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Associations between health-related quality of life, infertility-related psychological well-being, and relationship quality in individuals with endometriosis: A cross-sectional study

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Abstract

Background Endometriosis is the most frequent gynecological diseases and accompanied by both physical and psychological symptoms. An increasing number of studies suggested acknowledging endometriosis as a systematic disease due to the multifactorial effects throughout the body. The chronic disease significantly impacts daily life, including romantic relationships. This study aimed to investigate the associations between health-related quality of life (HRQoL), infertility-related psychological well-being (IPW), constructive communication, and relationship quality in individuals with endometriosis.

Methods A total of 627 individuals with endometriosis participated in this online cross-sectional study. We measured HRQoL in all participants and IPW specifically in those who reported an unfulfilled wish for a child. Additionally, relationship quality and constructive communication were assessed. We used Pearson's product moment correlation to examine the association of HRQoL/IPW and relationship quality. Mediation analysis was used to assess the role of constructive communication in the association between HRQoL/IPW and relationship quality. In an explorative analysis, differences between subsamples with and without an unfulfilled wish for a child were analyzed.

Results Poorer HRQoL was associated with lower relationship quality overall ($p = .002$) and specifically with three subscales of relationship quality: worse sexuality ($p = .016$), increased mistrust towards the partner ($p < .001$), and restriction of freedom/independence ($p = .003$). There was no significant association between IPW and relationship quality. The mediation analysis including constructive communication as mediator showed a full mediation between HRQoL/IPW and relationship quality. The subsamples with and without an unfulfilled wish for a child differed in HRQoL but not in relationship quality or constructive communication.

Conclusion The findings indicated an association between HRQoL in individuals with endometriosis and relationship quality. In addition, we observed a full mediation between HRQoL/IPW and relationship quality, when constructive communication was considered as a mediator. Therefore, constructive communication plays a key role in effectively

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managing the impact of the disease within a relationship. Individuals with endometriosis experiencing difficulties conceiving should have access to appropriate psychological counseling.

Keywords Endometriosis, Health-related quality of life, Infertility-related psychological well-being, Relationship quality, Constructive communication

Introduction

Endometriosis affects particularly individuals in reproductive age and is the most common gynecological disease [1]. Originally, endometriosis was primarily associated with pelvic pain. However, increasing evidence shows the multifactorial effects in the system, including changes in cardiovascular, neurological, metabolic, and immune processes. Endometriosis manifests beyond the aspects of a gynecological disease, which explains the shift in the perspective from a gynecological disease toward a full-body, systematic disease [2]. The chronic condition is defined by a manifold clinical picture without specific biomarkers. While some individuals suffer from severe dysmenorrhea; deep dyspareunia; chronic pelvic pain; ovulation pain; cyclic or perimenstrual symptoms with or without abnormal bleeding; infertility; and chronic fatigue [3], others are asymptomatic and do not have any health-related restrictions [4]. Psychological consequences are higher rates of depression, anxiety, and emotional distress [5]. In addition to physical and psychological symptoms, endometriosis can have a profound impact on everyday life [5].

Based on prior research, it is widely recognized that chronic illnesses affect couple's romantic relationships [6–10]. Studies dealing with endometriosis revealed similar findings. For example, individuals with endometriosis have consistently reported a detrimental effect of the disease on their relationship. In certain instances, endometriosis has even been reported as a contributing factor to divorce and relationship breakup [5, 11–13]. One significant concern is sexuality. Numerous affected individuals have outlined reduced sexual satisfaction and challenges in intimate relationships due to pain during sex (dyspareunia) [5, 12, 14]. However, in addition to dyspareunia, the partners reported also other causes such as fatigue, reduced sexual desire due to medication, stress in the course of trying to get pregnant, bleeding during or after sex, and the feeling of unattractiveness [15]. Moreover, endometriosis necessitates couples to adapt and reorganize their everyday life, such as social activities, household tasks, and financial behaviors due to decreased work hours and expenses connected with treatments [16].

