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ACCEPTED MANUSCRIPT

What should we be studying? Research priorities according to women and gender diverse individuals with Sexual Interest/Arousal Disorder and their partners

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Abstract

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Background

Sexual Interest/Arousal Disorder (SIAD) is one of the most common sexual problems for women. In clinical research, there are often misalignments between the research priorities of patients and researchers, which can negatively impact care, and gender diverse individuals are often excluded from clinical research. Inclusion of patient perspectives when establishing research priorities may help to reduce these gaps, however, the research priorities of women and gender diverse individuals with SIAD and their partners remain unclear.

Aim

To identify the research priorities of women and gender diverse individuals with SIAD and their partners.

Methods

In an online survey, couples coping with SIAD provided consent and responded to an open-ended question asking them to list the top 3 things they think are important for researchers to focus on related to couples coping with low sexual desire. A team-based, content analysis was conducted to identify themes and their frequency of endorsement.

Outcomes

An author-developed open-ended question.

Results

Analysis of 1279 responses ($n = 667$ from women and gender diverse individuals with

53 SIAD, $n = 612$ from partners) resulted in our identification of 6 main themes: *general causes*,
54 *general treatment and coping*, *biophysiological*, *relationship*, *psychological*, and
55 *environmental/contextual*. Additionally, we identified 4 sub-themes within each of the latter 4
56 main themes: *general*, *cause*, *treatment*, and *impact*. For women and gender diverse individuals
57 with SIAD, their partners, and specifically gender diverse participants, the three most endorsed
58 themes were *psychological general factors* (24.3%, 21.2%, 24.3%; e.g., stress and the link between
59 SIAD and anxiety), *relationship general factors* (15.7%, 13.2%, 18.6%; e.g., relationship length and
60 communication on sexual desire), and *biophysiological general factors* (12.3%, 12.4%, 14.3%;
61 e.g., research on medications and hormones).

62 **Clinical Implications**

63 Clinical researchers should consider the research priorities of couples coping with SIAD
64 to ensure their work aligns with the needs of the affected population.

65 **Strengths and Limitations**

66 This study is the first to identify the research priorities of both women and gender diverse
67 individuals with SIAD and their partners. Most participants identified as heterosexual, North
68 American, and of middle to high socioeconomic status (SES).; results may not generalize.
69 Responses were sometimes brief and/or vague; interpretation of these responses was therefore
70 limited and may have required more contextual information.

71 **Conclusion**

72 Findings suggest that women and gender diverse individuals with SIAD, their partners,
73 and gender diverse participants have similar research priorities that are consistent with a
74 biopsychosocial approach to research. Heterogeneity of responses across themes support a
75 multidisciplinary, patient-oriented approach to SIAD research.

76 **Keywords:** Sexual Interest/Arousal Disorder, Patient-Oriented Research, Sexual Desire, Sexual
77 Arousal, Sexual Function, Couples.

78

79 **What should we be studying? Research priorities according to women and gender**
80 **diverse individuals with Sexual Interest/Arousal Disorder and their partners**

81 Low sexual desire and/or arousal that is distressing and persistent—Sexual
82 Interest/Arousal Disorder (SIAD)*—is the most common sexual problem among women and one
83 of the most frequent reasons for women[†] and couples to seek sex therapy.¹⁻³ Low sexual desire
84 and/or arousal can significantly impact a person’s well-being across a variety of domains.
85 Women with low sexual desire report adverse psychological (e.g., depression, poor self-
86 confidence), relationship (e.g., lower relationship satisfaction), and sexual (e.g., lower sexual
87 satisfaction) effects associated with this difficulty.⁴⁻⁶ In couples, partners of affected women also
88 report lower sexual satisfaction and higher sexual distress compared to partners of women
89 without SIAD, however, partner experiences have been primarily excluded from SIAD
90 research.^{6,7} Likewise, there is a dearth of literature investigating the experiences of gender
91 diverse populations with SIAD, limiting our understanding of SIAD primarily to the experiences
92 of cisgender women. Although researchers are dedicated to producing high-quality work that
93 benefits patients, including those affected by SIAD, their own priorities and those of patients are
94 not always harmonious.^{8,9} To optimize the benefits of research for patients, health research
95 organizations have developed patient-oriented research frameworks to provide guidance to

*The DSM-V-TR diagnosis is *Female* Sexual Interest/Arousal Disorder.¹³ Women who do not identify as female (e.g., transgender women, intersex individuals, and non-binary people) can also meet the diagnostic criteria. Consistent with best practices for inclusive research, we omitted “Female” from the diagnostic label and refer to participants as women and gender diverse individuals with SIAD.¹⁴

[†]Previous studies have referred to participants as women or female, but it is unclear whether their samples consisted of exclusively cisgender women.

