Exploring and managing inequalities in RMD healthcare

Keywords: Quality of life, Systemic lupus erythematosus, Self-management

Methods: The Peer Approaches to Lupus Self-Management (PALS) study was a randomized controlled trial wherein modeling and reinforcement of disease self-management skills by peers (mentors) to other African American women with SLE (mentees) was achieved through a combination of educational and informal phone or video interactions with each other. The control condition included small support groups that met on the same schedule as peer mentoring sessions. The Lupus Quality of Life questionnaire (LUP-QOL), which incorporates the Medical Outcomes Study (MOS) Short Form 36 Health Survey (SF-36) and the Functional Assessment of Chronic Illness Therapy-Fatigue (FACT-F), was used to determine HRQOL, and the Patient Activation Measure (PAM) assessed disease self-management or an individual’s knowledge, skill, and confidence for managing their health and healthcare. Generalized Linear Mixed Models were used to determine whether the intervention produced a greater change in these main outcomes from baseline, controlling for education, income, and age, reported.

Results: Of the 314 enrolled PALS participants, 138 were mentored (experimental), 132 participated in small support groups (controls), and 44 served as mentors. Although not statistically significant, there were incrementally improving trends in patient activation as the intervention progressed, among mentors and experimental participants and decreasing trends in depression and anxiety among experimental participants. Measures of social functioning (from the LUP-QOL) and coping (or lupus self-efficacy) significantly improved from baseline, among experimental participants (both p < 0.05).

Conclusion: Our findings suggest that participation in a peer mentoring intervention led to improvements in disease self-management and HRQOL, in areas of social functioning, coping, depression, and anxiety, among African American women with SLE. Since these factors are related to disease activity and morbidity/damage, future investigations should consider ways in which this approach can augment clinical care on a larger scale.

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Mind the gap: improving communication and outcomes

Keywords: Patient information and education, Gender/diversity issues, Pregnancy and reproduction

Methods: Genere Donna has been launched in July 2021. The website www.generedonna.it and the social media profiles are the heart of the project, promoting patients' empowerment and the importance of a gender approach in Public Health.

Results: Over 16 months of activity, there were about 160K website users (70% female, 56% of them are 18-44 years old), over 6.6Mln reach and over 220K informal interactions on social media, and a strong social community of around 27K people.

Conclusion: The strong need of clear and verified information around Gender and medicine is the key to raising awareness and promoting the importance of a gender approach in Rheumatology.

REFERENCES: