

Research Report

A Shared Decision-Making Model for Management of Small Renal Masses: Optimizing the Patient Experience

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Abstract.

Background: The finding of a small renal mass (SRM) on radiological imaging and the potential of a cancer diagnosis is anxiety provoking in most patients. The decision-making process often occurs in the absence of any framework regarding the nature and treatment outcomes. This project aimed to educate patients newly diagnosed with a SRM, implement a shared decision-making (SDM) model, and assess the educational attainment and effect on a SDM intervention.

Methods: This project assessed the educational attainment and its effect on a SDM intervention using a pre-and post-intervention survey, an educational video [Urology Care Foundation, “What is a renal mass?”], and a structured provider discussion. The survey incorporated eight knowledge questions and two questions which addressed anxiety related to diagnosis and confidence in decision-making.

Results: Fifty surveys were completed. The post intervention score showed a significant increase in patient knowledge. Wilcoxon signed rank test ($P = <0.001$; 2.0; CI 95% (1.54–2.46)). Thirty-nine demonstrated improvement in knowledge with a mean of 2.0, 9 were unchanged and 2 decreased. Approximately 42% of patients reported a decrease in anxiety rating by a mean of 40%. When confidence in decision-making improved, it improved by a mean of 45%.

Conclusions: A significant improvement in understanding of SRMs was demonstrated. This model showed improved knowledge, alleviation of anxiety and improved confidence and denotes the feasibility of implementing a SDM model in newly diagnosed patients. Results should encourage providers who aspire to incorporate a SDM as a *Best Practice*.

Keywords: Small renal masses, oncologic management, shared decision-making, best practice

INTRODUCTION

Cancer is the second leading cause of death in the U.S. with renal cell carcinoma (RCC) representing approximately 3–4% of all adult cancers [1]. With advanced imaging, there has been a stage migration

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Fig. 1. Oncologic Management of Small Renal Masses.

in the diagnosis towards small renal masses (SRMs) [2], which may be indolent or slow growing. The proportion of renal masses characterized as pT1, (≤ 7 cm) and limited to the kidney was 4% in 1989 versus 22% in 2000 [3], and is increasing. This is now over 50% [4]. This increased frequency in the detection of SRMs in the general adult population requires adjustment in oncologic management, however, the framework for the optimal approach for each patient is not immediately evident. One approach is to optimize patient choice in the adoption of shared decision-making (SDM) model which incorporates the use of an educational aid such as a video in combination with a structured provider discussion.

Shared decision-making “is a collaborative decision-making process between patients and their health care providers relevant to medical decisions where multiple options are considered clinically acceptable” [5]. Several issues go into treatment decision-making such as competing illness, general age, quality of life concerns, and the effectiveness of treatment [6]. We hypothesized that patients come to urology with variable degrees of knowledge and understanding (See Fig. 1). A model which is implemented seamlessly into the clinical encounter provides maximum benefit for all shareholders; patients, providers and healthcare system. A SDM pathway which clarifies the problem for the patient diagnosed with a SRM and eliminates confusion, may have significant value to the patient and provider.

The aim of this project was to investigate the introduction of a SDM focused on individual patient choices and preferences, based on evidenced based management options, as to whether the SDM could improve knowledge of SRM [7].

MATERIALS AND METHODS

Adult patients diagnosed with a SRM < 4.0 cm were asked to watch the Urology Care Foundation video, “What is a renal mass?” and participate in a SDM discussion during a clinic visit with the urologist and/or NP. The objectives were:

1. Assess patient knowledge of treatment options for a SRM pre-and post- intervention.
2. Evaluate the influence of an intervention of an educational video followed by a structured discussion during a clinic visit as part of a SDM process which assesses patient knowledge, anxiety surrounding diagnosis and confidence in treatment choice.

The project setting was the urology division outpatient clinic located at the Perelman Center for Advanced Medicine, University of Pennsylvania. The participants were chosen from provider schedules of those patients referred for evaluation of a SRM. The impetus for this project was to optimize the patient experience with the potential to standardize an approach for all patients across the Genitourinary service lines.