96 researchers on how to effectively engage patients and ensure their voices are integrated in
97 research.¹⁰⁻¹² Although investigators have begun to include patients as partners in sex research,
98 no studies to our knowledge have directly consulted individuals with SIAD and their partners
99 about the research topics that are important to them.¹⁵⁻¹⁷ Thus, the goal of the current study was
100 to identify the research priorities of a sample of couples coping with SIAD. Findings may
101 provide investigators with a preliminary foundation for engaging in patient-oriented SIAD
102 research by showcasing the priorities of the affected population.

103 **Sexual Interest/Arousal Disorder**

104 Low sexual desire and/or arousal is a common experience for women.^{1, 2} Indeed,
105 population-based studies suggest that 8% to 23% of women report experiencing distressing
106 levels of low and persistent sexual desire and/or arousal.^{2, 18} Similar findings have been reported
107 among transgender women.^{19, 20} The *Diagnostic and Statistical Manual of Mental Disorders-Text*
108 *Revision 5th Edition* (DSM-5-TR) defines SIAD as an absence or decrease in sexual interest
109 and/or arousal for at least six months, that is distressing to the individual, and is not attributable
110 to an alternative source (e.g., other mental disorders, severe relationship distress, substance use,
111 or medical condition).¹³ The development and maintenance of SIAD is complex and multi-
112 faceted, consisting of biological, psychological, social, and interpersonal factors and has been
113 linked to a variety of individual and interpersonal challenges.⁷ Women affected by SIAD report
114 more symptoms of anxiety and depression and lower sexual and relationship satisfaction
115 compared to healthy controls and decreased quality of life.^{4, 6, 21} SIAD can also impact the
116 partners of affected individuals, who have reported lower sexual and relationship satisfaction,
117 poorer sexual function, and more sexual distress compared to partners of women without sexual
118 dysfunctions, highlighting the dyadic nature of SIAD.⁶ Treatments for SIAD have focused on

119 pharmacological interventions, which have mixed and limited evidence of efficacy, and
120 psychological interventions, whose efficacy appears to be more promising.²²⁻²⁵ Overall, SIAD is
121 a complex, multifactorial sexual disorder in its etiology, impact, and treatment. Yet, there remain
122 significant deficiencies in the understanding and access to services for SIAD. Only one in five
123 women with sexual dysfunctions report discussing their problems with a healthcare provider,
124 while nearly 60% of women with sexual dysfunctions report barriers to accessing treatment.^{26, 27}
125 Notably, there is a lack of research available on SIAD in gender diverse samples. A better
126 understanding of what aspects of SIAD affected couples, including gender diverse couples,
127 consider to be important for researchers to investigate may inform and direct patient-oriented
128 research that will better meet their needs.

129 **Patient-Oriented Research**

130 Although most health researchers intend to conduct research that will benefit patients,
131 quantitative and qualitative studies suggest a significant misalignment between the research
132 priorities of individuals with lived experience and researchers.^{8, 9, 28} A study by Crowe et al.
133 compared 14 patient- and clinician-identified treatment priorities for a variety of health
134 conditions with active studies evaluating treatments for the same conditions within the same time
135 period.⁸ Their findings suggested that despite patients and clinicians prioritizing a need for non-
136 drug treatments, researchers tended to prioritize drug trials.⁸ Pharmaceutical interventions have
137 also been emphasized in the treatment of SIAD.^{22, 29} Health research organizations frequently
138 allocate large sums of funding towards pharmaceutical research, which may incentivise
139 researchers to prioritize drug trials.^{30, 31} In contrast, disorders which primarily affect women are
140 historically underfunded, and psychological interventions for SIAD are comparatively
141 understudied, which may contribute to further misalignments in SIAD research.³² Studies which

