a technique called "snowballing," whereby individuals shared the survey to assist with recruiting. Patient reported data were analyzed using Chi-square and Kruskal–Wallis's tests to explore characteristics associated with surveillance and outcomes as related to region and provider type.

Results Over 3 months, the post "reached" 14,288 Facebook users, among which 5,653 (40%) clicked on the post. A total of 2,357 respondents with MCDA pregnancies completed the survey. Total 1,928 (82%) were from the United States (US) and 419 (18%) from other countries. Total 85% of patients had co-management with maternal–fetal medicine (MFM), more in the US compared with the rest of the world (87 vs. 74%, $p < 0.01$). MFM involvement led to increased adherence to biweekly ultrasounds (91 vs. 65%, $p < 0.01$), diagnosis of monochorionicity by 12 weeks (74 vs. 69%, $p < 0.01$) and better education about twin–twin transfusion syndrome (90 vs. 66%, $p < 0.01$). Pregnancies with MFM involvement had a higher take-home baby rate for both babies (92 vs. 89%, $p < 0.01$) or for at least one baby (98 vs. 93%, $p < 0.01$) compared with those without MFM involvement.

Conclusion A survey distributed via social media can be effective in evaluating real-life management and outcomes of an uncommon obstetrical diagnosis. This survey elucidates wide international variation in adherence to guidelines, management, and outcomes.

Keywords
- Facebook
- monochorionic diamniotic
- social media
- survey
- web-based research
- twins

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Twin gestations comprise 3 to 4% of all naturally occurring pregnancies, among which 20% are monochorionic.[1] The majority (80%) of monochorionic–diamniotic twin gestations (MCDA) are uncomplicated; however, 20% have complications specific to monochorionicity, including twin–twin transfusion syndrome (TTTS), spontaneous twin-anemia polycythemia syndrome (TAPS), and selective intrauterine growth restriction (sIUGR).[2] Many studies have reported on the optimal surveillance and treatment regimens for MCDA pregnancies complicated by TTTS. Most international societies recommend initiating biweekly screening at 16 weeks of gestation (►**Supplementary Table S1**, available in the online version).[1–6] Management strategies for TTTS include intrauterine laser ablation, selective termination, amnioreduction, or expectant management. Little is known on differences in management and outcomes based on provider and regions of the world.

One research strategy that has broad reach is web-based research. Web-based research has been increasingly used to answer medical questions of rare or sensitive issues, such as abortion[7] or infertility.[8] We aimed to investigate the utility of social media as the vehicle through which to perform web-based research to answer our clinical question on contemporary management of MCDA pregnancies. Our objective was twofold: (1) to evaluate the utility of social media to distribute a survey and (2) to describe regional and provider variation in management and outcomes of MCDA pregnancies.

Materials and Methods

An anonymous survey of 33 questions was created using Research Electronic Data Capture (REDCap[9]; ►**Supplementary Material**, available in the online version). The survey included questions on demographics, frequency of surveillance, patient education of complications of MCDA twins, pregnancy outcomes, and delivery data. The survey was created by referencing international management guidelines from the Society of Maternal Fetal Medicine (SMFM) and the International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) and then reviewed by expert colleagues. The link to the survey was posted to a private, English-language, MCDA twins patient-centered support group within the social media site, Facebook from April 2, 2018 to June 26, 2018. Participants were recruited through the technique of "snowballing." This was a nonprobability sampling technique where existing study subjects "share" the survey to assist with recruitment. Anyone with the survey could freely repost the link to their own profile page or share with members outside of the group. Items in the questionnaire were not randomized and adaptive questioning was employed. Results were only available for participants who completed and submitted the survey though not every question was mandatory and included nonresponse options. The results were only analyzed among women who self-reported their age 18 years or older and who had completed their MCDA pregnancy. We determined unique respondents by data cleaning for duplications in timestamps and free text responses. We monitored Facebook activity daily for click-through rates and reposted the survey link weekly to increase visibility. Participation was voluntary and participants did not receive any compensation for participation. This study was approved by our Institutional Review Board (UCLA IRB# 18–000052).

