

Emotions, identity and situated agency in systemic lupus erythematosus: patient-reported outcomes from an adapted aquatic intervention

La Brazada (The Stroke) for the Rights of People with Lupus: an emotional and a political practice

TORNEO DE NATACIÓN
Brazada por los derechos
de las personas con LUPUS®
¡Nadar y volar!

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PARE Innovations in RMD health care and support

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1. BACKGROUND

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease associated with pain, fatigue, mobility limitations and emotional distress, significantly affecting quality of life and daily functioning. Although Patient-Reported Outcomes (PROs) have become increasingly important in rheumatology care, most studies continue to focus primarily on physical symptoms and functional measures. Limited research has explored how non-pharmacological interventions influence emotional experience, identity construction and patient agency. This study is based on the Stroke for the Rights of People with Lupus (*La Brazada*), an adapted aquatic collective activity developed in Mexico by Cetlu A.C. since 2022. Adapted aquatic activities may constitute not only a physical rehabilitation strategy, but also an affective and collective space where people living with lupus renegotiate embodiment, wellbeing and social participation.

2. METHODS

Mixed-methods multicentric study (2022–2026) conducted across 10 cities in Mexico. Data included structured surveys and open-ended responses from people living with SLE and other autoimmune diseases participating in adapted aquatic activities. Quantitative data were analyzed descriptively using Patient-Reported Outcomes (PROs), while qualitative responses were examined through discourse analysis focusing on emotions, positioning and situated agency. The quantitative component included structured surveys from 306 participants (217 reported a confirmed diagnosis of SLE). Data were analyzed descriptively and stratified by years since diagnosis (1–3, 4–7, 8–10, 11+), following PROs methodology and qualitative coding informed by Grounded Theory, identifying emergent categories and lexical patterns across testimonies.

3. OBJECTIVE

To analyse how adapted aquatic participation is associated with emotional experience, identity positioning, situated agency and the development of patient agency in people living with systemic lupus erythematosus (SLE), using Patient-Reported Outcomes (PROs) to explore the relationship between physical wellbeing, affective regulation, agency and collective participation and processes of bodily and identity positioning.

TABLE 1. Patient-Reported Outcomes (PROs)

Traditional PROs	PROs observed in this study	PROs expanded toward identity and Language Sciences
• pain • fatigue • functionality	• identity • emotion • agency • belonging • visibility • collective experience	• subjective experience • narrative dimension • affective dimension of lupus

Source: Author's own elaboration based on the Cetlu multicentric study (2022–2026).

4. IDENTITY POSITIONING AND AGENCY

Agency (Ahearn, 2001), is understood as the socioculturally mediated capacity to act, expressed through collective participation, emotional regulation and processes of bodily and discursive repositioning in people living with lupus. Positioning refers to the dynamic discursive process through which individuals locate themselves and others within interaction, assigning identities, rights, duties and possibilities for action inside socially and culturally situated narratives (Davies & Harré, 1990).

TABLE 2. Lexical Patterns Linked to Positioning and Agency in People with SLE Participating in *La Brazada*

Analytical axis	Main findings associated with swimming	Representative testimonies from participants
Emotional regulation through swimming	Emotional relief and reduced stress.	"Swimming has helped me with resistance, happiness and friendship. / It allows me to feel calm and helps a lot during flare days."
Identity and bodily repositioning	Recovering confidence in the body and experiencing movement.	"It helps me physically and emotionally. / Swimming makes me feel capable again."
Collective belonging and visibility	Visibility, accompaniment and collective recognition of lupus and autoimmune diseases.	"I want to continue making the disease visible and continue meeting sisters and brothers in illness."
Situated agency and participation	Participation in a public collective event linked to advocacy, awareness and mutual support.	"The event helps society understand what living with lupus really means."
Emotional trajectories over time	Varied according to years living with lupus, showing processes of adaptation, relief and resignification.	"Over time I have learned to reconnect with my body through water."

Source: Author's own elaboration based on the Cetlu multicentric study (2022–2026).

5. RESULTS

Among participants with SLE (n=217), 71.5% women and 28.5% men (mean disease 9.37 years). The most frequently reported benefits were: mobility/flexibility (32.65%), reduced pain (20.41%), increased energy (10.20%), better breathing/resistance (8.16%), reduced inflammation (4.08%).

