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Therapeutic Photography, Photovoice and Expressive Writing in Cardiovascular Rare Diseases: A Pilot Study for Psychological Well-Being in Marfan Syndrome

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Abstract

Background: Therapeutic photography (TP), Photovoice (PV) and expressive writing (EW) are creative practices that leverage visual imagery and narrative disclosure, supporting the expression of emotions through low-cost and scalable interventions. These psychologists-guided approaches assist patients' expressive processing of psychological distress, stigma, and disease identity in chronic conditions. Marfan syndrome (MFS), an autosomal-dominant connective tissue disorder with cardiovascular, ocular, and skeletal manifestations, profoundly impacts health-related quality of life (HRQoL).

Purpose: This pilot study evaluates the feasibility of implementing TP, PV and EW in the clinical pathway of MFS patients and their impact on psychological well-being, emphasizing patients' experiences of disease expressivity in multidisciplinary care.

Methods: In a mixed-methods sequential exploratory design, 10 MFS patients (>13 years) from a rare diseases reference center in Milan participated in 11 monthly 120-minute theoretical and practical sessions (in-person/online), facilitated by a psychologist and a nurse, exploring photography-based activities and expressive writing techniques.

Psychological well-being was assessed pre/post via Psychological General Well-Being Index questionnaire (PGWBI), while semi-structured interviews and User Experience Questionnaire (EUQ) detected changes in the expression of illness-related emotions and thoughts.

Results: Patients reported transformative experiences: novices discovered TP, PV, EW as novel tools to visually/narratively express disease embodiment, emotions, and identity, overcoming reluctance via guided reflection. Thematic analysis revealed enhanced emotional granularity, sharing of "invisible" burdens, and reframed self-perception. PGWBI improved significantly across domains ($p=0.034$, Cohen's $d=1.08$, large effect; Mann-Whitney U); EUQ indicated high efficiency (mean=-1.25 on satisfaction scale; others neutral).



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Conclusion: TP, PV and EW empower MFS patients to articulate and process unique disease experiences, fostering self-care, empowerment and coping. Larger trials in rare diseases are warranted to validate this patient-centered approach for improving HRQoL.

Keywords: Therapeutic photography; Photovoice; Expressive writing; Marfan syndrome; Psychocardiology