

参考文献

- Ackerman, I. N., Jordan, J. E., Van Doornum, S., Ricardo, M., & Briggs, A. M. (2015). Understanding the information needs of women with rheumatoid arthritis concerning pregnancy, post-natal care and early parenting: A mixed-methods study. *BMC Musculoskeletal Disorders, 16*, 194. <https://doi.org/10.1186/s12891-015-0657-4>
- Ackerman, I. N., Briggs, A. M., Ngian, G., & Van Doornum, S. (2016). Closing the pregnancy-related information gap for women with rheumatoid arthritis. *Rheumatology, 55*(8), 1343-1344. <https://doi.org/10.1093/rheumatology/kew024>
- Andreoli, L., Lazzaroni, M. G., Carini, C., Dall'Ara, F., Nalli, C., Reggia, R., Rodrigues, M., Benigno, C., Baldissera, E., Bartoloni-Bocci, E., Basta, F., Bellisai, F., Bortoluzzi, A., Campochiaro, C., Cantatore, F. P., Caporali, R., Ceribelli, A., Chighizola, C. B., Conigliaro, P., ...Tincani, A. (2019). "Disease knowledge index" and perspectives on reproductive issues: A nationwide study on 398 women with autoimmune rheumatic diseases. *Joint bone spine, 86*(4), 475-481. <https://doi.org/10.1016/j.jbspin.2018.12.002>
- 安西英雄 (2017). 患者中心の医療:米国流「全人的医療」への道. 全人的医療. *Comprehensive Medicine, 16*(1), 22-32.
- Barry, M. J., & Levitan, S. E. (2012). Shared decision making-pinnacle of patient-centered care. *The New England journal of medicine, 366*(9), 780-781. <https://doi.org/10.1056/NEJMp1109283>
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215. <https://doi.org/10.1037/0033-295X.84.2.191>
- Berwick, D. M. (2002). A user's manual for the IOM's 'Quality Chasm' report. *Health affairs, 21*(3), 80-90. <https://doi.org/10.1377/hlthaff.21.3.80>
- Brouwer, J., Hazes, J. M., Laven, J. S., & Dolhain, R. J. (2015). Fertility in women with rheumatoid arthritis: influence of disease activity and medication. *Annals of the rheumatic diseases, 74*(10), 1836-1841. <https://doi.org/10.1136/annrheumdis-2015-026300>

0.1136/annrheumdis-2014-205383

- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social science & medicine* (1982), 44(5), 681-692. [https://doi.org/10.1016/s0277-9536\(96\)00221-3](https://doi.org/10.1016/s0277-9536(96)00221-3)
- Coulter, A., Stilwell, D., Kryworuchko, J., Mullen, P. D., Ng, C. J., & van der Weijden, T. (2013). A systematic development process for patient decision aids. *BMC Medical Informatics and Decision Making*, 13(2). <https://doi.org/10.1186/1472-6947-13-S2-S2>
- Elwyn, G., O'Connor, A. M., Bennett, C., Newcombe, R. G., Politi, M., Durand, M. A., Drake, E., Joseph-Williams, N., Khangura, S., Saarimaki, A., Sivell, S., Stiel, M., Bernstein, S. J., Col, N., Coulter, A., Eden, K., Harter, M., Rovner, M. H., Moumjid, N., ... Edwards, A. (2009). Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). *PloS One*, 4(3). <https://doi.org/10.1371/journal.pone.0004705>
- Faulkner L. (2003). Beyond the five-user assumption: benefits of increased sample sizes in usability testing. *Behavior research methods, instruments, & computers : a journal of the Psychonomic Society, Inc*, 35(3), 379-383. <https://doi.org/10.3758/bf03195514>
- Freire, P. (2011). 被抑圧者の教育学 (三砂ちづる訳.). *Pedagogy of the Oppressed*. (Original work published 1968)
- 福田公子, 菊沢康子, 中村一枝. (1982). 家庭科教育における家族計画の教材化に関する研究—現状の把握と教材化の構想—. *日本教科教育学会誌*, 7(3), 162-168.
- 舟久保ゆう. (2015). 関節リウマチの治療と妊娠の両立. *日本臨床免疫学会会誌*, 38(1), 45-56.
- Götestam Skorpen, C., Hoeltzenbein, M., Tincani, A., Fischer-Betz, R., Elefant, E., Chambers, C., da Silva, J., Nelson-Piercy, C., Cetin, I., Costedoat-Chalumeau, N., Dolhain, R., Förger, F., Khamashta, M., Ruiz-Irastorza, G., Zink, A., Vencovsky, J., Cutolo, M., Caeyers, N., Zumbühl, C., & Østensen,