Emotional outcomes were mainly positive: joy/happiness (89.5%), reduced stress/anxiety (24.49%), hope/gratitude (5.3%) and peace/tranquility (2.6%). Fear or anxiety prior to swimming was low (2.6%), suggesting a regulatory effect of aquatic participation. Among participants with previous experience in the program (22.31%), perceived improvements in mobility (50%) and pain reduction (22.22%) were higher, with joy predominating (71.43%).

Agency was expressed through motivations to participate, particularly supporting advocacy and disease visibility (5%), illustrating the collective dimension of agency (Figure 1).

Emotional patterns varied according to years since diagnosis. Participants in the early stage (1–3 years) reported higher levels of residual pain and anxiety, alongside lower perceptions of relief, suggesting an initial period of bodily and emotional adjustment. In contrast, individuals in the 4–7 year group showed the highest levels of joy and marked reductions in anxiety, indicating a phase of greater bodily confidence and emotional regulation. Participants with 8–10 years since diagnosis displayed more stable emotional patterns, characterized by sustained relief and low pain intensity. The findings suggest a progressive transformation of emotional experience over time (Figures 1 and 2).

6. CONCLUSIONS

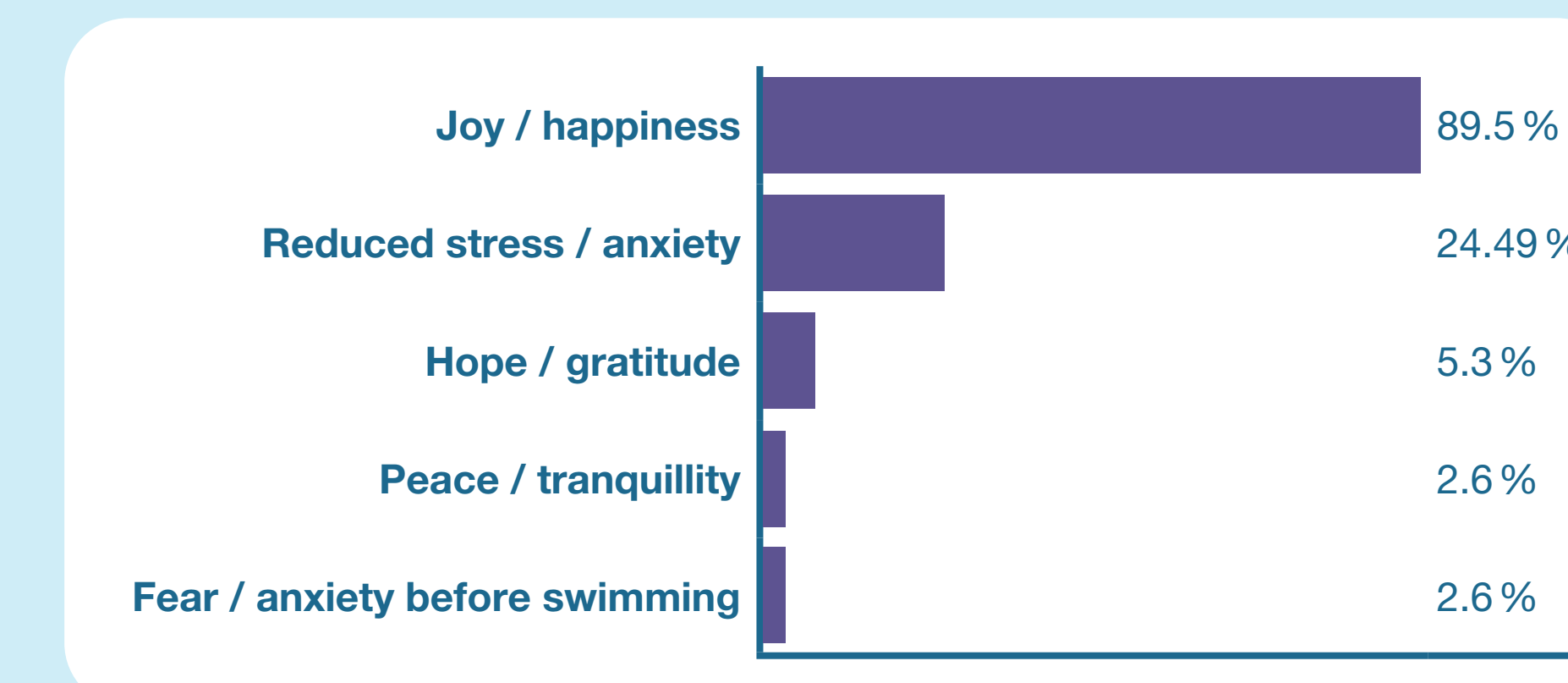
The aquatic space functions as an affective, collective and embodied environment where people living with lupus regulate emotions, renegotiate bodily identity and develop situated forms of agency through shared participation and visibility.