Intervention

Project participants

The project participants were male and female patients between the ages of 18 and 80 in the urology division newly diagnosed with a SRM < 4 cm. Patients with renal masses > 4 cm were excluded. Additionally, patients being treated for a secondary cancer were excluded. The patients received a written description of the purpose of the project and a letter of

Table 1
Preintervention Survey

<ul style="list-style-type: none"> • Are small renal masses uniformly aggressive or latent? • Is the removal of the kidney the best way to treat a small renal mass? • Are you familiar with partial nephrectomy as an option? • Are you familiar with ablative therapy? • Can small renal masses be observed? • Do small renal masses < 4cm regularly spread to other sites? • Can focally treated small renal masses recur? • Can you retreat small renal masses? • How anxious are you related to your diagnosis of a SRM? (with 1 being not at all anxious and 4 being extremely anxious) 	1	2	3	4
<ul style="list-style-type: none"> • How confident are you in your ability to make a decision about managing your diagnosis of a SRM? (with 1 being not at all confident and 4 being extremely confident) 	1	2	3	4

Table 2
Postintervention Survey

<ul style="list-style-type: none"> • Are small renal masses uniformly aggressive or latent? • Is the removal of the kidney the best way to treat a small renal mass? • Are you familiar with partial nephrectomy as an option? • Are you familiar with ablative therapy? • Can small renal masses be observed? • Do small renal masses < 4cm regularly spread to other sites? • Can focally treated small renal masses recur? • Can you retreat small renal masses? • How anxious are you related to your diagnosis of a SRM? (with 1 being not at all anxious and 4 being extremely anxious) 	1	2	3	4
<ul style="list-style-type: none"> • How confident are you in your ability to make a decision about managing your diagnosis of a SRM? (with 1 being not at all confident and 4 being extremely confident) 	1	2	3	4
<ul style="list-style-type: none"> • How helpful was the educational video in clarifying your treatment decision? Not helpful Somewhat helpful Very helpful 				
<ul style="list-style-type: none"> • How helpful was the structured discussion with the provider during your clinic visit in clarifying your decision? Not helpful Somewhat helpful Very helpful 				
<ul style="list-style-type: none"> • How helpful was the video in alleviating anxiety related to your treatment decision? (with 1 being not at all helpful and 4 being extremely helpful) 	1	2	3	4
<ul style="list-style-type: none"> • How helpful was the provider clinic visit in alleviating your anxiety related to your treatment decision? (with 1 being not at all helpful and 4 being extremely helpful) 	1	2	3	4
<ul style="list-style-type: none"> • How helpful was the video in improving confidence related to your treatment decision? (with 1 being not at all helpful and 4 being extremely helpful) 	1	2	3	4
<ul style="list-style-type: none"> • How helpful was the provider clinic visit in improving confidence related to your treatment decision? (with 1 being not at all helpful and 4 being extremely helpful) 	1	2	3	4

104 consent explaining that participation was completely
 105 voluntary, would not have any impact on the quality
 106 of care, and included a provision for confidentiality.

107 *Project design*

108 The project design incorporated a 10 item pre-
 109 and 16 item post-intervention survey focusing on the
 110 educational attainment and assessment of a baseline
 111 understanding of SRMs and the available treatment
 112 options. The pre-intervention survey was adminis-
 113 tered as the initial step (See Table 1). Prior to the
 114 start of each clinic, the NP identified the patients
 115 who were being evaluated for a new diagnosis of
 116 a SRM. Once the patient was in a room, the NP
 117 approached the patient, gave appropriate introduc-
 118 tions and explained the purpose of the survey. The
 119 NP informed the patient that their participation was
 120 completely voluntary, would not affect their care, and
 121 that no information will be collected in conjunction
 122 with the patient’s identity. Patients who gave verbal
 123 consent to participate were given a survey packet con-
 124 taining an informed consent cover letter explaining
 125 the purpose of the project, the survey, an envelope,
 126 and a writing utensil. Patients were then instructed
 127 to choose the best possible answer to each question
 128 and to write an answer where appropriate. The NP
 129 was available to answer any questions related to the
 130 survey content. Participants were instructed to place
 131 the completed survey in the envelope provided and
 132 return it to the NP. A completed and returned survey
 133 served as informed consent. After completing the pre-
 134 intervention survey, project participants watched the
 135 Urology Care Foundation’s video, “What is a renal
 136 mass?”[8]