Further, endometriosis is also often accompanied by problems becoming pregnant. For many couples, the desire to have children is an important aspect of their lives. Difficulties with conception can lead to societal and parental pressure and is connected to psychological, physical, and financial burdens [17]. The strain related to infertility affects not only the well-being of individuals, but also the stability of the relationships [18]. Thus, infertility is often considered a profound dyadic stressor in relationships [19]. Previous literature stated that 30–50% of individuals with endometriosis are infertile [20–22]. In a qualitative study with 22 couples, the majority reported that endometriosis affects their plans for having children. They either faced actual infertility or anticipated infertility. Emotions such as feelings of loss, grief, anxiety, distress, and disappointment are commonly experienced feelings by both partners [16]. An unfulfilled wish for a child in the context of endometriosis can be an additional source of extreme stress, potentially leading to relational issues within the couple [23]. Individuals with endometriosis reported that (anticipated) infertility has an impact on their marital relationship and raises concerns about possible separation [14]. Culley et al. [5] also indicated that infertility may lead to a split-up of the relationship. In contrast, there were reports that described the period navigating infertility as an opportunity for growth within the relationship [24]. It remains unclear whether psychological consequences stemming from the unfulfilled wish for a child, such as IPW, are associated with relationship quality.

Moreover, the current study assessed the role of constructive communication as mediator in the association of HRQoL/IPW with relationship quality. Constructive communication compromises mutual discussion of problems, finding solutions, making compromises, and showing emotions [25]. There is literature indicating an association between relationship satisfaction and constructive communication in couples dealing with a chronic disease [26]. In the context of endometriosis, participants from qualitative studies consistently reported that (constructive) communciation with the partner is essential [13, 16, 27], however problems in interpersonal exchange are not uncommon [16]. Endometriosis is complexly linked with a broad spectrum of emotions, such as guilt, frustration, loneliness, irritability, and anger. These feelings might hinder productive communication, potentially leading to tensions, disagreements and misunderstandings [16]. Understanding the role of constructive communications in the association of HRQoL/IPW with relationship quality as well as the associations of both paths (HRQoL/IPW with constructive communication and constructive communication with relationship quality), can have great practical implications for the support of couples.

After all, couples did not only report adverse consequences but also positive experiences when dealing with endometriosis [15, 16, 24]. They highlighted the growth of their relationship and the deeper understanding for each other and the situation. Dealing with endometriosis brought them closer together and fortified their commitment [15, 24]. Furthermore, certain couples took proactive steps to improve their communication skills, aiming to better support and comprehend each other [16]. Quantitative research examining the relationship between the psychological consequences of endometriosis and the unfulfilled wish for a child with relationship quality, including constructive communication, is scarce. Because relationship quality is a strong protective factor when facing illness [28] and the main source of support for individuals with infertility treatments [29], it is important to get a better understanding for the associations. Knowing the interplay of these factors is crucial for providing effective support to the affected person and their social environment. Hence, this study aimed to investigate the association of health-related quality of life (HRQoL), infertility-related psychological well-being (IPW), relationship quality as well as constructive communication among individuals with endometriosis.

Materials and methods

Participants

Data collection started on March 21st 2023 and ended ten days later on March 31st 2023. The data collection was primarily conducted via social media platforms. Informational flyers with a survey link were distributed online within Facebook groups and on Instagram. Furthermore, emails were dispatched to endometriosis associations in Austria (Endometriose Vereinigung Österreich - EVA), Germany (Endometriose Vereinigung Deutschland), and Switzerland (Schweizerische Endometriose Vereinigung Endo-Help). The inclusion criteria for the study encompassed (1) self-reported diagnosis of endometriosis or a presumptive diagnosis, (2) presently being in a partnership (by own definition), (3) being of legal age, and (4) providing informed consent. Regarding age, 21 participants were between 46 and 58 years. Despite peri- and postmenopausal endometriosis being relatively rare [30–32], we believe it was worth including these cases. Older individuals might be similarly affected as the younger participants.

During the ten days, $n = 974$ started the questionnaire. 297 individuals did not complete the survey, which lead to a drop-out rate of 30.4%. 49 participants did not meet one or more of the four inclusion criteria and were therefore not allowed to participate. Another two cases were excluded because they clicked trough the questionnaire without giving answers to the specific questions. The final sample consisted of $N = 627$ participants between the ages of 19 and 58 years. The average age was 31.7 years ($SD = 6.8$). 625 participants (99.7%) identified their gender as female, two individuals as diverse (0.3%). Highest completed level for most participants was high school (24.4%) or university/college (40.9%). The average duration of partnership was 7.4 years ($SD = 5.6$).