142 neglect patient priorities may contribute findings that are of less or little benefit to patients and
143 delay access to more impactful treatments.^{33, 34} This oversight is particularly concerning
144 considering the high costs associated with conducting clinical trials and extensive time-
145 commitment required for health research and to the individuals seeking treatment.^{35, 36} Indeed,
146 there is an economic burden amassed by individuals with SIAD, whose medical expenses are
147 28% higher in the year prior to diagnosis and 20% higher in the year post-diagnosis.³⁷
148 Misalignments in research priorities may also have implications for theoretical
149 conceptualizations of SIAD, knowledge translation, and the causal associations formed by
150 individuals with SIAD, which can be detrimental to an affected individual's health and well-
151 being.³⁸ Chalmers and colleagues argue that one of the primary methods in which research funds
152 and resources are "wasted" occurs when investigators ignore the needs of those who consume the
153 research (i.e., patients and clinicians.)³⁹

154 Previous research suggests that including patient perspectives while establishing research
155 priorities may help to reduce the misalignment between the priorities of patients and
156 researchers.^{39, 40} This recommendation has been well-received by the academic community as
157 researchers are increasingly integrating principles of patient-oriented research into their
158 studies.^{41, 42} Inclusion of patient perspectives in research has improved the quality and relevancy
159 of health-related research at each stage, including the identification of relevant research
160 questions, increased participation rates, improved quality of measurements, and development of
161 more effective knowledge dissemination.^{43, 44} Of particular importance, research that engages
162 patient partners is likely to contribute findings that are of greater relevance and benefit for
163 patients and clinicians.⁴⁵

164 Early collaboration with patient partners is a core factor of patient-oriented frameworks
165 such that research projects should be a collaborative process between researchers and individuals
166 with lived experience from their inception.¹⁰ Patients should be consulted on the topics and
167 problems that are relevant to their experiences (i.e., their research priorities) and to help with
168 identifying existing research gaps.¹⁰ Researchers in sexual medicine are beginning to consult
169 with patients and the public about their research priorities. For example, Browne et al. developed
170 a list of the top 10 research priorities for sexually transmitted infections by seeking input from
171 patients, clinicians, and stakeholders of a sexual health clinic.¹⁶ Other studies have included
172 individuals with sexual dysfunctions in their research as patient partner collaborators (e.g.,^{15, 46,}
173 ⁴⁷). However, no studies to our knowledge have directly asked couples coping with SIAD to
174 identify their research priorities. Given the dyadic nature of SIAD, the primary aim of this study
175 was to identify the research priorities of women and gender diverse individuals with SIAD and
176 their partners using a qualitative approach. A secondary aim was to compare the frequency of
177 their stated priorities to effectively and accurately direct future research towards the topics
178 deemed most important by those affected by SIAD.

179 **Method**

180 **Positionality Statement**

181 In the interest of transparency and reflexivity, we recognize that our social identities and
182 lived experiences influenced, to some extent, each stage of the research process. All authors have
183 been or are currently being trained in Canadian Clinical Psychology programs at the doctoral
184 level, where their research and clinical approaches to sexual dysfunction are informed by a
185 biopsychosocial framework. One author identifies as a mixed-race, non-binary, queer individual,
186 three identify as cisgender, heterosexual, White women, and one identifies as a cisgender Latina
187 woman.

188 **Participants**

189 The data for the present study were drawn from a larger study conducted from November
190 2020 to May 2022. The larger study comprised three longitudinal time-points (baseline, 6-, and
191 12-months) and a 56-day daily survey component. The present study used data collected from
192 the baseline survey only. Women and gender diverse individuals[‡] with SIAD ($n = 288$) and their
193 partners ($n = 274$) were recruited from Canada ($n = 428$) and the US ($n = 20$) through print and
194 online advertisements (e.g., Instagram, Facebook). Specific efforts were made to diversify
195 recruitment sources from underrepresented groups, for example, by contacting sexual and
196 gender/sex diverse and Black, Indigenous, and people of colour-identified community groups. To
197 participate, couples were required to be 18 years of age or older, fluent in English or French, and
198 in a committed relationship for at least one year with a minimum of four in-person contacts per

[‡]Participants could endorse multiple gender identities, including identifying as a woman with a gender diverse identity (e.g., transgender). The term “women” refers to any participants who self-identified exclusively as women. “Gender diverse” represents participants, including women, who self-identified with any other gender identity (e.g., transgender, non-binary, Two-Spirit). All participants with SIAD were assigned female at birth, however, we refer only to participant’s gender identities.