For survey results, we calculated summary statistics for screening, management, and outcomes. Furthermore, we performed univariate analysis to compare them by region and provider type using Chi-square and Kruskal–Wallis's tests. We also queried the take-home baby rates by TTTS treatment, stage of TTTS, and provider type. Statistical significance was set at p-value of 0.05. We used SAS 9.4 and R 3.4.2 to perform all the analyses.

Results

Characteristics of Study Subjects

During the study period of 3 months, 14,288 Facebook users were "reached" via the Facebook algorithm, among which 5,653 (40%) clicked on the post. A total of 2,357 respondents completed the survey. Age at delivery ranged between 18 and 50 years old. Most of the respondents were White, had MFM as their primary and ultrasound provider, were diagnosed with MCDA twins by 12 weeks of gestation, had biweekly ultrasounds, and received education about TTTS. Most had gestational age (GA) at delivery of $34^{0/7}$ to $37^{6/7}$ weeks, cesareans for both deliveries, birth weight discordance less than 20%, and took both babies home (►**Table 1**).

Surveillance and Management Differences by Region

Respondents were primarily from the the United States (US) ($n = 1{,}928$; 82%), compared with all other countries ($n = 419$; 18%). Within the US, 22% were from the northeast, 29% from the midwest, 30% from the south, and 19% from the west, based on US census-bureau designated regions. The majority of non-US participants (90%) responded from countries with board certification pathways for MFM, namely Australia, Canada, United Kingdom (UK), New Zealand, and South Africa. Compared with other countries, respondents in the US were more likely to be non-White (14 vs. 10%, $p = 0.03$). There was also more MFM involvement in the US (87 vs. 74%, $p < 0.01$), but there was no differences among the regions within the US ($p = 0.06$). MFMs were also more likely than radiologists to be the ultrasound provider in the US compared with other parts of the world (85 vs. 53%, $p < 0.01$). Chorionicity and amnionicity was more likely to be diagnosed earlier than 12 weeks in the US (75 vs. 64%, $p < 0.01$), but MCDA twins were less likely to have at least biweekly ultrasound surveillance in the US (86 vs. 90%, $p = 0.03$). The self-reported rates of TTTS and TAPS were lower among patients receiving care in the US (23 and 7%, $p < 0.01$) compared with the rest of the world (31 and 12%, $p < 0.01$). Respondents in the US were more likely to be educated about TTTS than non-US countries (87 vs. 81%, $p < 0.01$). The number of patients who delivered between $34^{0/7}$ and $37^{6/7}$ weeks of GA, the timing recommended by the

Table 1 Screening, management, and outcomes by region ($n = 2,357$)

Variable	Overall	US[a]	Non-US[b]	*p*-Value[c]
	$n = 2,357$	$n = 1,928$	$n = 419$	
Year of delivery				
2010 or earlier	6% (142)	7% (127)	4% (15)	<0.01
2011	2% (56)	3% (50)	1% (6)	
2012	3% (68)	3% (54)	3% (14)	
2013	6% (131)	5% (104)	6% (27)	
2014	7% (164)	7% (130)	8% (34)	
2015	14% (338)	13% (258)	19% (80)	
2016	20% (472)	21% (401)	17% (71)	
2017	30% (698)	30% (570)	31% (128)	
2018	12% (278)	12% (234)	11% (44)	
Maternal age at delivery				
18–24 years	11% (270)	12% (223)	11% (46)	0.05
25–35 years	73% (1,718)	74% (1,425)	69% (290)	
36–40 years	14% (326)	13% (246)	18% (75)	
41–50 years	2% (42)	2% (34)	2% (8)	
Ethnicity				
White	87% (2,046)	86% (1,661)	90% (377)	0.03
Non-White	13% (308)	14% (266)	10% (41)	
Primary provider				
MFM co-management	85% (1,999)	87% (1,681)	74% (310)	<0.01[d]
OBGYN/midwife	15% (354)	13% (245)	26% (108)	
Ultrasound provider				
With MFM	80% (1,877)	85% (1,648)	53% (221)	<0.01
Without MFM	20% (476)	15% (280)	47% (195)	
Gestational age at MCDA diagnosis				
< 12 weeks	73% (1,728)	75% (1,448)	64% (270)	<0.01
12–16 weeks	18% (434)	16% (309)	30% (125)	
17–21 weeks	7% (156)	7% (137)	5% (19)	
≥22 weeks	2% (39)	2% (34)	1% (5)	
Frequency of ultrasounds				
Every 1–14 days	87% (2,044)	86% (1,662)	90% (378)	0.03
Greater than every 14 days	13% (313)	14% (266)	10% (41)	
Self-reported rates of TTTS				
Yes	25% (582)	23% (451)	31% (129)	<0.01
No	71% (1,677)	73% (1,401)	64% (269)	
Unsure	4% (98)	4% (76)	5% (21)	
Self-reported rates of TAPS				
Yes	8% (191)	7% (140)	12% (51)	<0.01
No	91% (2,143)	92% (1,771)	86% (362)	
Unsure	1% (23)	1% (17)	1% (6)	
Educated about TTTS				<0.01
Yes	86% (2,027)	87% (1,681)	81% (338)	
No/unsure	14% (328)	13% (245)	19% (81)	

