



Social Support in Online Peer Groups for Celiac Disease

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Abstract: *Background:* While there is considerable evidence for the positive effects of *onsite* peer support on health outcomes, few studies have addressed the impact of *online* peer support. *Aims:* This study differentiates between emotional (ES) and informational (IS) online peer support for people with celiac disease. We hypothesize that receiving ES and IS positively correlates with self-reported well-being and dietary compliance and that these relations would be moderated by the duration of illness. *Method:* We used a correlational, cross-sectional design ($N = 369$). *Results:* Both functions of support were positively related to well-being and dietary compliance. The strengths of the positive relationships between ES and both outcomes and IS and well-being were independent of the duration of illness. IS was significantly positively related to dietary compliance among participants with a longer duration of illness, but unrelated among participants with a shorter duration. *Limitations:* Due to the correlational design, we cannot infer causality. *Conclusion:* Our findings advance the understanding of online support in contexts where proper self-management is crucial for health outcomes.

Keywords: online peer support, emotional and informational support, chronic diseases, dietary compliance, well-being

Peer support, especially online, is receiving increasing attention as effective and cost-efficient support for people living with chronic health conditions (e.g., Hossain et al., 2021). The present study examined the influence of online peer social support groups on well-being and dietary compliance among people living with celiac disease. Like most people living with a chronic condition, people with celiac disease need to learn and maintain self-management behaviors, consisting primarily of strict compliance with a lifelong gluten-free diet. A lifelong diet, however, requires effort and persistence, which people with celiac disease often perceive as diminishing their quality of life (Hall et al., 2009). Social support can help patients master this challenge (e.g., DiMatteo, 2004). Social support involves the interaction between two or more people in which the goal is to change or facilitate the endurance of a problem state that creates suffering in an individual (Schwarzer, 2004). Importantly, social support has been shown to positively correlate with patient adherence across a variety of disease conditions, including diseases (e.g., diabetes mellitus) that require, similar to celiac disease, complex and long-term health behaviors such as a strict and life-long diet (DiMatteo, 2004).

However, all kinds of social support from all kinds of supporters are not considered equally helpful, especially when it comes to chronic diseases (e.g., Cutrona & Russell, 1990). Specifically, social support seems most likely to have positive effects when it is delivered by people coping with the same stressors (e.g., Ussher et al., 2006), who are often

considered to be more empathetic and credible compared to healthy persons (Mehnert et al., 2018). In daily life, it is often hard to identify and meet with people affected in a similar way. Opportunities to connect online with peers are thus an especially valuable resource. However, while there is good evidence for the positive effects of *onsite* peer social support on well-being and health behavior (e.g., Fisher et al., 2012), there are only a few inconsistent findings on the impact of *online* self-help groups (Hossain et al., 2021; Rains & Young, 2009) with some suggesting positive and others no effects.

The aim of the present research is twofold. First, it seeks to determine whether reports of received online peer social support are positively related to self-reported dietary compliance and well-being among people living with celiac disease. In doing so, we differentiate between two functions of social support that have been consistently shown to make up the most share of posts in online peer support groups (e.g., Mo & Coulson, 2008), and explore whether they are similarly related to dietary compliance and well-being: Informational online peer support (IS), which refers to experiential advice or information shared online in response to a question, and emotional online peer support (ES), which includes receiving understanding, reinforcement, and affirmation from peers by recognizing and responding to feelings in an encouraging manner (Mo & Coulson, 2008). Second, we aim to explain inconsistent findings in previous research by considering the duration of the chronic condition as a moderator. Specifically, we assume that IS should

become less important over the course of the illness, as people's own knowledge about how to deal with a chronic condition should usually increase over time (e.g., Chen, 2016). The importance of ES, on the other hand, should remain relatively constant over time, as sticking with a strict diet usually remains a challenge and results in recurring problems in social life (Lee & Newman, 2003). These assumptions are in line with previous work. For instance, Cutrona and Russell (1990) suggest that IS facilitates stress management, especially at the beginning of a stressful event, while long-lasting events make ES necessary. A study by Drageset et al. (2012) supports this assumption by showing that women with breast cancer considered IS especially important at the beginning, while ES remained significant at later time points.