Measures

Health-related quality of life (HRQoL)

We used the Endometriosis Health-Profile Questionnaire (EHP-30) developed by Jones et al. [33] to assess HRQoL in regard to the last 4 weeks. This instrument consists of a core questionnaire and extra modular subscales. We used only the core questionnaire that includes 30 items distributed across five subscales: pain (e.g., "Been unable to go to social events because of the pain"), control and powerlessness (e.g., "Felt frustrated because your symptoms not getting better"), emotional well-being (e.g., "Felt depressed"), social support (e.g., "Felt unable to tell people how you feel"), and self-image (e.g. "Lacked confidence"). Answers were rated on a 5-point Likert scale (0=never; 4=always). Each subscale was standardized on a scale from 0 to 100, with higher scores indicating a poorer HRQoL. All five subscales demonstrated high internal reliability, with Cronbach's alpha ranging from 0.83 to 0.93.

Infertility-related psychological well-being (IPW)

The Psychological Evaluation Test for Infertile Couples (PET) developed by Franco et al. [34] assesses psychological well-being of couples experiencing infertility. Only participants who indicated an unfulfilled wish for a child completed this questionnaire. The PET includes 15 questions aiming to assess emotional reactions to various statements and situations. Examples of these statements include: "Are you bothered by the fact that you don't have children?" or "I feel irritated when a friend or relative becomes pregnant". Answers were rated on a 4-point Likert scale (1=never or rarely; 4=always), resulting in a score ranging from 15 to 60 points. A score of 30 was considered a cut-off point, with higher scores indicating the need for specific psychological counseling [34]. Internal reliability of the PET was good with a Cronbach's alpha coefficient of .88.

Relationship quality

We used the German questionnaire for the assessment of relationship quality (FPQ) developed by Siffert and Bodenmann [35]. This 26-item instrument comprises six subscales: fascination (e.g., "I find my partner attractive and desirable"), engagement for the relationship (e.g., "I invest in our relationship"), sexuality in the relationship (e.g., "I enjoy sex with my partner"), future perspective of the relationship (e.g., "I think our relationship has a

future"), mistrust towards the partner (e.g., "I am asking myself whether my partner is faithful to me"), and restriction of freedom/independence (e.g., "I feel restricted in our partnership"). Respondents provided answers using a 5-point Likert scale (1=I do not agree; 5=I totally agree). In terms of the overall scale as well as of the subscales fascination, engagement, sexuality and future perspective, higher scores indicated a better relationship quality. However, with regard to the subscales "mistrust towards the partner" and "restriction of freedom/independence", higher scores showed worse relationship quality. The internal reliability of this questionnaire was 0.78. The internal consistency of the six subscales ranged from α=0.75 to α=0.94.

Constructive communication

To assess constructive communication, we used a subscale from the revised German version [36] of the Communication Patterns Questionnaire [37, 38]. The subscale constructive communication includes seven items (e.g., "When a problem arises in the partnership, both partners try to discuss the problem"), with respondents providing answers on a 9-point Likert scale (1=very unlikely; 9=very likely). This resulted in total scores between 7 and 63 points. A higher score on this scale indicated a more distinctive perceived constructive communication pattern within the partnership. The subscale showed acceptable internal reliability with a Cronbach's alpha coefficient of 0.77.

Sociodemographic and disease-specific data

The questionnaire included sociodemographic questions regarding age, gender (male/female/diverse), education (compulsory school/intermediate school/apprenticeship diploma/high school/bachelor degree/master degree/doctorate/other), and duration of partnership (open-ended question). It also included disease-specific items and asked for the diagnostic delay (open-ended question), an unfulfilled wish for a child (yes/no), endometriosis treatment (yes/no) as well as fertility treatment (yes/no).

Data analysis

In order to test the associations of HRQoL/IPW and relationship quality, Pearson's product moment correlations were conducted. All analyses involving IPW were done only with the subsample of $n=210$, who indicated that they were experiencing infertility. Before the main analyses, linearity was tested and outliers were located. Since there were only a few slight outliers, it was decided to keep them in the analysis. The SPSS-Makro PROCESS by Hayes [39] was used to examine the mediation effect of constructive communication on the association between HRQoL/IPW and relationship quality. Because PROCESS uses bootstrapping, normal distribution was not indispensable. The exploratory analysis examined differences regarding relationship quality, HRQoL, and constructive communication in the subsamples with and without an unfulfilled wish for a child. Because the data was not normally distributed and contained outliers, a non-parametric Mann-Whitney-U test was used. A sensitivity analysis was performed where those individuals above 45 years (peri- and postmenopausal; [31]) were excluded from the sample. For the analyses the mean values of the raw scores were used. The statistical analysis was conducted using IBM SPSS Statistics 28.