Adapted aquatic exercise (*La Brazada*) is associated with positive patient-reported physical and emotional outcomes in people living with SLE and other autoimmune diseases.

Swimming operates as a biopsychosocial space where emotions such as joy, relief and motivation circulate, shaping identity and collective belonging. From a situated agency perspective, agency emerges not only through individual participation but also through collective action and shared practices.

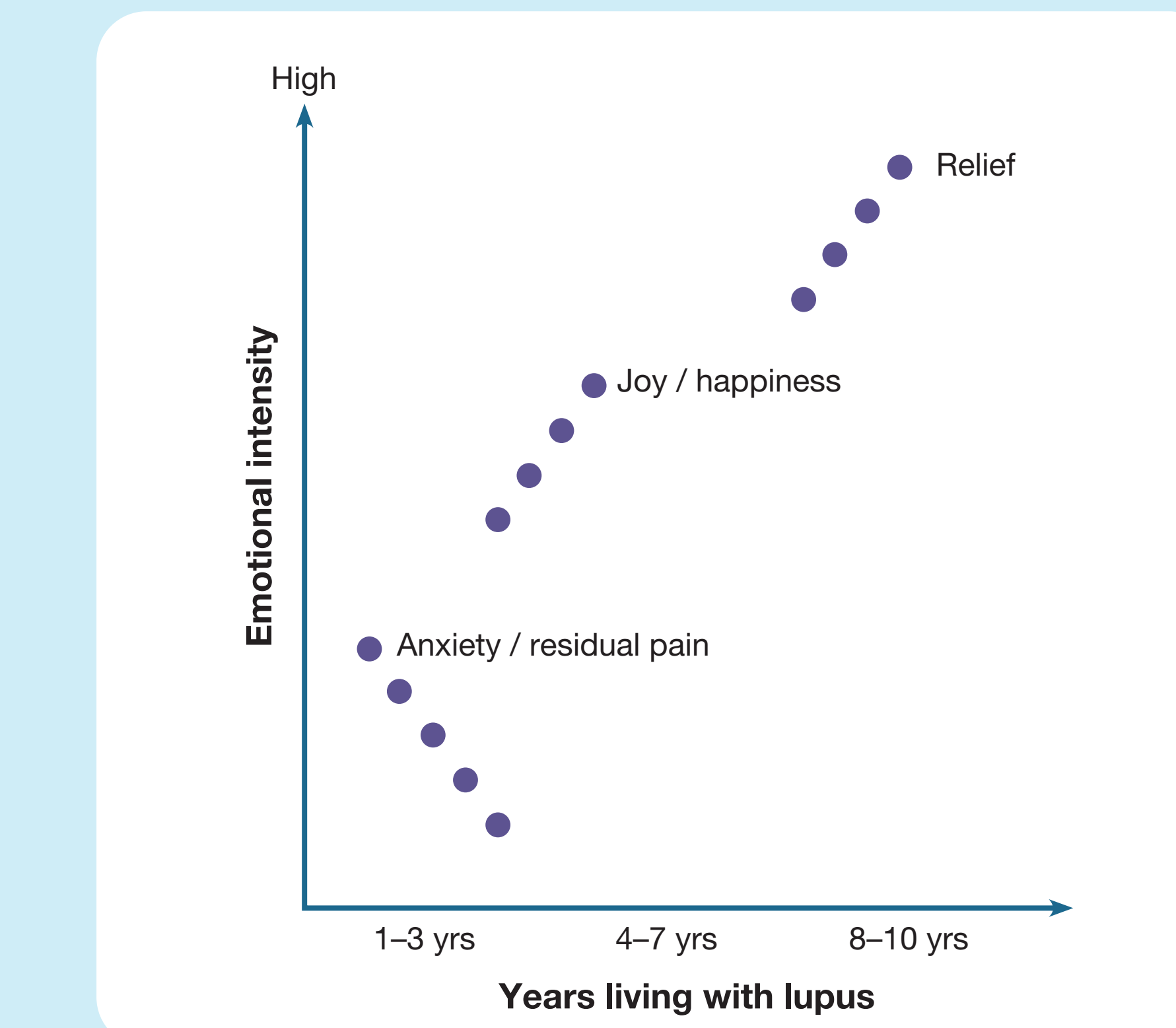
These findings highlight the importance of integrating PROs and emotional dimensions into rheumatology care, supporting a more participatory and human-centred model (Figures 3 and 4).

