Original Article

Support Needs and Gaps for Black and African American Individuals With Fibromyalgia During Pregnancy

Katelyn Matkin; Ph.D.[1], Susan Smedema; Ph.D.[2], Megan Baumunk; Ph.D.[2], Jina Chun; Ph.D.[2], Muna Bhattarai; Ph.D.[3]

1 Department of Rehabilitation and Health Services, University of North Texas, Denton, TX, USA
2 Department of Rehabilitation Psychology and Special Education, University of Wisconsin-Madison, Madison, WI, USA
3 Harris College of Nursing and Health Sciences, Texas Christian University, Fort Worth, TX, USA

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Abstract

Objective: Individuals with disabilities, including those with fibromyalgia, have historically faced barriers and stigma in healthcare settings. This issue extends to reproductive health areas, such as pregnancy. Previous research on the pregnancy experiences of individuals with disabilities has predominantly focused on physical or visible disabilities. Furthermore, many studies have overlooked the intersectionality of additional identities, including race and gender identity. This thematic analysis aimed to provide insight into the unique experience of pregnancy for individuals with fibromyalgia.

Materials and methods: A total of eight semi-structured interviews were conducted with participants who identified as having fibromyalgia, and had experienced a pregnancy with a live birth within the last 12 months at the time of the interview. Most participants identified as Black/African American. Interviews were analyzed using a reflective thematic analysis approach to identify key themes within the participants' responses.

Results: Participants articulated four major themes concerning their experiences of pregnancy with fibromyalgia: (1) acquiring a chronic and unpredictable condition; (2) the adjustment to pregnancy and parenting; (3) building trust and addressing doubt: healthcare dynamics in fibromyalgia management; and (4) seeking and receiving social support: a multifaceted experience. Each theme contains important subthemes that reflect the dynamic and varied experiences associated with pregnancy with fibromyalgia.

Conclusion: This study elucidates the unique experience of pregnancy among individuals with fibromyalgia, a historically marginalized population. The findings highlight substantial opportunities for improving the pregnancy-related care provided by healthcare providers, including rehabilitation professionals, for individuals with fibromyalgia.

Keywords: Reproductive Access; Pregnancy; Fibromyalgia; Individuals With Disabilities

Introduction

Fibromyalgia, a central nervous system disorder often referred to as fibromyalgia syndrome (FMS), has received limited attention in reproductive research despite its relevance. FMS is a chronic condition characterized by widespread pain and frequently co-occurs with migraines, irritable bowel syndrome,

Correspondence:
Dr. Katelyn Matkin
Email: katelyn.matkin@unt.edu

depression, and pelvic pain (1). The diagnosis of fibromyalgia has been controversial, partly due to confusion about its origins and symptom variability (2, 3). Predominantly affecting women of childbearing age, fibromyalgia is a critical consideration for reproductive care providers. Research shows conflicting outcomes regarding its impact on pregnancy, with some studies reporting increased symptoms and adverse outcomes (4, 5) and others finding no effect (6). Managing fibromyalgia during pregnancy poses challenges, as some medications are unsafe (7). Pregnancy often exacerbates symptoms like pain, depression, and anxiety, which can influence fetal outcomes (8). Additionally, individuals from minority ethnic backgrounds face systemic disparities in pregnancy and birth care (9).

Pregnancy and parenting are well-documented experiences where social support plays a critical role in well-being (10, 11). Social support encompasses various sources, including family, friends, partners, healthcare providers, and others, all of whom can significantly influence access to reproductive services (12). Higher social support is associated with improved well-being among pregnant individuals (13), but strained relationships with family or partners can exacerbate mental health symptoms such as anxiety during pregnancy and postpartum periods (14). For disabled individuals, social support is crucial across diverse cultural contexts (15-17). Healthcare providers play a key role in support, but their approach historically reflects a medical model of care; one that focuses on "curing" disability rather than providing holistic care and perpetuating ableism despite calls for inclusive practices (10, 18). This qualitative study seeks to address gaps in the literature related to the reproductive experiences of individuals with non-visible disabilities like fibromyalgia. While visible disabilities have been studied, little is known about how intersecting factors such as race and disability status shape pregnancy experiences in nonvisible disabilities. This research aims to explore these social factors and provide insights into this under-studied population.