Results

Descriptive results

A total of $N=562$ individuals responded to the question concerning diagnostic delay, which ranged from 0 to 34 years. On average, the duration between the onset of first symptoms and receiving a final diagnosis was around 9.2 years ($SD=6.0$). From the whole sample, 497 participants (79.3%) stated that they are undergoing treatment for endometriosis. 210 individuals (33.5%) indicated having an unfulfilled wish for a child. Of those, 100 participants (47.6%) reported that they are undergoing fertility treatment. The average score for IPW among participants with an unfulfilled wish for a child was 35.62 ($SD=8.58$). With regard to HRQoL, the subscale control and powerlessness had the highest scores with $M=73.82$ ($SD=16.07$), which indicated the greatest burden associated with endometriosis. It was followed by self-image ($M=67.62$; $SD=18.16$), emotional well-being ($M=66.57$; $SD=13.34$), and social support ($M=66.34$; $SD=16.75$). The subscale pain demonstrated the lowest value with $M=63.32$ ($SD=15.05$), even though 24% had a score over 75. Relationship quality was perceived quite good with $M=4.18$ ($SD=0.54$). All means and standard deviations of the variables and subscales are depicted in Table 1. In addition, we divided the sample into two groups, with ($n=210$) and without ($n=417$) an unfulfilled wish for a child. Differences in means and standard deviations of HRQol, relationship quality, and constructive communication are presented in Table 2.

Associations between HRQoL and relationship quality

HRQoL in individuals with endometriosis was negatively associated with relationship quality, $r=-.126$, $p=.002$. In a further analysis, the associations between HRQoL and the six subscales of relationship quality were examined. The subscales sexuality in the relationship ($r=-.096$, $p=.016$), mistrust towards the partner ($r=.193$, $p=<0.001$), and restriction of freedom/independence ($r=.119$, $p=.003$) were found to be significantly associated with HRQoL. None of the other three subscales (fascination, engagement for the relationship, future

Table 1 Means and standard deviations of each variable (incl. subscales)

	M	*SD*	Score range
HRQoL	66.90	12.19	0–100
Pain	63.32	15.05	0–100
Control and powerlessness	73.82	16.07	0–100
Emotion	66.57	13.34	0–100
Social support	66.34	16.75	0–100
Self-image	67.62	18.16	0–100
IPW	35.63	8.58	15–60
Relationship quality	4.18	0.54	1–5
Fascination	4.20	0.75	1–5
Engagement	4.41	0.58	1–5
Sexuality	3.24	1.10	1–5
Future perspective	4.62	0.68	1–5
Mistrust	1.78	1.00	1–5
Restriction of independence	1.60	0.76	1–5
Constructive communication	49.07	9.68	7–63

perspective) showed significant or clinically relevant results.

The mediation analysis assessing the mediating effect of constructive communication on the association between HRQoL and relationship quality showed a total effect between HRQoL and relationship quality, $B=-.1123$, $p=.002$. Upon including the mediator in the model, HRQoL was found to be significantly associated with the mediator constructive communication, $B=-.329$, $p<.001$. Subsequently, the mediator was significantly linked with relationship quality, $B=.223$, $p<.001$. Notably, with the mediator in the model, the direct effect between the relationship of HRQoL and relationship quality became non-significant, with $c' = -0.039$, $p=.190$. This suggested a complete mediation of constructive communication, with an indirect effect $ab=-0.073$, 95% CI [-0.113, −0.034]. The mediation model, including standardized path coefficients, is depicted in Fig. 1.

Associations between IPW and relationship quality

The model for IPW and relationship quality was not significant, with $r=-.039$, $p=.652$. Furthermore, IPW was not associated with any of the subscales of relationship quality.

A mediation analysis was conducted with regard to the association of IPW and relationship quality with constructive communication as mediator. The total effect of the association between IPW and relationship quality was not significant, $B=-.037$, $p=.534$. After including the mediator in the model, IPW was associated with constructive communication, $B=-.505$, $p=.003$, and constructive communication was linked with relationship quality, $B=.212$, $p=<.001$. In the model with the mediator, the direct effect was not significant, $c' = 0.070$, $p=.199$. Therefore, the association between IPW and relationship quality was fully mediated by constructive communication, $ab=-0.107$, 95% CI [-0.193, −0.035]. The mediation model with standardized values is presented in Fig. 2.