Please note that we were primarily interested in the potential role of support actually received in the past in people's well-being and dietary compliance, and less in the role of expected support in the future (in the sense of a stable personality trait). We thus included a measure of actually received support in our study, but no measure of perceived available support (see Schwarzer & Knoll, 2007, for the distinction between these two forms).

Method

The study's materials, data files, and analysis scripts are available at <https://osf.io/adf6b>.

The commissioner for research involving human participants of the FernUniversität in Hagen exempted this study from review.

Sample and Design

Based on effect sizes reported in two meta-analyses (DiMatteo, 2004; Rains & Young, 2009) an a priori power analysis ($\alpha = .05$, $1 - \beta = .80$) was conducted such that a small to moderate effect ($d = 0.4$, $r = 0.2$, $f^2 = 0.07$) was statistically detectable resulting in an N of 231 for our cross-sectional online study. Participants were recruited from Facebook's major German-language self-help groups for celiac disease. The final N consisted of 369 participants (307 female, $M_{\text{age}} = 35.98$ years, $SD = 11.55$; 66 additional participants were excluded due to preregistered exclusion criteria).

Procedure and Measures

After providing sociodemographic and celiac disease-specific information, participants completed a questionnaire containing the following measures. In line with Ciacci et al.

Table 1. Intercorrelations, means (M s), and standard deviations (SD s) of all theoretically relevant variables

Variable	1	2	3	4	5
1. Emotional support	–	.79**	.43**	.60**	-.16**
2. Informational support		–	.42**	.52**	-.19**
3. Well-being			–	.44**	.05
4. Dietary compliance				–	-.12*
5. Duration of illness					–
M	3.81	4.08	3.39	8.76	9.86
SD	0.95	0.77	0.80	2.51	10.09

Note. * $p < .05$; ** $p < .01$ (two-tailed).

(1998), we measured dietary compliance using a single-item, 10-point scale from 1 = *I never stick to my gluten-free diet* to 10 = *I always stick to my gluten-free diet*. We adopted the *Diabetes Social Support Scale* by Barrera et al. (2002) to measure received ES ($\alpha = .85$) and IS ($\alpha = .81$) with four items each on a 5-point scale from 1 = *I don't agree at all* to 5 = *I entirely agree*. Subjective well-being was measured with a five-item German translation (Janke & Glöckner-Rist, 2014) of Diener et al.'s (1985) *Satisfaction with Life Scale* on identical 5-point scales ($\alpha = .85$). Duration of illness was computed by subtracting participants' age at the time they were diagnosed with celiac disease from their age.

Results

Relationship Between ES/IS and Well-Being/Dietary Compliance

Table 1 presents intercorrelations, means, and standard deviations of all theoretically relevant variables.

To test how ES and IS relate to the proposed criteria, we computed two regression analyses with ES and IS as proposed predictors, and either well-being or dietary compliance as a proposed criterion (see Table 2). As expected, ES and IS were (marginally) significantly positively related to well-being and dietary compliance.

Duration of Illness as a Moderator

To test the assumption that IS becomes less important over the course of the illness while the importance of ES remains constant, we conducted two moderated regression analyses with either well-being or dietary compliance as the proposed criterion, in which IS, ES, and duration of illness (all mean-centered prior to analyses) were added in a first step and the relevant interaction terms ($IS \times \text{Duration}$, $ES \times \text{Duration}$) in a second step (see Table 3; Figure 1).

Table 2. Results from multiple regression analyses with well-being (upper part) and dietary compliance (lower part) as proposed criterion

Proposed predictors	<i>b</i>	CI [LL, UL]	<i>SE</i>	β	<i>t</i>	<i>p</i>	Cohen's f^2
Proposed criterion: Well-being							
Emotional support	0.22	95% CI [0.09, 0.34]	0.06	.26	3.44	< .001	0.03
Informational support	0.23	95% CI [0.07, 0.38]	0.08	.22	2.92	.004	0.02
Overall $R^2 = .20$, $F(2, 366) = 47.01$, $p < .001$							
Proposed criterion: Dietary compliance							
Emotional support	1.32	95% CI [0.97, 1.67]	0.18	.50	7.43	< .001	0.15
Informational support	0.42	90% CI [0.06, 0.78]	0.22	.13	1.94	.053	0.01
Overall $R^2 = .37$, $F(2, 366) = 106.38$, $p < .001$							