(*Continued*)

Table 1 (*Continued*)

Variable	Overall	US[a]	Non-US[b]	*p*-Value[c]
	n = 2,357	*n* = 1,928	*n* = 419	
GA delivery $34^{0/7}$–$37^{6/7}$ weeks				
Yes	67% (1,571)	68% (1,293)	65% (270)	0.20
No	33% (757)	32% (608)	35% (147)	
Method of delivery				
Vaginal for both	29% (689)	29% (555)	32% (133)	0.36[e]
Cesarean for both	69% (1,603)	69% (1,317)	67% (278)	
Combination	2% (47)	2% (41)	1% (6)	
Birth weight smaller twin (g)[f]	2,097.9 (1,644.3– 2,438.1)	2,126.2 (1,644.3– 2,438.1)	2,012.8 (1,587.6– 2,384.5)	0.09[g]
Birth weight larger twin (g)[f]	2,381.4 (1,962.6– 2,693.2)	2,381.4 (1,984.5– 2,721.6)	2,322.4 (1,950.4– 2,664.9)	0.23[g]
Birth weight discordance (%)[f]	9.9 (4.1– 19.0)	9.8 (4.1– 18.9)	10.5 (4.3– 20.2)	0.37[g]
Birth weight discordance				
≤20%	77% (1,767)	77% (1,459)	74% (299)	0.15
> 20%	23% (532)	23% (427)	26% (105)	
Take-home baby rate				
Two	91% (2,073)	92% (1,705)	89% (364)	0.33
One	6% (134)	6% (105)	7% (29)	
None	3% (64)	3% (49)	3%(14)	

Abbreviations: GA, gestational age; MCDA, monochorionic diamniotic; MFM, maternal–fetal medicine; OBGYN, obstetrician gynecologist; TAPS, twin-anemia polycythemia syndrome; TTTS, twin–twin transfusion syndrome.
[a]Northeast = 22%, Midwest = 29%, South = 30%, West = 19%.
[b]Australia = 28%, Canada = 28%, United Kingdom and Northern Ireland = 27%, New Zealand = 5%, Other =12%.
[c]Fisher's exact test.
[d]Primary provider by region, $p = 0.06$.
[e]Method of delivery by region, $p = 0.07$.
[f]Median (IQR).
[g]Kruskal-Wallis's test.

American College of Obstetricians and Gynecologists,[2] was similar in the US as the rest of the world (68 vs. 65%, $p = 0.20$). Overall, vaginal delivery of both babies was reported in 29% of respondents. There was neither national nor international differences in mode of delivery ($p = 0.07$ and $p = 0.36$, respectively). There were no differences in twin birthweight discordance or take-home baby rate between patients in the US and rest of the world ($p > 0.10$; ►Table 1).