Materials and methods

This study was approved by the University of Wisconsin-Madison Institutional Review Board. Participants were recruited via Facebook groups targeted towards women, individuals with fibromyalgia, and those experiencing pregnancy. To be eligible, participants needed to be over the age of 18, identify as having fibromyalgia before their most recent pregnancy and have experienced pregnancy and birth to a live child within the last 12 months. Eligible participants were identified through a screening questionnaire via Qualtrics, which received 261 total responses. Once participants who fit the study's criteria were identified, additional screening was implemented to assist in the avoidance of 'imposter participants,' (19). Participants were screened out if multiple responses came from the same IP addresses, if they provided the same email address in their contact information, if they provided a phone number that was not from the United States, and if they provided the same responses to all screening questions.

Through this screening protocol, 12 participants were identified as meeting all criteria and were contracted for an interview. Of the 12, 8 completed the initial scheduling and interview (67%). Of those who did not complete the process, two participants' interviews were canceled due to repeated IP addresses (17%), one never confirmed their interview time (8%), and one participant confirmed their interview time but did not attend (8%).

The screening questionnaire contained the study's informed consent form. Additionally, at the beginning of each interview, participants were required to confirm again that they read the informed consent and agreed to participate.

Interviews were conducted by the primary investigator via Zoom and were recorded with caption features. Captions of interviews were edited until they were accurate and were uploaded to DeDoose software for coding.

Reflective Thematic Analysis: Transcripts were analyzed using a reflective thematic analysis approach (20). A six-phase data analysis procedure, as outlined by Nowell and colleagues (21), was followed. With the assistance of a coder, the primary investigator created the themes and codes until they agreed that they were representative of what participants shared. This process was fluid and flexible and included numerous reflections as documented via an audit trail (22). Once a report was generated, it was reviewed by an auditor to ensure reliability and understandability.

As highlighted by Scharp & Thomas (23), to effectively engage in social science research, researchers must reflect on their identities as they may relate to the interpretation of findings. The primary investigator identifies as a cis-gender, White woman with a chronic health condition. The researcher has experienced barriers and facilitators to reproductive healthcare and has worked directly with pregnant/parenting individuals with various chronic disabilities, both of which sparked interest in this topic. Collaboration with research team members and other professionals was utilized throughout this project to avoid bias and increase the trustworthiness of the study.

Results

The final sample for this study consisted of eight participants. All participants were diagnosed with fibromyalgia before their most recent pregnancy, and almost all (n=7) identified as Black/African American. Most recent pregnancies ranged from 11 months to 4 months ago at the time of the interview. Five participants had experienced a prior pregnancy, although not all resulted in the birth of a child; two participants noted experiencing miscarriages in the past. A summary of participant characteristics can be found in Table 1. Data analysis resulted in a robust description of the experience of pregnancy with fibromyalgia. A final version of all themes and subthemes can be found in Table 2.

Theme 1: Acquiring a Chronic and Unpredictable Condition

Subtheme 1: Acquiring a chronic and unpredictable condition. Participants described fibromyalgia primarily through its most salient symptom: pain. This pain, often the first noticeable symptom before diagnosis, was characterized as persistent, sharp, intermittent, severe, achy, stiff, and widespread.

Table 1: Participant Characteristics Summary

Parameters	Frequency (n)
Race/Ethnicity	
African American/Black American	7 (88%)
White	1 (12%)
Marital Status	
Married	6 (75%)
Living with domestic partner(s)	1 (12.5%)
Single	1 (12.5%)
Education Level	
Some postsecondary experience	1 (12.5%)
College degree (Bachelor’s)	6 (75%)
Graduate degree (Master’s level or higher)	1 (12.5%)
Employment Status	
Employed full time	6 (75%)
Employed part time	1 (12.5%)
Non-paid work (e.g., volunteering or freelance work)	1 (12.5%)
Household Income (US dollars)	
$10,000 to $29,999	2 (25%)
$30,000 to $49,999	2 (25%)
$50,000 to $69,999	0
$70,000 to $99,999	4 (50%)
Type of Insurance	
Medicaid	5 (62.5%)
Medicare	1 (12.5%)
PPO	1 (12.5%)
HMO	1 (12.5%)
Number of Pregnancies	
1	3 (37.5%)
2	5 (62.5%)
Comorbid Disabilities/Diagnoses*	
Chronic Migraines	1 (12.5%)
Posttraumatic Stress Disorder	1 (12.5%)