- M. (2016). The EULAR points to consider for use of antirheumatic drugs before pregnancy, and during pregnancy and lactation. *Annals of the rheumatic diseases*, 75(5), 795-810. <https://doi.org/10.1136/annrheumdis-2015-208840>
- 橋本就子, 村島温子. (2016). 妊娠希望患者における治療選択. 内科, 117(5), 203-208.
- Hoefel, L., O'Connor, A. M., Lewis, K. B., Boland, L., Sikora, L., Hu, J., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework Part 1: A Systematic Review of the Decisional Needs of People Making Health or Social Decisions. *Medical decision making: an international journal of the Society for Medical Decision Making*, 40(5), 555-581. <https://doi.org/10.1177/0272989X20936209>
- 印南一路. (2011). すぐれた意思決定とは. 看護, 63(1), 42 - 47.
- Jonsen, A. R., Siegler, M., & Winslade, W. (2006). 臨床倫理学—臨床医学における倫理的決定のための実践的なアプローチ (赤林朗, 蔵田伸雄, 児玉聡, 訳; 5th ed.). *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. (Original work published 1982)
- Joseph-Williams, N., Newcombe, R., Politi, M., Durand, M. A., Sivell, S., Stacey, D., O'Connor, A., Volk, R. J., Edwards, A., Bennett, C., Pignone, M., Thomson, R., & Elwyn, G. (2014). Toward Minimum Standards for Certifying Patient Decision Aids: A Modified Delphi Consensus Process. *Medical decision making: an international journal of the Society for Medical Decision Making*, 34(6), 699-710. <https://doi.org/10.1177/0272989X13501721>
- 香川英俊, 竹本玲加, 山中龍太郎, 廣政敏. (2015). 抗リウマチ薬および生物学的製剤の選択に関する考察. 姫路赤十字病院誌, 39, 14-20.
- Katz, P. P. (2006). Childbearing decisions and family size among women with rheumatoid arthritis. *Arthritis and Rheumatism*, 55(2), 217-223. <https://doi.org/10.1002/art.21859>
- 慶應義塾大学湘南藤沢キャンパス. おかしら日記. 武田祐子. 意思を尊重した支援を再考する. (2020). Retrieved 2020-01-23 from https://www.sfc.keio.ac.jp/deans_diary/014320.html