Surveillance and Management Differences by Provider Type

MCDA twins were managed in part or by a MFM in 85% of respondents, or were managed solely by midwives or general obstetrician in 15% (►Table 2). Pregnancies managed by MFM were more likely to have diagnosis of monochorionicity earlier than 12 weeks of gestation (74 vs. 69%, $p < 0.01$) and at least biweekly ultrasounds (91 vs. 65%, $p < 0.01$). Respondents managed by MFM reported better education on the potential for TTTS (90 vs. 66%, $p < 0.01$). Pregnancies with MFM involvement had higher take-home baby rates for both babies compared with those without MFM involvement (92 vs. 89%, $p < 0.01$). Furthermore, the take-home baby rate for at least one baby was higher

Table 2 Screening, management and outcome by provider type ($n = 2,353$)

Variable	MFM involvement	No MFM involvement	*p*-Value[a]
	n = 1,999	*n* = 354	
Year of delivery			
2010 or before	5% (99)	12% (43)	<0.01
2011	2% (48)	2% (8)	
2012	3% (58)	3% (11)	
2013	5% (108)	7% (23)	
2014	7% (131)	9% (33)	
2015	14% (282)	16% (56)	
2016	21% (416)	18% (62)	
2017	31% (611)	25% (87)	
2018	12% (246)	9% (31)	
Maternal age at delivery			<0.01
18–24 years	10% (206)	18% (63)	
25–35 years	73% (1463)	71% (253)	

Table 2 (*Continued*)

Variable	MFM involvement	No MFM involvement	*p*-Value[a]
	n = 1,999	*n* = 354	
36–40 years	15% (294)	9% (32)	
41–50 years	2% (36)	2% (6)	
Ethnicity			0.52
White	87% (1740)	86% (303)	
Non-White	13% (258)	14% (50)	
Gestational age at MCDA diagnosis			<0.01
< 12 weeks	74% (1483)	69% (243)	
12–16 weeks	18% (363)	20% (70)	
17–21 weeks	7% (131)	7% (25)	
≥22 weeks	1% (22)	5% (16)	
Frequency of ultrasounds			<0.01
Every 1–14 days	91% (1812)	65% (229)	
Greater than every 14 days	9% (187)	35% (125)	
Educated about TTTS			<0.01
Yes	90% (1793)	66% (233)	
No/unsure	10% (205)	34% (120)	
Take-home baby rate			<0.01
Two	92% (1771)	89% (299)	
One	6% (121)	4% (12)	
Zero	2% (39)	7% (25)	

Abbreviations: MCDA, monochorionic diamniotic; MFM, maternal–fetal medicine; TTTS, twin–twin transfusion syndrome.
[a]Fisher's exact test.

if MFM was involved during the pregnancy (98 vs. 93%, $p < 0.01$).

Outcomes of TTTS

Diagnosis of TTTS was reported in 22% (497) of the 2,237 respondents that answered these items, of which 22% were diagnosed before 16 weeks, 60% at 17 to 20 weeks and 18% after 27 weeks. Patients diagnosed with TTTS before 16 weeks were more likely to have undergone biweekly instead of monthly screening (91%) compared with pregnancies diagnosed with TTTS at 17 to 26 weeks (83%) or after 27 weeks (88%, $p < 0.01$). Regarding treatment for respondents with TTTS, 51% (246) had fetoscopic laser ablation, 9% (42) had amnioreduction, and 16% (79) were delivered upon diagnosis (►Table 3). Treatment was performed in stage I, II, III, IV, and V in 20, 24, 35, 15, and 6% of cases, respectively. Method of treatment had no effect on take-home baby rate ($p = 0.14$). Having MFM involvement increased the double take-home baby rate in MCDA twins complicated by stage III TTTS from 46 to 70% ($p < 0.01$), but not the other stages.

Social Media Experience

Within 3 months of survey distribution, at least 14,288 social media users were exposed to the survey, not accounting for additional exposure after "snowballing." Of those who were exposed, 5,653 users clicked on the post (40%) and one third of these women (1,810) then clicked on the survey link. Given the total survey response of 2,357, we estimate at least 20% of survey responses were a result of "snowballing." Given the anonymity of the study, we were unable to identify the exact domain of each survey respondent. Most survey respondents ($n = 1,428$, 61%) were members of the Facebook group during their MCDA pregnancy, with the remaining joining postpartum ($n = 836$, 36%). Women reported their experience with the Facebook support group as positive (50%), negative (3%), mixed (13%), or neutral (34%; ►Table 4). Specifically, women said the group provided social support (47%), improved their understanding of the disease process (42%), added to their anxiety (11%), or changed their choice in healthcare provider (6%).