Table 2: Summary of themes and subthemes from data analysis

Themes	Subthemes
Acquiring a chronic and unpredictable condition	Fibromyalgia symptomology Adjusting to fibromyalgia diagnosis Mental and emotional impact
Adjustment to pregnancy/parenting	Pregnancy decision-making Fibromyalgia and pregnancy symptomology Mental and emotional impact
Healthcare dynamics in fibromyalgia management	Stigma and invalidation in healthcare Competence in fibromyalgia Establishing trust between provider and patient Demographic match Individualized approach
Seeking and receiving social support: A multifaceted experience	Physical presence and daily support Support impacting emotional well-being Financial support Received support vs. desired support

Pain locations varied, including the back, hips, and joints, and often disrupted daily functioning, particularly sleep. Many struggled with getting comfortable at night, leading to poor sleep and excessive daytime fatigue. This fatigue, described as unrelenting and unaffected by rest, contributed to frequent "brain fog," confusion, and difficulty concentrating.

The unpredictability of symptoms was a shared challenge. Some participants expressed immense frustration at not knowing when symptoms would arise, while others adapted by accepting the lack of control. One participant stated they “can’t…control (their) life” and were less upset when symptoms emerged. Regardless of their outlook, unpredictability often hindered the participants' ability to complete daily tasks, care for children, or work. It necessitated frequent changes to plans, flexibility, and access to resources.

Subtheme 2: Adjusting to fibromyalgia diagnosis. Receiving a fibromyalgia diagnosis was rarely straightforward. Many participants described seeing multiple doctors and specialists before obtaining an official diagnosis. Some faced dismissive attitudes, as one participant shared: “No one seemed to like, you know, know what was wrong with me. (It was) just like, okay take pain medications and stuff like that, and I knew it was more than just ordinary pain.” For others, the process involved months of trial and error and extensive medical testing to rule out other conditions.

Emotional responses to the diagnosis varied. Two participants described feeling relief, with one stating, “I was relieved that…finally, I knew exactly what was wrong, like there was a name for it.” However, this relief was often accompanied by stress. While information on management strategies was helpful, the lifelong nature of the symptoms felt overwhelming. Many participants expressed feeling like a burden to loved ones. As one noted, “I feel like I’m stressing everyone else…because everyone has to take care of me when I go through (flares).”

Subtheme 3: Mental and emotional impact. The adjustment to fibromyalgia and its chronic symptoms was closely tied to psychological challenges. Participants reported feeling anxious during periods of low symptom impact, anticipating potential flare-ups. During severe symptoms with low mobility, fatigue, and reduced ability to meet daily obligations, feelings of depression were most intense.

Discussing these psychological experiences was difficult for many, with participants hesitant to delve deeply, often summarizing it as “hard.” Some expressed visible emotions during interviews, such as shaky voices, tears, or sighs. When asked about coping strategies, many highlighted the importance of social support. Notably, no participant recalled psychological symptoms being addressed during their diagnosis process.

Theme 2: Adjustment to Pregnancy/Parenting.

Subtheme 1: Pregnancy-decision making. Uncertainty about how fibromyalgia symptoms might worsen made pregnancy “a hard decision to make” for many participants. This uncertainty often led to reluctance and extended deliberation before deciding to become pregnant. One participant shared, “I actually don’t think I would want to go through the pain and stress that I did go through (again).” Another expressed, “I don’t know if saying this makes me sound like a bad mother, but I went through hell and I do not want to go through or live that again.”

For some, the challenges of a pregnancy with fibromyalgia were enough to dissuade them from considering it again. However, not all participants felt conflicted. Two participants were certain they would have children despite their condition. As one explained, “I’ve always wanted a baby, so I knew at some phase in my life I would definitely have a baby.”

Subtheme 2: Fibromyalgia and pregnancy symptomology. The combination of fibromyalgia and pregnancy created unique challenges for participants. For some, pregnancy symptoms like high blood pressure, swelling, pre-eclampsia, and nausea were difficult to manage on their own and compounded the difficulties of fibromyalgia. Most participants reported that pregnancy intensified their fibromyalgia symptoms. The added weight and strain of pregnancy worsened pain, particularly in the back, hips, thighs, and legs—areas already sensitive before pregnancy.