199 week in the last month to ensure opportunities for in-person contact. Participants were eligible
200 regardless of their current gender identity (e.g., transgender, non-binary, women), however, one
201 couple member was required to have been assigned female at birth and met DSM-5-TR criteria
202 for SIAD.¹³ Specifically, participants (with SIAD) were eligible if they reported at least three of
203 six symptoms indicative of an absence or decrease in sexual interest and/or arousal and satisfied
204 all other criteria.¹³ Participants were excluded if they were pregnant, breastfeeding, one year
205 postpartum, had no prior sexual experience, or were being actively treated for SIAD. The
206 complete flow of participants into the larger study can be found on the Open Science Framework
207 (OSF; https://osf.io/sdrjm/?view_only=85330520771045e1ad37eea8f244e607). In some couples,
208 only one member completed the baseline survey, however, their data were still included in the
209 final sample for the current study. A total of 57 participants with SIAD and 57 partners did not
210 respond to the question relevant for the current study and were excluded. Therefore, the final
211 sample size for the current study was 231 with SIAD and 217 partners. Descriptive statistics for
212 participant demographics are found in Table 1.

213 **Procedures**

214 Interested participants first completed a brief screening phone call with a member of our
215 research team to assess initial eligibility. Screening calls were conducted with both couple
216 members, however, if both partners were unavailable, screening was completed with the
217 individual with SIAD, and assent was obtained from their partner via email. Then, to confirm the
218 diagnosis of SIAD, a semi-structured 30- to 45-minute clinical interview was scheduled with the
219 couple member experiencing low sexual desire and/or arousal via phone or Zoom video
220 conferencing with a member of the research team trained in assessing SIAD. Prior to the clinical
221 interview, the couple member with low sexual desire and/or arousal completed a consent form

222 via Qualtrics for both the clinical assessment and the study. Eligible couples were sent a
223 welcome email which included the key components of the informed consent form. Separate
224 emails were then sent to each couple member via Qualtrics with individualized links to the
225 baseline survey, and partners of individuals with SIAD provided informed consent at the
226 beginning of their survey. Participants were instructed to complete their survey independently
227 from their partner. The survey took approximately 40 to 60 minutes to complete. Survey links
228 expired after four weeks. Each participant was compensated \$15 CDN (or USD equivalency),
229 paid by either gift card or e-transfer upon completing the baseline survey. Participants were also
230 provided a list of SIAD relevant resources at the end of the larger study. The study was approved
231 by (*masked for review*).

232 **Measures**

233 *Demographics*

234 Participants reported their age, gender, sexual orientation, culture, education, relationship
235 status and length, and combined annual income. Participants with SIAD also reported their
236 duration of SIAD.

237 *Important Research Topics in SIAD*

238 Participants responded to the following open-ended question: “*We are interested to know*
239 *what you think is important for researchers to study when it comes to the experiences of couples*
240 *coping with low sexual desire. In the space below, please list the top 3 things that you would like*
241 *to see researchers focus on. Please be as specific as possible in your answer.*”

242 **Data Analyses**

243 The current study applied inductive methodologies, which allowed participants to
244 identify their priorities in their own words, using the question as a starting point.⁴⁸ Participant

245 responses ranged from a single word to five sentences and a majority of responses were one
246 sentence long. Analyses were based upon Marks team-based, qualitative analysis approach using
247 NVivo for Mac software (version 1.7.1).⁴⁹⁻⁵¹ Marks team-based approach is a form of content
248 analysis which allows researchers to both identify core themes and quantify their prevalence
249 within the data, a method Marks refers to as Numeric Content Analysis, adding greater
250 methodological rigor relative to traditional content analyses.^{49, 50, 52} Initially, participant
251 responses were exported from Qualtrics and uploaded to NVivo. To identify initial themes, two
252 coders (*initials masked for review*) independently open-coded each participant response. Open-
253 coding involves reading each participant response and assigning a code that reflects the general
254 meaning of the response.⁴⁹ Coders then met with the study lead (*initials masked for review*) to
255 identify common themes among the open-codes. At this team meeting, each coder presented
256 their most frequently recorded codes, while the team lead noted each code and frequency counts.
257 After deliberation, we identified 6 main themes (general causes, general treatment and coping,
258 biophysiological, relationship, psychological, and environmental/contextual) and 4 sub-themes
259 (general, cause, treatment, and impact) for each of the latter 4 main themes, resulting in 18
260 possible codes. A detailed definition of each code was established. Independently from one
261 another, the two coders then used these 18 codes to systematically code each participant
262 response. Responses relevant to more than one theme were coded under multiple codes.⁵⁰ Upon
263 completion, the two coders met to review their systematic codes and resolve discrepancies, while
264 tracking agreements and disagreements for interrater reliability (IRR). Agreements were
265 identified when researchers initially disagreed upon the classification of a code, but unanimously
266 agreed to keep, change, or remove the code.⁵⁰ Unresolvable disagreements were identified in
267 instances where an agreement on the classification of a code could not be made, but was added