- 国立社会保障・人口問題研究所. (2015). 第15回出生動向基本調査. https://www.ipss.go.jp/ps-doukou/j/doukou15/doukou15_gaiyo.asp
- 公益財団法人 日本医療機能評価機構. (2014). 関節リウマチ診療ガイドライン 2014. <https://minds.jcqhc.or.jp/n/med/4/med0064/G0000706/0011>
- 厚生労働省. (2013). リウマチ・アレルギー対策委員会報告書. <https://www.mhlw.go.jp/stf/houdou/2r9852000001nfao-att/2r9852000001nfdx.pdf>
- 厚生労働省. (2018). 平成30年人口動態統計月報年計の概況. <http://www.mhlw.go.jp/tokei/saikin/hw/jinkou/geppo/nengai18/dl/h3-4.pdf>
- 厚生労働省. (2019). 育成疾患克服等次世代育成基盤研究事業. <https://www.mhlw.go.jp/seisakunitsuite/bunya/hokabunya/kenkyujigyou/hojokin-koubo-2019/gaiyo/04.html>
- Kriston, L., Scholl, I., Hölzel, L., Simon, D., Loh, A., & Härter, M. (2010). The 9-item Shared Decision Making Questionnaire (SDM-Q-9). Development and psychometric properties in a primary care sample. *Patient education and counseling, 80*(1), 94-99. <https://doi.org/10.1016/j.pec.2009.09.034>
- Kuh D. & Shlomo B. Y. (2004). A Life Course Approach to Chronic Diseases Epidemiology. Oxford Medical Publications.
- Meade, T., Sharpe, L., Hallab, L., Aspanell, D., & Manolios, N. (2013). Navigating motherhood choices in the context of rheumatoid arthritis: women's stories. *Musculoskeletal Care, 11*(2), 73-82. <https://doi.org/10.1002/msc.1031>
- Meade, T., Dowswell, E., Manolios, N., & Sharpe, L. (2015). The motherhood choices decision aid for women with rheumatoid arthritis increases knowledge and reduces decisional conflict: a randomized controlled trial. *BMC Musculoskeletal Disorders, 16*, 260. <https://doi.org/10.1186/s12891-015-0713-0>
- 村本淳子, 高橋真理. (2005). ウイメンズヘルスナーシング概論 女性の検討と看護. ヌーヴェルヒロカワ.
- 村島温子, 金子佳代子, 綿貫聡. (2019). 膠原病・リウマチ疾患と妊娠・授乳ハンドブック. 南山堂. 内閣府. (2019). 少子化社会対策に関する意識調査. https://www8.cao.go.jp/shoushi/shoushika/research/h30/zentai-pdf/pdf/pd_s2.pdf
- 中山和弘, 岩本貴. (2012). 患者中心の意思決定支援 納得して決めるためのケア. 中央法

規.

- 中山和弘. (2019). 患者中心の意思決定支援. *手術医学*, 40(2), 35-40.
- 中山健夫. (2017). これから始める！シェアードディジションメイキング 新しい医療のコミュニケーション. 日本医事新報社.
- 難治性疾患政策研究事業. (2018). 関節リウマチ (RA) や炎症性腸疾患 (IBD) 罹患女性患者の妊娠, 出産を考えた治療指針の作成. <https://ra-ibd-sle-pregnancy.org/data/sisin201803.pdf>
- 日本医学会医学用語辞典. <http://jams.med.or.jp/dic/terminology/technicalterm.html>
- O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, 15(1), 25-30. <https://doi.org/10.1177/0272989X9501500105>
- O'Connor, A. M. (2003). User Manual-Stage of Decision Making. ©2000[updated 2003]. https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Stage_Decision_Making.pdf
- O'Connor, A. M., Stacey, D., & Boland, L. (2005). Ottawa Decision Support Tutorial. <https://decisionaid.ohri.ca/odst/pdfs/odst.pdf>
- O'Connor, A. M., Stacey, D., & Jacobsen, M. J. (2015). Ottawa Hospital Research Institute & University of Ottawa. <https://decisionaid.ohri.ca/docs/das/OPDG.pdf>
- 岡本紀代香. (2016). 関節リウマチ患者が妊娠, 出産, 育児中に感じた思い. *日本看護学会論文集慢性期看護*, (46), 146-149.
- 大坂和可子, 米倉佑貴, 有森直子, 青木裕見, 檀谷ひとみ, 藤田美保, 萩原加奈子, 中山和弘. (2017). [https://www.healthliteracy.jp/pdf/Japanese%20version%20of%20IPDASi%20\(v4.0\)%20.pdf](https://www.healthliteracy.jp/pdf/Japanese%20version%20of%20IPDASi%20(v4.0)%20.pdf)
- Østensen, M., von Eisebeck, M., & Villiger, P. M. (2007). Therapy with immunosuppressive drugs and biological agents and use of contraception in patients with rheumatic disease. *The Journal of rheumatology*, 34(6), 1266-1269.
- Østensen M. (2014). Rheumatoid arthritis: The effect of RA and medication on female fertility. *Nature reviews. Rheumatology*, 10(9), 518-519. <https://doi.org/10.1038/nrrheum.2014.113>