Managing both conditions simultaneously was often described as a ‘balancing’ act. One participant explained that the unpredictability of fibromyalgia and pregnancy required constant attention and flexibility, as strategies that worked before pregnancy were often ineffective during it. For example, “during pregnancy, medication options are limited, so managing my pain became…much more difficult.” To cope, participants engaged in symptom management activities recommended by healthcare providers, such as specific physical exercises, massage, stretching, physical therapy, walking, and meditation. The effectiveness and ease of these techniques varied, but they were viewed as the only available options for support during pregnancy.

Subtheme 3: Mental and emotional impact. Adjusting to parenting with fibromyalgia brought continued anxiety and depression, compounded by pregnancy-related hormone changes and parenting demands. The combination of these physically and mentally intense experiences was unique to this study's population. Social support remained the most cited source of emotional relief, helping participants navigate these challenges.

Theme 3: Healthcare Dynamics in Fibromyalgia Management

Subtheme 1: Stigma and invalidation in healthcare. Participants often described feeling dismissed by healthcare providers, who suggested simple solutions like over-the-counter medication or mindfulness. This prolonged the diagnosis process and left participants questioning their own experiences. One participant wondered why she should think her condition was severe or important if her doctor did not. Others emphasized the need for self-advocacy. As one participant explained, “I wish more people understood fibro is something that forces you to really be in tune with your body. So if I’m saying ‘this isn’t right,’ hear me.”

Subtheme 2: Competence in fibromyalgia. Having a healthcare provider competent in fibromyalgia was highly beneficial during pregnancy. Some providers took the time to support individuals with medication alternatives that were safe for pregnancy. Others reassured patients by disclosing that it was not their first time treating a pregnant patient with fibromyalgia. However, finding a knowledgeable provider was often difficult and required switching providers, sometimes with the help of word-of-mouth recommendations from support groups. When such resources were not available, participants had to research providers themselves, which was time-consuming.

For those with providers not competent in fibromyalgia, the need for better support was clear. One participant explained, “The best way I think (healthcare providers) can actually support pregnant women with fibromyalgia is to know what they are doing and how to handle the whole situation.” Competent providers alleviate the burden of self-advocacy, creating a more comfortable, safe space and ensuring the best care possible.

Subtheme 3: Establishing trust between provider and patient. Trust was defined as comfort with the provider, belief in their commitment to the patient’s best interest, and confidence in their ability to keep both the individual and their baby safe. This trust took time to build through actions such as attentive listening, body language, and time spent during appointments. Limited appointment time or rushed visits made trust harder to establish. One participant shared.

They listen(ed) to my concerns about managing my symptoms during pregnancy and they walked with me to make sure I got the best kind of treatment. It was good to know I had someone to rely on…it gave me this sense of security. I felt like I was in good hands and nothing would go wrong.

Not all participants developed strong trust, especially when their provider lacked competence in fibromyalgia. This was the most frequently cited area for improvement. Participants recommended that providers focus on listening and understanding their patients, even if they don't know about fibromyalgia. As one participant stated, "Working on the trust and connection with the patient will go a long way."

Subtheme 4: Demographic match. Racial and gender matches were important for participants' comfort with their healthcare providers. One participant shared, "The fact that she's a lady, I feel like she could resonate with me…and I feel like I understand her more." Without this match, participants struggled to feel heard and supported, sometimes seeking new providers. For a Black woman paired with a White male provider, the struggle was clear:

I couldn't resonate with him. Maybe it has something to do with the race, ethnicity, or stuff like that…I would love to not feel like that's the reason. (But) the body language tells me a lot and I couldn't just open up and be vulnerable and communicate with him. There was just no connection. The vibe is not there and I couldn't just be myself around him. I couldn't just be vulnerable.

She found a new provider with a better match and felt more comfortable. However, finding a provider with a demographic match or the ability to switch was not always easy. Many participants were assigned providers without input, limiting their autonomy in choosing someone with whom they felt comfortable and understood. Ideally, patients should have more autonomy to select providers and access diverse options, fostering comfort, trust, and relatability.