Table 3. Results from moderated regression analyses with well-being (upper part) and dietary compliance (lower part) as proposed criterion

Proposed predictors	<i>b</i>	95% CI [LL, UL]	<i>SE</i>	β	<i>t</i>	<i>p</i>	Cohen's f^2
Proposed criterion: Well-being							
Step 1							
Emotional support (A)	0.22	[0.10, 0.34]	0.06	.26	3.53	< .001	0.03
Informational support (B)	0.25	[0.10, 0.40]	0.08	.24	3.24	.001	0.02
Duration of illness (C)	0.01	[0.004, 0.02]	0.004	.14	2.96	.003	0.02
$R^2 = .22$, $F(3, 365) = 34.93$, $p < .001$							
Step 2							
(A) $\times$ (C)	0.01	[−0.004, 0.02]	0.01	.10	1.30	.196	0.007
(B) $\times$ (C)	−0.003	[−0.02, 0.01]	0.01	−.04	−0.48	.631	0.003
$\Delta R^2 = .01$, $F(2, 363) = 1.20$, $p = .303$; overall $R^2 = .23$, $F(5, 363) = 21.46$, $p < .001$							
Proposed criterion: Dietary compliance							
Step 2							
Emotional support (A)	1.32	[0.97, 1.67]	0.18	.50	7.42	< .001	0.15
Informational support (B)	0.41	[−0.02, 0.85]	0.22	.13	1.89	.060	0.01
Duration of illness (C)	−0.004	[−0.03, 0.02]	0.01	−.02	−0.41	.683	0.003
$R^2 = .37$, $F(3, 365) = 70.82$, $p < .001$							
Step 2							
(A) $\times$ (C)	−0.01	[−0.04, 0.03]	0.02	−.02	−0.29	.772	0.007
(B) $\times$ (C)	0.04	[0.01, 0.08]	0.02	.16	2.26	.024	0.02
$\Delta R^2 = .02$, $F(2, 363) = 5.31$, $p = .005$; overall $R^2 = .39$, $F(5, 363) = 45.62$, $p < .001$							

Well-Being as Proposed Criterion

The ES $\times$ Duration of illness interaction was non-significant (see Table 3, upper part). Subsequent simple slope analyses (Hayes, 2018) indicated that ES was (marginally) significantly and positively related to well-being independently of the duration of illness, that is, among participants scoring in the 16th percentile (shorter duration of illness) and participants scoring in the 84th percentile (longer duration of illness) (see Figure 1A; see Electronic Supplementary Material, ESM 1 for a more detailed description of the results of all simple slopes analyses). The IS $\times$ Duration interaction was non-significant as well (see Table 3, upper part), indicating that IS was significantly positively related to well-being independent of the duration of illness (see Figure 1B).

Dietary Compliance as Proposed Criterion

The ES $\times$ Duration interaction was again non-significant (see Table 3, lower part), with ES being significantly and

positively related to dietary compliance independent from the duration of illness (see Figure 1C). The IS $\times$ Duration interaction term was significant (see Table 3, lower part), indicating that, contrary to expectations, IS was significantly positively related to dietary compliance among participants with a longer duration of illness, but unrelated among participants with a shorter duration (see Figure 1D).

Discussion

Our results confirm that people with celiac disease can benefit from both functions of online peer social support, though effect sizes were larger for received ES compared to received IS. This finding is in line with other studies emphasizing the crucial role of ES in online contexts (e.g., Oh et al., 2013). Moreover, the observed effect sizes are