- Phillips, R., Pell, B., Grant, A., Bowen, D., Sanders, J., Taylor, A., Edwards, A., Choy, E., & Williams, D. (2018). Identifying the unmet information and support needs of women with autoimmune rheumatic diseases during pregnancy planning, pregnancy and early parenting : mixed-methods study. *BMC Rheumatology*, *2*, 21-4. eCollection 2018. <https://doi.org/10.1186/s41927-018-0029-4>
- Prunty, M. C., Sharpe, L., Butow, P., & Fulcher, G. (2008). The motherhood choice: a decision aid for women with multiple sclerosis. *Patient education and counseling*, *71*(1), 108-115. <https://doi.org/10.1016/j.pec.2007.10.021>
- 社団法人日本リウマチ友の会. (2015). 流 242 号 創立 45 周年記念『2015 年リウマチ白書』ーリウマチ患者の実態<総合編>ー10, 障害者団体 定期刊行物協会.
- Stacey, D., Legare, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews*, *4*(4). <https://doi.org/10.1002/14651858.CD001431.pub5>
- Sun, Q. (2005). Predicting downstream effects of high decisional conflict: Meta-analysis of the Decisional Conflict Scale. *Thesis, University of Ottawa, Master of Science in Systems Science, School of Management*. <https://dx.doi.org/10.20381/ruor-18514>
- 鈴木智津子. (2008). エタネルセプトを導入する患者の意思決定を支える看護援助. *看護技術*, *54*(13), 41-45.
- Talabi, M.B., Clowse, M. E. B., Blalock, S. J., Switzer, G., Yu, L., Chodoff, A., & Borrero, S. (2019). Development of ReproKnow, a reproductive knowledge assessment for women with rheumatic diseases. *BMC Rheumatology*, *3*, 40. <https://doi.org/10.1186/s41927-019-0091-6>
- 富板美奈子. (2013). 特集 慢性疾患と妊娠・周産期・トランジション. *小児科診療*, *12*(75), 1933-1940.
- 東京大学病院医学部附属病院アレルギーリウマチ内科. (2019). 膠原病で妊孕性に影響を与える治療を受けたことのある方、および、受けることを勧められたことのある方

へ. <http://ryumachi.umin.jp/rinsho/2019244NI.html>

渡邊明美, 山際清貴, 安達拓, 佐藤恵里, 川村孝一郎. (2010). 関節リウマチ患者の妊娠・出産・育児に関する交流機会の必要性と意義. 日本作業療法学会抄録集, 44, 291.

綿貫聡, 村島温子, 金子佳代子. (2019). 座談会. 膠原病・リウマチ疾患と妊娠・授乳ハンドブック. 南山堂.

山田香. (2017). 子育て期にある関節リウマチ患者の母親としての経験と意思. 日本難病看護学会誌, 22(1), 35.

World Health Organization, Family Planning. http://www.who.int/topics/family_planning/en/

Woodruff T. K. (2010). The Oncofertility Consortium--addressing fertility in young people with cancer. *Nature reviews. Clinical oncology*, 7(8), 466-475. <https://doi.org/10.1038/nrclinonc.2010.81>

Zadro, J. R., Traeger, A. C., Décary, S., & O'Keefe, M. (2020). Problem with patient decision aids. *BMJ evidence-based medicine*, bmjebm-2020-111371. Advance online publication. <https://doi.org/10.1136/bmjebm-2020-111371>