Subtheme 5: Individualized approach. Participants recognized that both fibromyalgia and pregnancy are unique experiences, making individualized care essential. Tailored treatment should consider each person's symptoms, health, and safety. One participant shared that it was important for their provider to, "(help) me with health advice…and guidance and care throughout my pregnancy while (considering) my condition and everything. They always put everything I have into consideration." An individualized approach might also include referrals to support groups or other relevant resources, fostering trust and a sense of safety. Without this, fibromyalgia symptoms may go unacknowledged, leaving participants feeling like just another name on a provider's list.

Theme 4: Seeking and Receiving Social Support: A Multifaceted Experience

Subtheme 1: Physical presence and daily support. Participants with fibromyalgia and pregnancy often relied on partners and family for daily tasks like cleaning, shopping, and meal preparation. For those with children, this support included caregiving, allowing the participant to rest. Physical assistance alleviated stress for many, enabling them to focus on self-care and symptom management. However, not everyone had family nearby, leading to inconsistent support. This placed more pressure on partners, who sometimes lacked the time or energy to help. Participants felt guilty for burdening their partners, especially when they were the primary breadwinners. Many wished for family members or close supporters to live closer for more consistent assistance.

Subtheme 2: Support impacting emotional well-being. Many social support figures lacked an understanding of fibromyalgia before diagnosis, making it a shared learning experience. Participants valued loved ones who actively sought knowledge through research or by learning together. One participant shared how their partner initially saw the diagnosis as overwhelming and severe but became calmer and more supportive after understanding more about it. This support was especially important during pregnancy. A partner who served as a pseudo-advocate, challenging disbelief, and validating symptoms, was appreciated.

Support also came from online communities, offering emotional encouragement, advice, and role models. Participants valued these spaces for fostering optimism and self-advocacy. Simple acts like checking in—via texts, calls, or visits—boosted emotional well-being, conveying care and creating a sense of safety.

Subtheme 3: Financial support. Financial support was crucial but less commonly received. It often came from partners, family, or friends to cover essential expenses, medications, and other needs. Many participants expressed a desire for more financial help, regardless of its source—family, support groups, or community organizations. This assistance would aid in managing fibromyalgia and help cover pregnancy and parenting-related expenses.

Subtheme 4: Received support vs. desired support. Participants acknowledged the positive contributions of their social support providers, yet many expressed a gap between what was received and what they desired. While support figures were "doing their best," it often left participants feeling unfulfilled, such as when fibromyalgia was dismissed or when family lived far away. Some participants struggled to voice specific needs, wishing for more help.

However, some needs were impossible to fulfill. Certain aspects of pregnancy with fibromyalgia cannot be supported physically, mentally, or financially, leaving individuals to manage alone. One participant stated, "There was nothing anyone could do. Nobody could help me carry the baby... Nobody could help through the pain. I (felt this way) even though there were people there. They can't take the pain away." Participants recognized that no one could fully understand their embodied experience.

Discussion

This study explored the experiences of pregnancy among Black and African American individuals with fibromyalgia, focusing on the role of social support. Through in-depth interviews, key themes emerged highlighting the physical and emotional challenges of managing fibromyalgia during pregnancy, and the significant influence of healthcare providers and support networks. The findings offer new insights into the intersection of chronic illness and reproductive health, particularly for individuals with non-apparent disabilities like fibromyalgia.

Fibromyalgia: It's real

All participants in this study emphasized the reality of their fibromyalgia experiences, which varied but were often dismissed by healthcare providers, family, and friends. This aligns with previous research highlighting the stigma and difficulty around fibromyalgia (24). Participants faced disbelief from family members, healthcare providers minimizing symptoms, and a general lack of awareness. These experiences negatively affected emotional well-being and hindered trust-building with healthcare providers. Participants expressed a desire for more acknowledgment and discussion of fibromyalgia as a real, chronic condition, particularly among healthcare providers.

Fibromyalgia and Pregnancy: A Unique Experience

Participants detailed how fibromyalgia's hallmark symptoms-chronic pain, fatigue, and unpredictability-greatly impacted their pregnancy experiences. Many found their fibromyalgia symptoms, which were already difficult to manage, to worsen during pregnancy. This is consistent with research (25) suggesting pregnancy can intensify fibromyalgia-related pain and fatigue, particularly in areas like the back, hips, and joints. The physical demands of pregnancy, such as weight gain and hormonal changes, further compound these symptoms, leaving participants feeling physically exhausted.