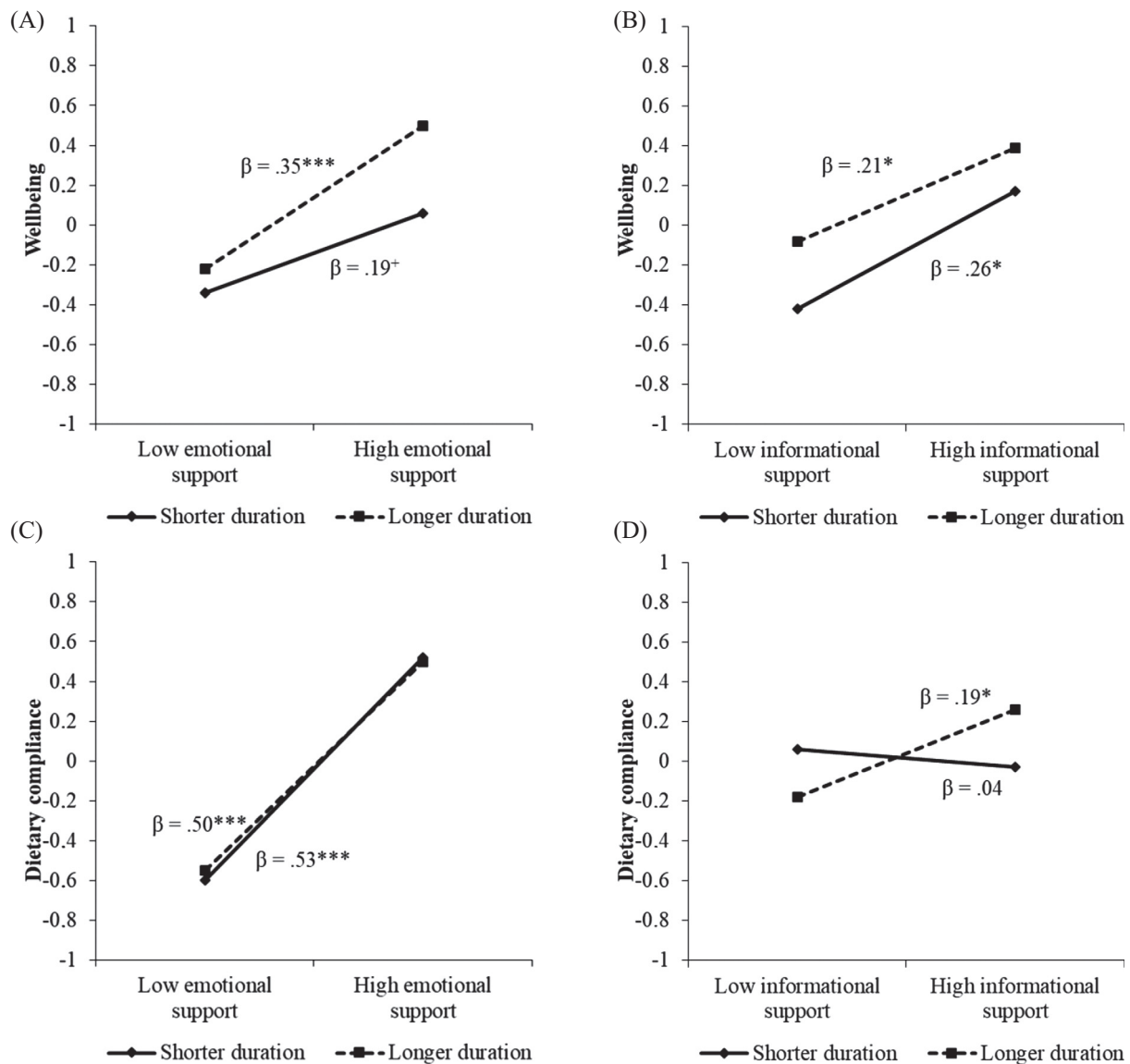


Figure 1. Well-being and dietary compliance as a function of levels of emotional support, informational support, and duration of illness (graphed at the 16th and 84th percentile). Coefficients are standardized regression weights and proposed criterion variables were z-standardized for the ease of comparison. (A) Well-being as a function of levels of emotional support and duration of illness; (B) Well-being as a function of levels of informational support and duration of illness; (C) Dietary compliance as a function of levels of emotional support and duration of illness; (D) Dietary compliance as a function of levels of informational support and duration of illness. $^+p < .10$; $^*p < .05$; $^{***}p < .001$.

comparable to those found in offline settings (see DiMatteo, 2004), suggesting that online peer ES can affect health behavior to a similar extent as face-to-face ES. Future research is needed to address the underlying mechanisms of the relationship between online peer social support and health outcomes. Numerous studies found that such adaptive outcomes are not affected directly by social support, but indirectly by increasing self-efficacy expectations (e.g., Schwarzer & Knoll, 2007). The present study included a measure of self-efficacy that was positively related to both functions of social support as well as both health outcomes

(see ESM 1). However, due to the cross-sectional design, we cannot address the predictive direction of this relationship.