Exploratory analyses

The exploratory analysis was conducted to examine differences between those with an unfulfilled wish for a child and those without in the variables relationship quality, HRQoL, and constructive communication. Individuals with an unfulfilled wish for a child showed worse HRQoL and constructive communication. Mean score in relationship quality was minimal lower in individuals without an unfulfilled wish for a child. No statistically

Table 2 Descriptive statistics and Mann-Whitney-U test results of the subsamples with and without an unfulfilled wish for a child

	With an unfulfilled wish for a child		Without an unfulfilled wish for a child				
	M	*SD*	*M*	*SD*	Score range	*Z*	*p*[a]
HRQoL	68.58	12.20	66.05	12.11	0–100	-2.476	0.013*
Pain	65.01	15.02	62.46	15.01	0–100	-2.326	0.020*
Control and powerlessness	76.51	15.28	72.46	16.30	0–100	-2.810	0.005*
Emotion	67.41	13.17	66.15	13.42	0–100	−0.934	0.350
Social support	69.00	15.79	65.00	17.08	0–100	-2.634	0.008*
Self-image	67.62	18.68	67.63	17.91	0–100	−0.295	0.768
Relationship quality	4.19	0.54	4.17	0.54	1–5	−0.535	0.592
Fascination	4.20	0.73	4.20	0.75	1–5	−0.267	0.789
Engagement	4.42	0.57	4.40	0.59	1–5	−0.312	0.755
Sexuality	3.22	1.13	3.24	1.08	1–5	−0.273	0.785
Future perspective	4.65	0.67	4.61	0.68	1–5	−0.672	0.502
Mistrust	1.78	1.03	1.78	0.99	1–5	−0.087	0.931
Restriction of independence	1.54	0.74	1.63	0.77	1–5	-1.628	0.104
Constructive communication	48.09	10.44	49.57	9.25	7–63	-1.364	0.172

Note.[a] *p* = significance value; *** $p<.001$, * $p<.05$

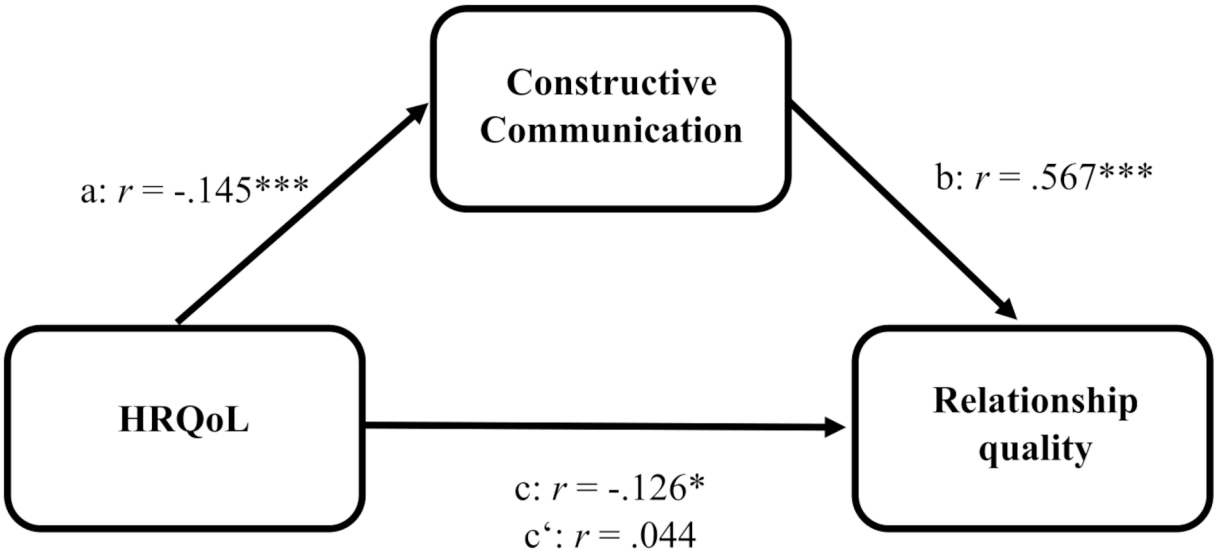

Fig. 1 Mediation model including health-related quality of life (HRQoL) in endometriosis patients and relationship quality with constructive communication as mediator. *Note.* Standardized coefficients; ***$p < .001$, *$p < .05$; c demonstrates the total effect between HRQoL and relationship quality without considering the mediator; c' demonstrates the direct effect between HRQoL and relationship quality including the mediator