137 <http://www.urologyhealth.org/urologic-conditions/>
 138 kidney-cancer/videos. The project participants then
 139 participated in a structured SDM discussion. The
 140 SDM discussion replicated the SDM model pub-
 141 lished by Elwyn et al. 2012 [9]. The patient’s initial
 142 preference was documented followed by the choice
 143 talk, option talk and decision talk. Following the
 144 structured SDM discussion, the patient’s informed
 145 preferences were documented in the electronic med-
 146 ical record. The treatment options discussed with the
 147 patient included active surveillance, ablative therapy,
 148 and surgery. At the conclusion of the clinic visit,
 149 the project participants received a post- intervention
 150 survey (See Table 2). The same number was assigned
 151 to each pair of pre- and post-intervention surveys
 152 so that pre- and post- intervention results from each
 153 project participant could be matched for comparison.

154 *Study of the intervention*

155 The approach chosen for assessing the impact of
 156 implementing standardized patient education and the
 157 SDM model was a pre-and post- intervention survey
 158 assessing patient knowledge, anxiety surrounding
 159 diagnosis and confidence in treatment choice. The
 160 patient's initial preference and informed preferences
 161 were also documented. The pre-and post-surveys
 162 were completed during the clinic visit.

163 *Measures*

164 The data collection tools included a pre-and post-
 165 intervention survey with a combination of yes or no
 166 questions, and Likert questions with answer options
 167 on a 4-point Likert scale. Face validity of the sur-
 168 vey was determined through an informal process by
 169 asking a few individuals who were representative
 170 of the patient population whether or not the ques-
 171 tions made sense and if they were easily understood.
 172 Content validity was determined by carefully review-
 173 ing educational content, components of the SDM
 174 pathway, and survey questions with several provider
 175 colleagues. The majority of survey questions were
 176 knowledge questions based on the video content and
 177 questions pertaining to anxiety related to diagnosis
 178 and confidence in choosing a management strategy.

179 The post-intervention survey included additional
 180 questions designed to evaluate the intervention. The
 181 questions were written to measure the combined
 182 effect of the educational video content and the struc-
 183 tured SDM discussion during a single clinic visit.
 184 Basic demographic questions were also included in
 185 the survey and stratified by age range 18–34, 35–64
 186 and >65 years old, sex, educational status and co-
 187 morbidities.

188 A Flesh- Kincaid reading readability formula
 189 assessed the pre- and post- surveys at a fifth-grade
 190 reading level, and a compellation of test readabil-
 191 ity scores of 8 readability formulas gave a score of
 192 a fourth-grade reading level [10]. The educational
 193 video is a product of the Urology Care Foundation.
 194 The language in the video was consistent with the
 195 language used in the pre- and post-intervention sur-
 196 veys. The data was collected in entirety at the time of
 197 the clinic visit.

198 *Analyses*

199 Data was compiled and organized in Microsoft
 200 Excel. The outcome measured was the pre-and

201 post- survey knowledge, anxiety surrounding diag-
 202 nosis and confidence in management choice by the
 203 project participants regarding the treatment options
 204 for SRMs. A table was used to display the participant
 205 sample, demographic data and size of the SRM. The
 206 Wilcoxon signed rank test was used to analyze the
 207 post intervention response as measured by post inter-
 208 vention score improvement and a histogram was used
 209 to display this data. Descriptive statistics were used
 210 to describe the self-assessment responses pertaining
 211 to anxiety and confidence as well as the responses
 212 related to the helpfulness of the interventions and to
 213 document the change in preferences.

Ethical considerations

214 There were no specific ethical considerations or
 215 conflicts of interest identified in the IRB process. This
 216 project was categorized as a quality improvement
 217 process during an IRB review process to enhance
 218 the patient encounter. The project design allowed
 219 for an easy intervention and administration of the
 220 pre-and post- intervention survey, and overall, was
 221 non-disruptive in the clinical encounter.
 222

223 **RESULTS**

224 Fifty surveys were completed and returned with
 225 a response rate of 100 percent. Sample demograph-
 226 ics revealed 60% male and 40% female with 42%
 227 of participants in the 34–65 years of age cate-
 228 gory and 54% >65 years of age. Forty percent of
 229 the participants completed high school education
 230 and 38% obtained a college degree. The principle
 231 co-morbidities were hypertension in 33%, diabetes
 232 mellitus in 23%, cancer in 18% and other in 22%
 233 respectively in participants (See Table 3). The sam-
 234 ple size was $n = 50$. The median size for the SRM was
 235 2.0×1.0 cm.