268 or removed based upon the opinion of one coder.⁵⁰ IRR was calculated by taking the number of
269 agreements and dividing by the sum of agreements and unresolvable disagreements.⁵⁰ IRR
270 between coders was high (99%). Finally, coders performed a Numeric Content Analysis by
271 documenting how frequently each theme was identified within responses.⁵⁰

272 **Results**

273 Analysis of 1279 responses ($n = 667$ from women and gender diverse individuals with
274 SIAD, $n = 612$ from partners) resulted in our identification of 6 main themes: *general causes*,
275 *general treatment and coping*, *biophysiological*, *relationship*, *psychological*, and
276 *environmental/contextual*. We also identified 4 sub-themes within each of the last four
277 aforementioned themes: *general*, *cause*, *treatment*, and *impact*. Detailed descriptions of each
278 theme, definitions, example responses, and the codebook can be found within our supplementary
279 materials and are available on OSF:
280 (https://osf.io/sdrjm/?view_only=85330520771045e1ad37eea8f244e607). Ranked order of the
281 frequency of the themes for both participants with SIAD and their partners can be found in Table
282 2. Given the scarcity of SIAD research among gender diverse populations, we also present the
283 frequency of themes among only gender diverse participants (Table 3). To maintain saliency and
284 digestibility, themes that comprised less than 5% of all responses for women and gender diverse
285 individuals with SIAD and/or their partners (e.g., *environmental/contextual impact*; 0.0%, 0.7%)
286 are not presented here but are listed in the supplementary materials (theme definitions and
287 examples) and Table 2 (frequency of all themes). Thus, the following sections present, in rank-
288 order, the most salient key themes: *general causes*, *general treatment and coping*, two
289 biophysiological sub-themes (*general* and *cause*), three relationship sub-themes (*general*,

290 *treatment*, and *impact*), two psychological sub-themes (*general* and *cause*), and one
291 environmental/contextual sub-theme (*general*).

292 ***Psychological General***

293 *Psychological general* was the most common theme coded among participants.
294 *Psychological general* was coded when participants indicated that researchers should focus on a
295 broad psychological factor, without specifying it in relation to cause, treatment, or impacts. For
296 example, one partner (age 26)[§] wrote: “Relation to mental health issues (stress, depression,
297 anxiety, PTSD).” Within this theme, many participant responses made general references to
298 vague psychological factors such as “stress” (partner age, 41) and “self-esteem” (participant with
299 SIAD, age 60).

300 ***Relationship General***

301 The theme of *relationship general* was coded when participants indicated a broad
302 mention of a relationship factor for researchers to focus on, without specifying it in relation to
303 cause, treatment, or impacts. While many responses reported that researchers should focus on
304 “communication about sexual desire between partners” (participant with SIAD, age 36), another
305 example in this code referenced non-monogamy: “The sexual openness of couples, having a
306 sexual partner other than their spouse” (partner, age 47).

307 ***Biophysiological General***

308 The theme of *biophysiological general* was coded when participants indicated that
309 researchers should focus on a broad mention of a biophysiological factor, that is without
310 specifying it in relation to cause, treatment, or impacts. This code included instances where it
311 was unclear whether participant responses reflected a cause, treatment, or impact, such as the

[§] To maintain anonymity, participant ages were adjusted ± 5 years.

312 response of a 45-year-old participant with SIAD: “Hormonal changes.” Some participants made
313 general references to health, including a 40-year-old partner who wrote “Medical issues.”

314 *General Treatment and Coping*

315 The theme of *general treatment and coping* was coded when participants indicated that
316 researchers should focus on unspecific or general solutions and management of low desire.
317 Responses indicated a general need for effective methods for the management of low desire. For
318 instance, a participant with SIAD (age 25) identified “Coping mechanisms that work” as an
319 important research topic, while a partner (age 21) wrote “Possible treatments or therapies for low
320 desire.”

321 *General Causes*

322 The theme of *general causes* was coded when participant responses reflected an
323 unspecific or general cause for low desire. Responses coded under this theme were consistently
324 vague, for example, a partner (age 35) indicated “Cause of low sexual desire” as important for
325 researchers to study. Likewise, a participant with SIAD (age 27) wrote “Figuring out the
326 reason(s) for low desire.”