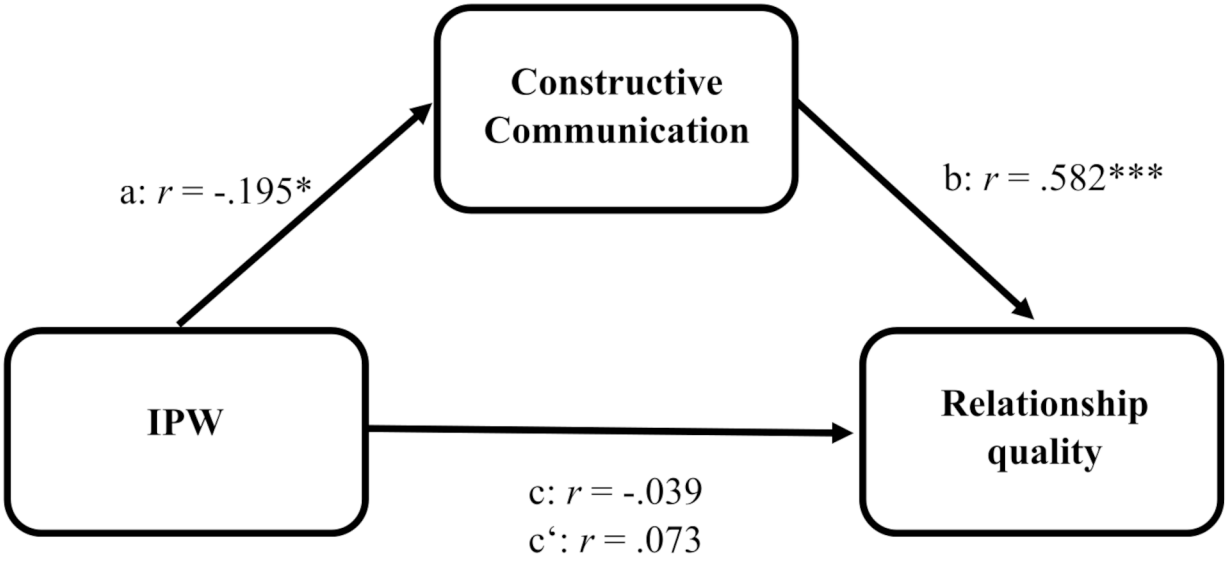

Fig. 2 Mediation model including infertility-related psychological well-being (IPW) in endometriosis patients and relationship quality with constructive communication as mediator. *Note.* Standardized coefficients; ***$p < .001$, *$p < .05$; c demonstrates the total effect between IPW and relationship quality without considering the mediator; c' demonstrates the direct effect between IPW and relationship quality including the mediator

significant differences were found regarding relationship quality and constructive communication. However, there was a significant difference in the median of HRQoL between the group with an unfulfilled wish for a child ($Mdn = 3.50$) and without ($Mdn = 3.40$), $U = 38484.50$, $Z = -2.476$, $p = .013$, $r = -.10$. The mean values, standard deviations, and Mann-Whitney-U test results are depicted in Table 2.

Sensitivity analyses

The results of analyses that did not include participants above 45 years (peri- and postmenopausal) showed only minimal differences with regard to associations between HRQoL and relationship quality, and similar patterns were found for correlations between IPW and relationship quality.

Discussion

Based on data from qualitative studies focusing on endometriosis and romantic relationships, a healthy relationship is considered important for individuals with endometriosis and their partners [e.g., 5, 16]. This is in line with the observation that relationship quality is a protective factor in times of illness [28] and is of great support in fertility treatment [29]. The majority of couples reported strain on their relationship when facing endometriosis [5, 13–16]. However, some couples also mentioned some positive experiences and growing in these tough times [15, 16, 24]. Yet, there is no clear picture of how the psychological consequences stemming from endometriosis, or subsequently from an unfulfilled wish for a child, are associated with relationship quality. The current study aimed to provide quantitative evidence on the associations between HRQoL, IPW, and relationship quality in individuals with endometriosis. The results showed mixed findings.