Managing fibromyalgia during pregnancy was complicated by medication restrictions due to safety concerns for the fetus. Participants turned to alternative strategies, like physical therapy, stretching, and massage, which varied in effectiveness. This aligns with the literature recommending non-pharmaceutical approaches for pregnant individuals with fibromyalgia (26). Despite these efforts, participants struggled to maintain normal function, feeling their ability to perform daily tasks was severely compromised.

These challenges underscore the need for healthcare providers to offer holistic care, addressing both the physical and emotional aspects of reproductive health for individuals with disabilities. This includes equitable access to reproductive services, fostering autonomy, and understanding the unique challenges of this population. Providers should also be aware of intersecting identities—such as race, ethnicity, gender, and socioeconomic status—that influence care experiences and health decisions, with greater emphasis on training to support diverse populations.

The Mental and Emotional Impact of Fibromyalgia and Pregnancy

The unpredictability of fibromyalgia symptoms caused significant emotional distress, increasing anxiety and depression, especially during pregnancy. The combination of flare-ups, fatigue, and pain heightened emotional strain and concerns about their child's well-being. Many participants felt their mental health needs were overlooked by healthcare providers, highlighting a gap in holistic care. Integrating mental health services into prenatal and postnatal care, along with improved coordination among healthcare professionals, counselors, and social workers, could better address the emotional needs of pregnant individuals with fibromyalgia.

Healthcare Providers and Trust: An Important Dynamic

The relationship between participants and their healthcare providers was a critical factor in their pregnancy experiences. Many participants reported mixed experiences with their healthcare providers, highlighting both positive and negative aspects of their care. Some participants found their healthcare providers to be supportive and knowledgeable about managing fibromyalgia during pregnancy. In these cases, participants emphasized the importance of trust and communication, which allowed them to feel more comfortable and less anxious throughout their pregnancy. Research supports the idea that a trusting patient-provider relationship is associated with better maternal well-being and lower stress during pregnancy (27).

However, many participants also encountered stigma and a lack of understanding from healthcare providers. In some instances, providers appeared to dismiss the severity of fibromyalgia symptoms, echoing a well-documented pattern of stigmatization in healthcare settings (24). This lack of awareness and empathy from healthcare providers often left participants feeling invalidated and unsupported, which in turn undermined their ability to manage both their pregnancy and their chronic condition effectively. These findings reinforce the need for improved education and training for healthcare professionals on chronic conditions like fibromyalgia, particularly in reproductive health contexts. This may allow providers to feel more prepared to educate their patients on fibromyalgia or other health conditions and their impact on reproductive plans. Doing so must be partnered with listening and validation of the patient’s experiences to foster a supportive and trusting healthcare environment.

The Role of Social Support: A Multifaceted Experience

Social support played a crucial role in shaping participants' pregnancy experiences with fibromyalgia. Practical support, such as assistance with household chores, childcare, and transportation, was especially valuable during symptom flare-ups, helping alleviate stress and manage daily tasks. Emotional support from family, friends, and partners, including check-ins and encouragement, fostered hope and validation, empowering participants to manage both fibromyalgia and pregnancy. However, some participants encountered dismissive attitudes, especially from those lacking an understanding of fibromyalgia, leading to feelings of isolation. While practical support was appreciated, emotional understanding was often lacking. This gap highlights the need for social support responsive to individual challenges, as emphasized in other research on chronic illness (28, 29). Overall, while social support—both practical and emotional—was instrumental in participants’ experiences, its effectiveness was dependent on the depth of understanding and empathy of those providing it.

Conclusion

This study is one of the first to explore the experience of fibromyalgia during pregnancy, highlighting implications for counselors, healthcare providers, and support persons. These groups would benefit from a deeper understanding of fibromyalgia and its interaction with pregnancy. Healthcare providers can better support women by addressing unique symptoms and treatment strategies. Additionally, support from family, friends, and partners remains crucial in managing both fibromyalgia and pregnancy.

Conflict of Interests

Authors declare no conflict of interests.

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During the preparation of this work, the author(s) used AI (ChatGPT) to identify areas of the dissertation that could be removed without hindering the value of the work. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the publications.

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