327 *Environmental/Contextual General*

328 This theme was coded when participants indicated broad mention of an environmental or
329 contextual factor as something that researchers should focus on, that is without specifying it in
330 relation to cause, treatment, or impacts. This is illustrated by participants with SIAD who stated:
331 “Effects of the pandemic” (age 27) and “Work responsibilities and family responsibilities” (age
332 35).

333 *Relationship Treatment*

334 The theme of *relationship treatment* was coded when participants indicated that
335 researchers should focus on solutions or management of low desire in a relationship context.
336 Responses under this theme included: “How to make the other partner understand more”
337 (participant with SIAD, age 34) and “How to communicate better when talking about sex”
338 (partner, age 27).

339 ***Psychological Cause***

340 The theme of *psychological cause* was coded when participants reported that researchers
341 should focus on a psychological reason for low desire. Participant responses often reflected a
342 broad interest in the psychological causes for low desire, such as this 51-year-old participant
343 with SIAD: “psychological causes.” Other participants indicated specific psychological factors
344 such as “How stress affects desire” (partner, age 22) and “Is it related to past trauma?”
345 (participant with SIAD, age 31).

346 ***Relationship Impact***

347 The theme of *relationship impact* was coded when participants indicated that researchers
348 should focus on effects of low desire on their romantic relationship. Participants reported interest
349 in understanding the impact of SIAD on various aspects of relationship well-being such as a
350 participant with SIAD (age 26) who wrote: “If/how the lack of desire puts strain on the
351 relationship.” Another example of a response in this theme highlighted interest in research that
352 examines the impacts of sexual rejection on the relationship: “The consequences of repeated
353 refusals on the relationship” (partner, age 31).

354 ***Biophysiological Cause***

355 The theme of *biophysiological cause* was coded when participants indicated that
356 researchers should focus on a biophysiological cause for low desire. Participant responses

357 indicated that researchers should focus on the associations between aging and low desire, such as
358 a 39-year-old partner who responded, “How desire changes with age.” Some participants,
359 including a 37-year-old with SIAD expressed interest in the biological origins of SIAD: “Could
360 it be genetic?”

361 **Research Priorities of Gender Diverse Participants**

362 Additionally, we analyzed only the responses from participants who identified as gender
363 diverse (i.e., any gender identity other than cisgender man or woman). To maintain anonymity,
364 responses from gender diverse individuals with SIAD and gender diverse partners were analyzed
365 as one group. Analysis of 140 responses ($n = 51$) revealed that gender diverse participants
366 endorsed the same three most important (i.e., *psychological general*, *relationship general*, and
367 *biophysiological general*) and least important (i.e., *environmental/contextual treatment*,
368 *biophysiological impact*, and *environmental/contextual impact*) research priorities as the larger
369 sample.[¶]

370 **Discussion**

371 This study aimed to identify the research topics deemed important by couples coping
372 with SIAD. To our knowledge, this was the first study to identify the research priorities of
373 couples coping with sexual dysfunction. Participant responses were classified into six main
374 themes: *general causes*, *general treatment and coping*, *biophysiological*, *relationship*,
375 *psychological*, and *environmental/contextual*. Furthermore, four sub-themes were identified for
376 each of the aforementioned latter four themes and included: *general*, *cause*, *treatment*, and
377 *impact*. The three most endorsed themes overall were *psychological general* factors (24.3%,
378 21.2%, 24.3%; e.g., stress and anxiety), *relationship general* factors (15.7%, 13.2%, 18.6%; e.g.,

[¶] When all responses from gender diverse participants were removed from the full sample, the most and least endorsed themes of the larger sample remained unchanged.

379 relationship length and communication about sexual desire), and *biophysiological general*
380 factors (12.3%, 12.4%, 14.3%; e.g., research on medications and hormones). In contrast, for
381 individuals with SIAD, their partners, and gender diverse participants, the three least endorsed
382 themes were *environmental/contextual treatment* (0.9%, 0.2%, 0.0%; e.g., public education),
383 *biophysiological impact* (0.3%, 0.5%, 0.0%; e.g., effect of SIAD on health), and
384 *environmental/contextual impact* (0.0%, 0.7%, 0.0%; e.g., effect of SIAD on employment).
385 Taken together, these findings suggest that participants are especially interested in research that
386 generally taps into psychological, relationship, and biological factors broadly speaking, which is
387 consistent with a biopsychosocial approach to this sexual dysfunction.⁵³