Discussion

Principal Findings

This study utilized a robust support group on social media to conduct a patient-centered survey of 2,357 women that elucidated wide variation in the regional and provider differences in the management and outcomes of MCDA twins.

Results

Through this survey, we were able to identify several key conclusions based on region. First, there is more MFM involvement in MCDA twin pregnancies in the US but higher frequency of ultrasound surveillance in other parts of the world. These differences are likely multifactorial in origin due in part to: (1) the lack of MFM board certification in 10% of the non-US countries in this study (2% of the surveyed cohort), (2) differences in guidelines from societies (SMFM in US vs. ISUOG elsewhere), and (3) differences in healthcare systems (privatized in US vs. public in UK, Canada, and Australia). Additionally, while statistical significance exists, we acknowledge the clinical significance of 86 versus 90% is less meaningful. Furthermore, there were no regional differences in timing, method of delivery, twin birthweight discordance, or take-home baby rates. There were higher self-reported rates of TTTS and TAPS among patients outside of the US, which could be associated with differences in surveillance protocols and the increased frequency of ultrasound surveillance outside the US. ISUOG calls for routine middle cerebral artery, peak systolic velocity surveillance to aid in detection of TAPS, while SMFM guidelines only include deepest vertical pocket, fetal bladder, and growth surveillance. Furthermore, for diagnosis of TTTS, ISUOG[5] uses a deepest vertical pocket of fluid >10 cm in the recipient twin after 20 weeks, compared with some centers in the US that use a cutoff of >8 cm for all GAs. Because the TTTS rates of monochorionicity should be relatively stable across regions, the different rates of reported TTTS is likely attributable to selection bias. It is reasonable to believe that patients with

Table 3 Take-home baby rate by twin–twin transfusion syndrome treatment ($n = 485$)

Variable	Laser $n = 246$	Amnioreduction $n = 42$	Delivery $n = 79$	None $n = 118$	p-Value[a]
Take-home baby rate					0.14
Two	68% (165)	71% (30)	82% (65)	71% (84)	
One	26% (62)	17% (7)	14% (11)	20% (24)	
None	6% (14)	12% (5)	4% (3)	8% (10)	
GA at diagnosis					
12–16 weeks	31% (76)	15% (6)	1% (1)	19% (22)	<0.01
17–20 weeks	50% (122)	41% (17)	4% (3)	40% (47)	
21–26 weeks	19% (46)	39% (16)	20% (15)	21% (24)	
≥27 weeks	1% (2)	5% (2)	66% (50)	15% (17)	
In labor	0% (0)	0% (0)	9% (7)	6% (7)	

Abbreviation: GA, gestational age.
[a]Fisher's exact test.

complications are more likely to seek guidance from a support group than those without complications.

Conversely, the survey identified several key differences based on provider type. MFM primary or co-management had higher rates of biweekly surveillance, earlier diagnosis of monochorionicity, better patient education of potential complications, and a higher take-home baby rate. It has been shown previously that well-informed patients experience better quality of life.[10] The US Institute of Medicine and the US Center for Medicaid and Medicare Services named patient-centered care a fundamental aim in improving healthcare.[11] Finally, we conclude that in most cases inclusion in an online patient-centered group may provide social support and valuable patient education in this complicated and uncommon disease process. This support is important because maternal stress may further exacerbate outcomes in these high-risk pregnancies.[12]

Clinical Implications

The impetus for this investigation was to assess the real-life practice patterns in management of MCDA twins on a global scale. To date, this is the largest patient survey of MCDA twin pregnancies. Fischbein et al[13] reported on a patient survey of 312 women in the United States who completed a pregnancy complicated by TTTS and evaluated surveillance before and after the publication of the SMFM guidelines in 2014.[6] They reported an increase in biweekly ultrasound surveillance from 31.7 to 52.7% since guideline publication, and similar to our study, the highest adherence being among pregnancies with MFM involvement. Our data supplement the literature with data on contemporary management of uncomplicated MCDA pregnancies, in addition to elucidating the regional heterogeneity by including data on over 400 women who received care outside of the US. In our study, biweekly surveillance that is endorsed by most professional societies[1–6] led to greater detection of TTTS at the extremes of GA (≤16 and ≥27 weeks) but did not change the rate of diagnosis between 17 and 26 weeks in our cohort. Given that 22% of patients with TTTS reported diagnosis before or at 16 weeks, consideration could be made to initiating the screening even earlier, for example, at 14 weeks. Although the inclusion of first-trimester nuchal translucency (NT) or ductus venosus evaluation in the screening or prediction of TTTS is controversial,[14] the high frequency of early development of TTTS in this cohort suggests that other screening before 16 weeks should be considered. Additionally, about a quarter of patients who developed TTTS received treatment in stage I, for which the best treatment is still under investigation.[15] Of note, the survey did not evaluate for patient enrollment in research protocols.