236 The post intervention score showed a signifi-
 237 cant increase in patient knowledge. Each participant
 238 stayed the same or demonstrated improved knowl-
 239 edge level with an average improvement of 2 items.
 240 Thirty-nine demonstrated improvement in knowl-
 241 edge with a mean of 2.0, 9 were unchanged and 2
 242 decreased. Wilcoxon signed rank test ($P = <0.001$;
 243 2.0; CI 95% (1.54–2.46)). The raw scores were
 244 tabulated and the change or delta is displayed on
 245 the histogram (See Fig. 2). This statistical analysis
 246 demonstrated support for the intervention.

247 One question pertained to the self-assessment of
 248 the patient's anxiety related to the diagnosis and one

Table 3
Demographic Data for Oncologic Management of Small Renal Masses

Age	Sex	Education	Co-Morbidities	Size of SRM (cm)
>65	Male	College	Htn, DM, MI, CA	3.2 × 2.7
>65	Male	College	Htn, CA	1.4 × 1.3
35–64	Female	High School	Neuroendocrine Tumor, CA	1.5 × 1.5
35–64	Male	High School	Htn, DM, CA	1.0
>65	Male	High School	Htn, DM, Cerebral Amyloid Angiopathy	1.9 × 1.7
>65	Male	College	Htn, CA	2.4 × 2.1
>65	Male	High School	Htn, DM, MI,	2.5 × 1.5 × 2.5, 2.3 × 2.7 × 2.4
35–64	Male	High School	Htn, DM,	3.0
35–64	Female	College	None	1.9 × 1.4 × 2.0
35–64	Male	High School	Htn, Valve Replacement	2.6 × 2.1 × 1.9
35–64	Male	College	Htn, DM, CA, Lung Disease	1.2, 2.4, 2.2
>65	Male	High School	Htn, DM	3.0
35–64	Female	High School	Htn, DM, TB	2.0
>65	Female	High School	Htn, CA	1.7 × 2.4
>65	Male	Graduate School	Htn, CVA	2.0
>65	Female	High School	CA	3.0 × 2.6 × 3.1
>65	Male	High School	Pacemaker, Heart Valve	2.3 × 1.2 × 1.7
>65	Male	College	Htn, CA, Aortic Replacement	1.1 × 0.8
>65	Male	College	Htn, DM, CA	1.3 × 1.3
>65	Male	College	CA, Colon Cancer	1.0
>65	Male	High School	DM, MI, CA, Valve, Pacemaker	2.1 × 1.9, 0.1 × 0.9
35–64	Male	College	None	1.6 × 1.1 × 1.2
35–64	Male	College	Htn	2.6 × 2.7 × 3.4
>65	Male	College	Htn, CA, CAP, Marginal Cell Lymphoma	1.6 × 1.7 × 1.7, 0.9 × 0.9 × 0.9
>65	Male	Graduate School	CA	1.8
>65	Female	Graduate School	Htn	1.7 × 1.7 × 1.7
35–64	Male	College	Htn, DM	0.9 × 0.9
35–64	Male	Graduate School	Htn, DM	1.3 × 1.2
>65	Male	College	Htn, DM	1.7 × 1.3, 2.3 × 2.0
>65	Male	Graduate School	Htn, Renal Insufficiency, Hypothyroidism	1.9
>65	Male	Graduate School	MI, Cardiac Ablation	1.8 × 1.9
>65	Female	College	None	1.9
35–64	Male	High School	DM	2.3 × 2.2 × 2.3
35–64	Female	High School	Htn, DM	3.1 × 2.9 × 2.9
35–64	Female	College	None	1.0 × 1.1
35–64	Male	High School	Htn, DM, HIV	1.0, 0.5
35–64	Female	College	Htn, DM, CA,	2.0 × 2.5 × 2.3
18–34	Female	College	None	2.0 × 1.5 × 0.7
35–64	Female	High School	Htn, GERD, Sleep Apnea	1.0 × 1.5 × 1.5
35–64	Female	College	Htn, CA	0.9 × 0.9 × 0.8
35–64	Female	High School	DM	1.4
>65	Female	High School	Ulcerative Colitis	1.0
>65	Male	Graduate School	Aflutter/AFib	1.4 × 1.2
35–64	Male	Graduate School	Htn, DM, GERD	1.6
18–34	Male	College	None	2.8
>65	Female	Graduate School	Thyroid Disease	1.6
>65	Female	High School	Htn, DM, Lymphoma, Sleep Apnea	0.7
>65	Female	High School	Htn, DM, Depression	1.0
>65	Female	High School	Htn, Osteoporosis	1.0, 1.8 × 1.6, 1.0 × 0.9, 1.2 × 1.2, 0.9 × 0.8
35–64	Female	High School	Crohn's Disease, ITP	1.1