388 **A Multidisciplinary Approach to SIAD Research**

389 The most frequently endorsed themes in this study align with biopsychosocial
390 conceptualizations of women's sexuality, which argue that sexual function should be approached
391 with consideration of the associated biological, psychological, and social factors.⁵³ This model
392 has also been reflected in both research and theoretical models that examine the etiology,
393 consequences, and treatment approaches to SIAD.⁵³⁻⁵⁶ For example, a review by Parish and Hahn
394 explained that the onset of distressing low sexual desire is associated with both biological (e.g.,
395 hormonal imbalances, neural variations in encoding sexual stimuli) and social factors (e.g.,
396 relationship status), while other studies have linked a variety of biopsychological factors, such as
397 the roles of cortisol and depressive symptoms in low sexual desire.^{7, 57} In terms of consequences,
398 research by Rosen et al. found that both people with SIAD and their partners experience more
399 negative consequences compared to those without sexual dysfunction including biological (e.g.,
400 comorbid sexual dysfunction, pain), psychological (e.g., sexual distress, depressive symptoms),
401 and relational (e.g., poor sexual communication, lower relationship satisfaction) consequences.⁶

402 Treatments for SIAD have generally focused on biological and psychological interventions, with
403 no empirically-supported (i.e., randomized controlled trial) couple-based treatments currently
404 available.^{22, 25}

405 In the current study, while participants reported interest in each theme, responses were
406 widely distributed across the six main themes. The heterogeneity of responses across themes
407 suggests that couples coping with SIAD have diverse perspectives, likely rooted in their
408 individual experiences that are not uniform. Indeed, there is evidence that the experience and
409 impact of SIAD for couples differs according to age, relationship status, and how partners
410 respond to low sexual interest/arousal.⁵⁸⁻⁶⁰ That participants endorsed priorities across
411 psychological, relational, and biological factors supports a multidisciplinary approach to SIAD
412 research, such that researchers from across disciplines (e.g., psychology, gynaecology,
413 physiology) should work collaboratively to address the research priorities of this population
414 within a biopsychosocial framework. Within each of the main themes, responses were spread
415 across the four sub-themes, suggesting that couples coping with SIAD believe it is important for
416 researchers within each discipline to address the causes, treatments, and impacts of SIAD from a
417 biopsychosocial approach. Moreover, both participants with SIAD and their partners reported
418 similar themes for both their most and least endorsed research priorities, suggesting that couple
419 members have relatively similar priorities. Likewise, our findings suggest that people who
420 identify as gender diverse, also share these research priorities. Thus, researchers might consider
421 these priorities regardless of whether their sample consists of individuals with SIAD, their
422 partners, couples, and that these extend to gender diverse individuals and couples with SIAD.

423 In the current sample, individuals with SIAD and their partners, - including gender
424 diverse participants - endorsed *environmental/contextual treatment*, *biophysiological impact*, and

425 *environmental/contextual impact* as the three least important topics for researchers to study. It is
426 possible that treatments focused on changes to one's environment/context (e.g., public education)
427 may be perceived as less amenable to change at an individual level and outside of an individual's
428 control. As such, participants may prioritize research topics for treatment that they perceive to be
429 more accessible and achievable, such as biological, psychological, and relationship-focused
430 treatments. Responses were only coded as environmental/contextual impact when participants
431 endorsed topics that focused on SIAD directly impacting something in their
432 environment/context. The environmental/contextual impacts of SIAD may result in additional
433 effects (e.g., *stress* of work, which then impacts their experience of SIAD) that are perceived by
434 participants as more important and more distressing than the initial impacts of SIAD on their
435 environment/context. These additional effects may have been captured within a different theme
436 (i.e., psychological general). Likewise, responses were coded as biophysiological impact when
437 they reflected topics of low desire impacting one's biology or physical functioning. Low
438 endorsement of this topic may be related to participants' lack of familiarity with how low sexual
439 desire and arousal can be associated with physical function, or how aspects of their physical
440 function may be a precursor to their low desire (e.g., genito-pelvic pain, dysregulation of the
441 HPA axis).^{6, 61} If participants are unaware of the biophysiological correlates of SIAD then they
442 may prioritize research on topics that are more salient to their knowledge and experiences, and
443 consistent with sociocultural representations (e.g., relationship impacts).⁶ Alternatively, it is
444 possible that any factors that are perceived by participants as a biophysiological impact of SIAD
445 are seen as less distressing relative to the perceived impacts of SIAD on their relationship and
446 psychological well-being and hence of lower priority. It should be noted that these explanations
447 are speculative, and more research is required to identify the rationale behind the most and least

448 frequently endorsed research priorities of this population. Nonetheless, it is important for
449 researchers to be aware of the topics that are reported to be lower priority for couples coping
450 with SIAD so that they may allocate their resources towards the immediate needs of the affected
451 populations.