Finally, multiple free text responses in our survey reported positive themes of camaraderie among these patients with difficult and high-risk pregnancies. Patient care may be optimized by referring patients to support groups on social media. Our study provides further evidence to the fact that social media is revolutionizing the way patients receive health care information, cope with difficult medical decisions and even choose healthcare providers.

Table 4 Social media as a resource for monochorionic–diamniotic twin pregnancies ($n = 2,357$)

Variable	Overall
	$n = 2,357$
Feedback for Facebook group	
Positive	50% (1,190)
Negative	3% (59)
Mixed	13% (311)
Neutral	34% (797)
Were you a part of this group during your pregnancy?	
Yes	61% (1,428)
No	36% (836)
Unsure	4% (87)

Strengths and Limitations

While survey studies have their inherent limitations and biases, using this technique, we were able to obtain data from a large population of women with rare obstetric complications. The strength of this study is the collection of data on the largest cohort to date of MCDA pregnancies by leveraging social media and the "snowballing" technique. This methodology allows access to patients across institutional and regional boundaries to determine real-world practices and outcomes. Furthermore, the anonymity of surveys deployed outside of the healthcare setting may promote more candid answers.

While most publications using surveys report a response rate, we are not able to evaluate our true denominator given our pragmatic approach of allowing patients to share the survey freely outside of the original Facebook post. However, response rate does not always equate with validity[16] and perhaps more important are the disclosures and details of the participants. Since our social media group was primarily a support group for patients interested in advocacy or with complications in pregnancy, we acknowledge there is a selection bias to those patients with particularly positive or negative experiences. There is also likely a selection bias toward women who have the literacy and resources to be members of an English-speaking web-based support group. Nonetheless, the overall outcomes are comparable to established rates in the literature.[17] Lastly, there is no true way to confirm the data reported by these women are accurate, that is, confirmation of abnormal Dopplers in reported staging of TTTS, though there is no reason to suspect fabrication. Like most surveys, there is the potential for recall bias, given that patients who were most likely to respond, especially in a negative fashion, were those with MCDA-specific complications. Furthermore, there can be recall or "memory decay" given that many women delivered years before completing this survey.

Research Implications

Social media has become a mainstay in people's daily lives and its ease of use and accessibiltiy may be capitalized upon for medical research. Potential future questions that could be assessed include the management and outcomes of other complications of MCDA twins including sIUGR and twin reversed arterial perfusion sequence. While we did not assess long-term outcomes, this group could also serve as a perfect resource for such a future question. This research methodology can also be considered in and applied to other uncommon disorders affecting obstetrical populations.

Conclusion

In summary, we utilized a robust web-based patient support group to obtain a large number of responses, in a short amount of time, that elucidate how management of MCDA gestations varies widely internationally and by provider type. Patient-reported data suggests that MFM involvement in care is associated with earlier diagnosis of chorionicity, higher adherence to screening guidelines, and better patient education of potential MCDA complications. These conclusions must be interpreted cautiously given the limitations of patient-reported data. While these data should not be used to guide changes in practice, it is an important contribution to the voice of patients with MCDA pregnancies and their individual experiences. Nonetheless, social media is a potentially useful technique of surveying large number of patients with uncommon obstetrical conditions such as monochorionic pregnancy.

Note

The data were presented in part at the 28th World Congress on Ultrasound in Obstetrics and Gynecology on October 20 to 24, 2018 in Singapore.

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Conflict of Interest

None declared.

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