Note. The data demonstrate age, sex, educational level, co-morbidities' and size of SRM.

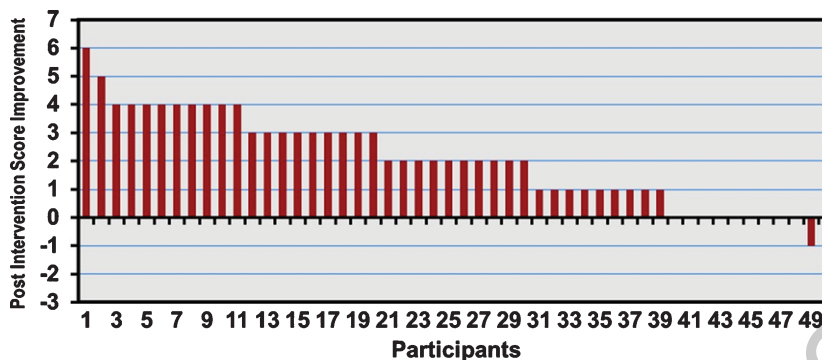


Fig. 2. Post Intervention Response for Oncologic Management of Small Renal Masses.

question pertained to confidence level in decision-making. Approximately 42% of patients reported a decrease in anxiety rating by a mean of 40%. When confidence in decision-making improved, it improved by a mean of 45%.

Seventy-two percent of the participants found the educational video very helpful. Ninety-two percent participants found the structured provider discussion very helpful in clarifying their treatment decision. All participants reported that both the video and the provider discussion were helpful or very helpful in alleviating anxiety and improving confidence. The treatment preference was noted relative to the initial preference and the informed preference.

The initial treatment preferences were determined *post hoc* analysis. Eighteen of fifty participants expressed an initial treatment preference at the outset of their encounter, the remainder were undecided. Twenty-five of the fifty participants who were undecided, once informed, chose surveillance as a preferred treatment strategy. One participant who initially preferred surgery opted for an ablative procedure. Three of fifty participants whose initial preference was surgery, decided on more conservative management with surveillance following the SDM model encounter. Ultimately, the final decisions were as follows: surveillance 32/50; surgery 15/50 and ablative therapy 3/50.

DISCUSSION

The finding of a SRM on radiological imaging and the potential of a cancer diagnosis is anxiety provoking in most patients [11]. Treatments may include management with surveillance, ablative therapy or surgery. One form of management may lead to overutilization of health resources while

another form of management may lead to undertreatment of a life-threatening mass. The consequences of a poor understanding of treatment options may lead to increased anxiety and lack of confidence in the chosen management strategy. Patients who are well-informed about strategies for managing a diagnosis of a SRM and who participate in SDM with their provider may experience decreased anxiety and greater confidence in their treatment plan.

Implementing SDM will help patients identify treatment goals and enable them to make well-informed treatment choices without compromising oncologic outcomes. This allows for rational choices and improved confidence with their chosen management strategy. SDM is a shift away from paternalism and a movement towards a more dynamic interaction between patients and providers. Implementing a process of SDM is an effective way to provide patient-centered care and improve the quality of the patient experience [12]. While common in internal medicine, there are few studies documenting the use of SDM in the urology practice setting. SDM is associated with increased patient knowledge, a better patient experience, a greater engagement with care and possible reduction of medical costs [9, 12].