Moderation analyses confirmed that the strength of the positive relationships between ES and both health outcomes were independent of the duration of illness, suggesting that ES is an important resource throughout the course of celiac disease. Contrary to expectations, the importance of IS for health outcomes did not diminish over time: It seems that IS is positively related to well-being throughout the course of celiac disease and becomes even stronger related to dietary compliance with increasing duration of

illness. One reason for this finding could be that knowing about the latest diet recommendation plays a particularly important role among people with celiac disease, thus making IS a valuable resource even later in the course of the disease.

One limitation of the study's design is that one cannot infer the causal role of IS and ES. Future work should thus attempt to replicate the present findings using a longitudinal or experimental design. Moreover, given that both functions of online social support were highly correlated, one might question whether a distinction between IS and ES can be justified in our study. Still, ES was more strongly related to dietary compliance than IS, suggesting the former to be more useful for people living with celiac disease (see optimal matching theory, e.g., Cutrona & Russell, 1990). Future research could test this assumption by explicitly measuring the perceived match between different functions of online social support and stressor demands in the context of chronic diseases. In addition, to gain a comprehensive understanding of the role of online peer social support in chronic conditions, further research examining additional potential moderators or contextual factors is needed (e.g., type of chronic condition). Finally, as in other research on online social support, the effects in our study are small to moderate. They are still of practical relevance, though: Given that online peer social support is a very cost-effective method that can reach large numbers of people – perhaps even especially those most in need of support – it can have a considerable impact on a societal level. It should thus be proactively advertised in addition to established therapies.

Electronic Supplementary Materials

The electronic supplementary material is available with the online version of the article at <https://doi.org/10.1027/2512-8442/a000126>

ESM 1. Simple slopes analyses and self-efficacy expectations: Measurement and correlations