452 **Limitations and Future Directions**

453 The present study has some notable limitations. First, most participating couples were
454 heterosexual, North American, and of middle to high socioeconomic status (SES). Thus,
455 generalizability of the present findings should be interpreted with caution. The minority stress
456 model suggests that historically marginalized populations (i.e., sexual and racial minorities, and
457 low SES) face unique stressors (e.g., stigma, prejudice, and discrimination) impacting health
458 outcomes.⁶² Moreover, consistent with this model, minority populations are at increased risk of
459 discrimination within health settings, which may limit accessibility to health services.⁶³⁻⁶⁶ As
460 such, it is plausible that the research priorities of those affected by SIAD who are from minority
461 populations may differ from those of majority groups. Future research should examine the
462 research priorities in a more diverse sample of couples coping with SIAD.

463 Second, participants responded to an open-ended question through an online survey.
464 Although this method allowed for the collection of data from a larger sample, the results of this
465 study are limited by our ability to interpret responses that were sometimes brief and/or vague and
466 may have required more contextual information. Moreover, participants responded to a
467 psychological survey related to SIAD. It is possible that participants in this study were biased
468 toward a greater interest in psychological factors (as reflected by this being the most endorsed
469 theme). As a result, this study may not capture the priorities of individuals with SIAD and their
470 partners who are less motivated to participate in psychological research. Notably, the specific

471 question posed to participants omitted reference to sexual arousal. As such, the current findings
472 may not fully represent the priorities of couples who experience challenges with sexual arousal.
473 Together, these limitations may significantly limit the generalizability of our findings.
474 Alternative methodologies such as qualitative interviews and focus groups, from a multi-
475 disciplinary perspective, may allow participants to expand upon their responses, ensure
476 responses are interpreted within sufficient context, and reveal research priorities that were not
477 captured in the current study. Furthermore, the current study did not ask participants to specify
478 why they wanted researchers to focus on the topics they endorsed. Such information would
479 contribute to a more comprehensive understanding of the research needs of couples coping with
480 SIAD and better inform researchers conducting patient-oriented research. Finally, although this
481 research took a patient-oriented perspective by consulting individuals with lived experiences
482 about their research priorities, it did not follow all principles of patient-oriented research (e.g.,
483 full involvement of patients on the research team). Future research may benefit from the
484 inclusion of patient perspectives at each stage of the research process.

485 **Conclusion**

486 The present study identified the research priorities of individuals affected by SIAD and
487 their partners. Identifying the research priorities of people with lived experience and their
488 families is a key component of patient-oriented research frameworks.¹⁰ Moreover, the inclusion
489 of patient perspectives when establishing research priorities may help to reduce the misalignment
490 between their priorities and those of researchers and improve the quality and relevancy of health
491 research.^{39, 40, 43, 44} As the first to our knowledge to identify the research priorities of women and
492 gender diverse individuals with SIAD and their partners, this study provides investigators with a
493 foundation for engaging in patient-oriented SIAD research by showcasing the priorities of the

494 affected population. Importantly, these findings provide empirical evidence that women and
495 gender diverse individuals coping with SIAD and their partners think that researchers should
496 prioritize psychological, relationship, and biological factors, which aligns with a biopsychosocial
497 approach and current recommendations from researchers and clinicians.⁵³ However, their
498 priorities were heterogenous overall, which may reflect the diversity of experiences of those
499 coping with SIAD; continued consultation and integration of the patient perspective is essential
500 for ensuring that the unique needs of this population are met. Importantly, there is a specific need
501 to identify the research priorities of women and gender diverse individuals with SIAD and their
502 partners from underrepresented populations, to develop a more comprehensive conceptualization
503 of SIAD. Such research may allow for the development of more inclusive and efficacious
504 interventions for women and gender diverse individuals with SIAD and their partners. We as
505 researchers should be studying topics that are a priority for couples coping with SIAD. As such,
506 consistent with recommendations from patient-oriented research frameworks, we encourage
507 researchers to consider the research priorities identified in this study to ensure their research
508 aligns with the current needs of the affected population.¹⁰⁻¹²

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