A goal of the AUA Quality Summit of 2016: Shared Decision-Making and Prostate Cancer Screening was to focus on techniques to identify and understand patient values around prostate cancer and promote incorporation of SDM into prostate cancer discussions. The Summit incorporated SDM and decision tools, and found that SDM supports collaboration between providers and patients in situations where there are multiple, preference-sensitive options [13].

Patient knowledge was improved and they were primed for active involvement in their decisions through the use of decision aids and decision coaches.

321 One of the biggest changes in the AUA 2017
322 Renal Mass and Localized Renal Cancer Guidelines,
323 was the panel's recommendation of individualized
324 counseling and management due to the patient, onco-
325 logical and functional characteristics [14]. A decision
326 aid specifically for small renal masses is available
327 online [15].

328 Survival is high for RCC due to the natural his-
329 tory of these masses and the spectrum of treatment
330 choices. Therefore, the optimal pathway for a partic-
331 ular individual is the focus of this project. The design
332 concept includes in-depth education and informed
333 decision-making. This approach may impact more
334 appropriate choices, potentially minimize the risk of
335 overtreatment and improve the patient experience. A
336 busy urologist may find that this model provides a
337 necessary educational primer prior to his provider
338 discussion, and lead to a more focused provider-
339 patient discussion. Advanced Practice Providers are
340 uniquely positioned to advocate for an individual-
341 ized approach by implementing the SDM model,
342 as they can manage this emerging population of
343 patients with SRMs and can do so with relative
344 autonomy.

345 *Interpretation*

346 The focus of this project was the application of a
347 SDM as a pathway to guide patients through this pro-
348 cess. The clinical implication of this effort was the
349 optimization of patient choices in the management
350 of SRMs. This may decrease overtreatment, avoid
351 unnecessary morbidity, and allow outcomes satisfac-
352 tory to patients and health providers.

353 The implementation was feasible in a busy
354 practice. An educational intervention and SDM dis-
355 cussion were implemented seamlessly during a clinic
356 visit with patients newly diagnosed with a SRM. The
357 project results demonstrated a significant improve-
358 ment in patient knowledge about the nature and
359 behavior of SRMs following an educational inter-
360 vention. This change in improvement was even
361 evident in the highly educated patients. Patients who
362 participated in a SRM discussion report increased
363 confidence in their management choice. Use of a
364 SDM model in a urologic practice setting with
365 patients diagnosed with a SRM addressed a gap not
366 previously documented in the literature.

367 The AUA/Urology Care Foundation resource tool
368 was well liked. An educational intervention paired
369 with a SDM model was an efficient and effective
370 way to improve patient knowledge about SRMs and

371 provide patient-centered, evidence based care. SDM
372 gives patients an opportunity to interact with their
373 provider and exercise more autonomy in choosing a
374 management strategy that best suits their individual
375 needs.

376 The initial outcomes demonstrated significantly
377 greater patient understanding of the nature and
378 behavior of SRMs. Project participants showed
379 improved patient knowledge, alleviation of anxi-
380 ety and improved confidence in decision-making
381 with their chosen management strategy. The more
382 informed patient generally has a better consultative
383 experience within the health system.

384 *Limitations*

385 An initial bias may exist for those willing or unwill-
386 ing to participate in the project. A selection bias may
387 exist by including only patients who seek care at
388 an academic medical center. Additionally, the educa-
389 tional allotment of the project participants was higher
390 than in the general population. In a less educated
391 cohort, one may have seen improved results. Anxiety
392 and confidence were measured subjectively. Future
393 projects may benefit from additional follow up and
394 should evaluate the influence of comorbid conditions
395 on treatment choice.

396 **CONCLUSIONS**

397 There was a statistically significant greater under-
398 standing of SRMs. A SDM model which incorporated
399 an educational video and structured provider discus-
400 sion showed improved patient knowledge, alleviation
401 of anxiety surrounding the diagnosis and improved
402 confidence with their chosen treatment plan. This ini-
403 tiative demonstrated the feasibility of implementing
404 a SDM model. Results should encourage providers
405 who aspire to incorporate a SDM as a *Best Practice*.
406 Future phases include expanding the SDM to a wide
407 variety of providers.

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AUTHOR CONTRIBUTIONS

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CONFLICT OF INTERESTS

The authors have no conflicts of interest to report.

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