The association of HRQoL in individuals with endometriosis and relationship quality was statistically significant, indicating that persons who reported worse HRQoL stated worse relationship quality. This is in line with previous qualitative literature, reporting strain on relationships due to endometriosis [4, 11, 12]. A more specific understanding emerged when examining the subscales. A decline in HRQoL was associated with reduced sexual satisfaction, aligning with previous literature that highlighted the association between strain on intimate relationships and endometriosis [e.g., 5, 12, 14, 40, 41, 42]. Besides dyspareunia, factors such as fatigue, diminished sexual desire, stress, and feelings of shame and unattractiveness can contribute to poorer sexual experiences within the partnership [15]. Further, HRQoL was associated with the level of trust within the relationship. The worse HRQoL was rated, the higher was the mistrust toward the partner. Being in a worse emotional and physical state was associated with increased negative assessments in terms of relationship and also trust concern. This is in line with studies, highlighting that high stress is associated with negative relationship behaviors [43, 44], including infidelity [45]. In addition, we found that a decline in HRQoL among participants with endometriosis correlated with a heightened sense of restriction of freedom/independence from the partner. Cully et al. [15] indicated that partners lack of sufficient professional support to help them deal with the impact of endometriosis. In the study, the partners reported that only few healthcare practitioners recognized the potential negative effect on them. They experienced strain and stress [15] and some of them simply did not know how to address the specific needs and act in a supportive way [16]. This lack of appropriate help by partners might lead to feelings of restrictions and not enough free space for the individuals with the condition. Of note, the current data also revealed that more social support as indicated by one of the subscales in the HRQoL assessment measure was associated with fewer feelings of restriction of freedom/independence. If the individual with endometriosis felt supported, understood, and able to talk about one's emotions, the perception of restriction in the partnership was less pronounced. This indicated that adequate support from others including partners is a crucial resource for individuals with the condition. Inappropriate support leads to the opposite, which is why this issue should be acknowledged in couples therapy. The association of HRQoL and the remaining three subscales (i.e., fascination, engagement, future perspective) was non-significant and no clinically relevant effect could be detected. Based on prior research, endometriosis is not only restricted to adverse consequences. Couples also reported positive experiences within the partnership, such as relationship growth/strengthening and improvement of communication skills [15, 16, 24]. However, such associations were not found in the current data. A possible explanation may be that, while some couples may have experienced some selected positive aspects in their relationships when dealing with endometriosis [15, 16, 24], the majority of couples may have overall experienced predominantly negative consequences.

In this study, IPW was not associated with relationship quality. While this is in line with the finding of [12], other research suggested that infertility is indeed associated with challenges in the relationship [14, 23]. Difficulties with conception may not impact relationship quality, but might be associated with other relationship related outcomes, such as communication patterns, affection, relationship stability, or relationship conflict. The exploratory analyses investigating differences in individuals with and without an unfulfilled wish for a child indicated no differences in relationship quality or constructive communication. However, in the exploratory analyses, we found that individuals with an unfulfilled wish for a child reported worse HRQoL outcomes than those without. A possible explanation may be that a widely used treatment option of endometriosis is hormonal treatment, specifically the oral contraceptive pill. It reduces dysmenorrhea and chronic pelvic pain, but, because it suppresses the ovarian cycle becoming pregnant is nearly impossible [4, 46]. Alternatives are either surgery or analgesics, which however do not have a direct impact on endometriosis lesions [47] and could result in increased use and thus possible long-term adverse effects [48]. Those individuals with child wish might not do either of those treatment options, leading to more suffering and therefore worse HRQoL.

It is important to note that the average score of IPW in the current study was $M = 35.63$. Franco et al. [34] pointed

out a cut-off value of 30 and outlined the importance of providing support and psychological counseling when the score exceeds this threshold. In the current sample, the participants experienced psychological distress due to infertility. Even though IPW was not associated with relationship quality and individuals with an unfulfilled wish for a child did not differ in relationship quality compared to those without, they showed a more pronounced adverse impact on mental health. Therefore, they can be supported in couple therapy similarly to those without an unfulfilled wish for a child, but they require specific help regarding the psychological consequences of endometriosis and fertility issues.

Further, the findings demonstrated that constructive communication acted as a mediator in the relationship of HRQoL and IPW with relationship quality. In case of HRQoL, the meditation was fully mediated by constructive communication. This means, the association of HRQoL and relationship quality could be completely explained by constructive communication. With regard to IPW, originally no association with relationship quality could be found. However, when including constructive communication as mediator in the model, the indirect effect became significant, while the direct effect remained non-significant.

Poorer quality of life and psychological well-being among individuals with endometriosis were both linked to decreased constructive communication. This negative correlation is plausible as chronic everyday stress leads to low quality of marital communication [49, 50]. In contrast, enhanced constructive communication was associated with increased relationship quality. This is in line with existing literature indicating that constructive communication is associated with relationship satisfaction in couples in general as well as in couples coping with chronic illnesses [26, 51].