References

- Barrera, M., Glasgow, R. E., McKay, H. G., Boles, S. M., & Feil, E. G. (2002). Do Internet-based support interventions change perceptions of social support? An experimental trial of approaches for supporting diabetes self-management. *American Journal of Community Psychology*, 30(5), 637–654. <https://doi.org/10.1023/A:1016369114780>
- Chen, A. T. (2016). The relationship between health management and information behavior over time: A study of the illness journeys of people living with fibromyalgia. *Journal of Medical Internet Research*, 18(10), Article e269. <https://doi.org/10.2196/jmir.5309>
- Ciacchi, C., Iavarone, A., Mazzacca, G., & De Rosa, A. (1998). Depressive symptoms in adult coeliac disease. *Scandinavian Journal of Gastroenterology*, 33(3), 247–250. <https://doi.org/10.1080/00365529850170801>
- Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Wiley Series on personality processes. Social support: An interactional view* (pp. 319–366). Wiley.
- Diener, E. D., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment*, 49(1), 71–75. https://doi.org/10.1207/s15327752jpa4901_13
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology*, 23(2), 207–218. <https://doi.org/10.1037/0278-6133.23.2.207>
- Drageset, S., Lindstrøm, T. C., Giske, T., & Underlid, K. (2012). “The support I need”: Women's experiences of social support after having received breast cancer diagnosis and awaiting surgery. *Cancer Nursing*, 35(6), E39–E47. <https://doi.org/10.1097/NCC.0b013e31823634aa>
- Fisher, E. B., Boothroyd, R. I., Coufal, M. M., Baumann, L. C., Mbanya, J. C., Rotheram-Borus, M. J., Sanguanprasit, B., & Tanasugarn, C. (2012). Peer support for self-management of diabetes improved outcomes in international settings. *Health Affairs*, 31(1), 130–139. <https://doi.org/10.1377/hlthaff.2011.0914>
- Hall, N., Rubin, G., & Charnock, A. (2009). Systematic review: Adherence to a gluten-free diet in adult patients with coeliac disease. *Alimentary Pharmacology & Therapeutics*, 30(4), 315–330. <https://doi.org/10.1111/j.1365-2036.2009.04053.x>
- Hayes, A. F. (2018). *Introduction to mediation, moderation, and conditional process analysis. A regression-based approach* (2nd ed.). Guilford Press.
- Hossain, S. N., Jaglal, S. B., Shepherd, J., Perrier, L., Tomasone, J. R., Sweet, S. N., Luong, D., Allin, S., Nelson, M. L. A., Guilcher, S. J. T., & Munce, S. E. P. (2021). Web-based peer support interventions for adults living with chronic conditions: Scoping review. *Journal of Medical Internet Research*, 8(2), Article e14321. <https://doi.org/10.2196/14321>
- Janke, S., & Glöckner-Rist, A. (2014). Deutsche Version der Satisfaction with Life Scale (SWLS) [German version of the Satisfaction with Life Scale (SWLS)]. *Zusammenstellung sozialwissenschaftlicher Items und Skalen*. <https://doi.org/10.6102/zis147>
- Lee, A., & Newman, J. M. (2003). Celiac diet: Its impact on quality of life. *Journal of the American Dietetic Association*, 103(11), 1533–1535. <https://doi.org/10.1016/j.jada.2003.08.027>
- Mehnert, L., Siem, B., Stürmer, S., & Rohmann, A. (2018). The impact of client-counselor similarity on acceptance of counseling services for women living with HIV. *AIDS Care*, 30(4), 461–465. <https://doi.org/10.1080/09540121.2017.1381329>
- Mo, P. K., & Coulson, N. S. (2008). Exploring the communication of social support within virtual communities: A content analysis of messages posted to an online HIV/AIDS support group. *Cyberpsychology & Behavior*, 11(3), 371–374. <https://doi.org/10.1089/cpb.2007.0118>
- Oh, H. J., Lauckner, C., Boehmer, J., Fewins-Bliss, R., & Li, K. (2013). Facebooking for health: An examination into the solicitation and effects of health-related social support on social networking sites. *Computers in Human Behavior*, 29(5), 2072–2080. <https://doi.org/10.1016/j.chb.2013.04.017>
- Rains, S. A., & Young, V. (2009). A meta-analysis of research on formal computer-mediated support groups: Examining group characteristics and health outcomes. *Human Communication Research*, 35(3), 309–336. <https://doi.org/10.1111/j.1468-2958.2009.01353.x>

Schwarzer, R. (2004). *Psychologie des Gesundheitsverhaltens: Einführung in die Gesundheitspsychologie* [Psychology of health behavior: Introduction to health psychology] (3rd rev. ed.). Hogrefe.

Schwarzer, R., & Knoll, N. (2007). Functional roles of social support within the stress and coping process: A theoretical and empirical overview. *International Journal of Psychology*, 42(4), 243–252. <https://doi.org/10.1080/00207590701396641>

Siem, B., Rohmann, A., & Köstlin, D. (2022). *Data and syntax for "Social support in online peer-groups for coeliac disease"*. <https://osf.io/adf6b>

Ussher, J., Kirsten, L., Butow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine*, 62(10), 2565–2576. <https://doi.org/10.1016/j.socscimed.2005.10.034>

History

Received April 20, 2022

Revision received November 9, 2022

Accepted November 11, 2022

Published online January 19, 2023

Acknowledgments

The study was conducted by Dorothee Köstlin as part of her master's thesis under the joint supervision of Anette Rohmann and Birte Siem.

Conflict of Interest

The authors declare that there are no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Publication Ethics

The commissioner for research involving human participants of the FernUniversität in Hagen exempted this study from review. The authors confirm that this article adheres to the ethical guidelines specified in the APA Code of Conduct as well as the authors' national ethics guidelines.

Authorship

All authors contributed equally to this work.

Open Data

The study's materials, data files, and analysis scripts are available at <https://osf.io/adf6b/> (Siem et al., 2022).

Funding

Open access publication enabled by FernUniversität in Hagen.

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