Implications

Given that partnership plays an important role in one's life and serves as a strong protective factor during times of illness [28], it is crucial to provide holistic support to couples. Relationship difficulties are common in couples dealing with endometriosis. Considering the fact that the problems especially existed in terms of sexuality, trust issues, and feelings of dependence, couples therapy appears to be a good option for addressing relationship difficulties. Open communication of these issues may lead to reduced tension and improved relationship quality. Constructive communication is a key principle of couples therapy [52]. With professional help, couples can learn strategies to improve constructive communication and minimize dysfunctional interactions. Understanding each other's needs, thoughts, emotions and behavior helps to increase care and support within the relationship. While this intervention may not reduce pain and suffering, it can help individuals cope with them. Facing the challenges of the disease together as a couple, the disease may become more manageable and less a strain. Maintaining relationship quality and satisfaction during challenging times is up most important.

Infertility is a predominant topic for individuals with endometriosis. Difficulties with conception and the challenges of fertility treatment can be extremely stressful and might lead to a decline in psychological well-being. In this study, the average score of psychological well-being exceeded the cut-off point, indicating the need for psychological support. Therefore, when it comes to consultations with specialists, it is necessary to address not only the disease and what can be done to reduce symptoms, but also inevitably consequences, like potential infertility. In addition, inclusive consulting involving both affected individuals and their partners are important to implement on a regularly base. Couples need to understand what this means for them and how they can cope with the situation as a couple but also as individual.

Moreover, it is necessary to raise awareness about these conditions. Unfortunately, infertility and endometriosis remain taboo topics, which contributes to a lack of understanding and support for those who are directly or indirectly affected [13, 53, 54]. Educational efforts on all levels (individual, social environment, health care providers) and information campaigns can help to improve understanding of the diseases and raise awareness of the impact on everyday life. Furthermore, improvements in the medical management and care are necessary to achieve better physical but also psychosocial health outcomes.

Limitations

There are some limitations of the current study. First, the study design was a cross-sectional approach and did not allow causal interpretations or temporal statements. The timely aspect needs to be considered with regard to the fact that endometriosis is marked by its dynamic nature, influenced not just by the menstrual cycle, but also by various factors such as treatments, pregnancy, and the changing characteristics of the disease itself. While the cross-sectional online survey reached more than 600 participants, it inevitably suffered from selection bias, leading to a limited representation of the general population. A substantial proportion of participants were recruited from online support groups. It might be the case that these groups contained a higher proportion of individuals with severe symptoms than individuals with less painful cycles or even asymptomatic. Similar concerns were discussed in [11]. Another limitation lies in the uncertainty with regard to medical information. Without precise definition and details about the received treatment,

the responses to the EHP-30 questionnaire lacked some reliability and was challenging to interpret accurately. Another significant variable that was not assessed in respondents was the presence of mental illnesses. In future research, mental ill health should be considered as a co-founding variable. Moreover, one of the inclusion criteria was either a self-reported diagnosis or a presumptive diagnosis of endometriosis. For future studies, either only individuals with a medical diagnosis should be included to reduce potential biases and prevent heterogeneity or a specific question regarding the diagnosis needs to be included in the questionnaire to assess potential differences in the outcomes. The most important limitation of this study is that the partners of the participants were left out due to limited resources. The impact of the chronic disease is not only on the individual with the condition, but also on their social environment, especially on their partners. Further research should include partners and conduct dyadic studies.

Conclusion

The findings of this study showed that the psychological consequences of endometriosis, and the often accompanied unfulfilled wish for a child, are associated with adverse effects on relationships, particularly in terms of sexuality, trust issues, and the perception of restriction. These challenges can be effectively addressed in couple therapy and by implementing constructive communication patterns, such as addressing emotions, fears, and and worries as well as the discussion and collaborative development of solutions for problems [52]. Moreover, it became clear that infertility can be a significant strain on individuals and couples. Professional psychological support is therefore necessary.

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Author contributions

MJ: conceptualization, project administration, methodology, investigation, formal analysis, writing – original draft; HW: supervision, writing – review & editing; TN: writing – review & editing; BT: writing – review & editing.

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Data availability

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Data collection in this study was fully conducted online. Participants were informed about the procedures of the survey and that they could end their participation at any time during the study on the starting page of the survey. Participants provided their consent by clicking on a button indicating that they have read and understood the provided information and agreed to participate in the survey. Study participation did not affect the participants' physical or psychological integrity, right for privacy or other personal rights, or interests. Furthermore, the study procedures presented in this work do not qualify as medical or clinical research. Therefore, this study was exempt from ethical approval according to national laws (Austrian Universities Act 2002). The study was conducted in accordance with standard procedures of data safety as well as confidentiality and anonymity criteria were met as charted by the Declaration of Helsinki and its later amendments. The research was also conducted in accordance with the guideline of the University of Vienna for ensuring compliance with good academic practice as well as the European Code of Conduct for Research Integrity.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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