FIGURE 1. Emotional outcomes after swimming among people living with SLE



Source: Author's own elaboration based on the Cetlu multicentric study (2022–2026).

FIGURE 2. Years living with lupus and emotional patterns after swimming

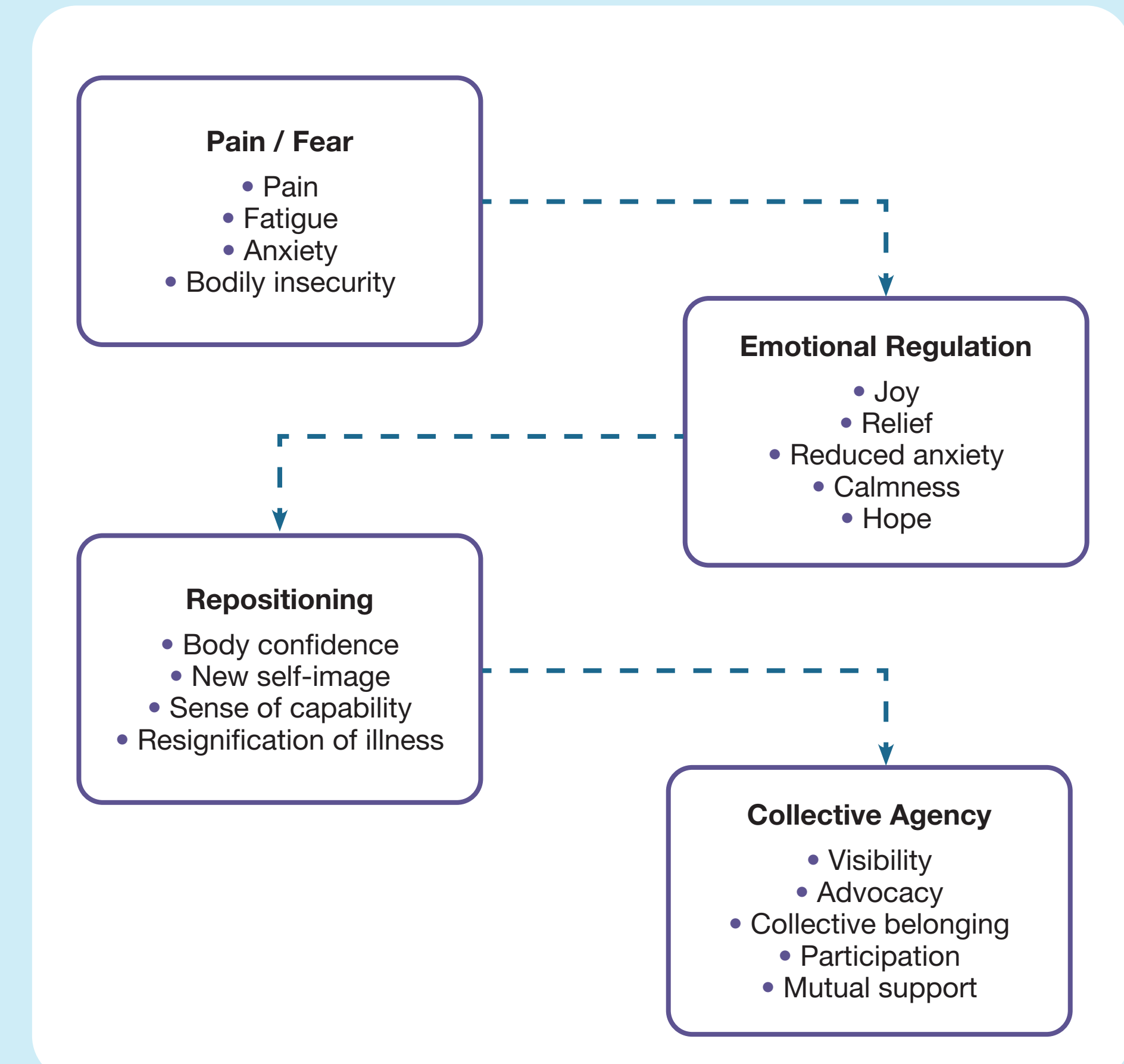


Source: Author's own elaboration based on the Cetlu multicentric study (2022–2026).

Legend:

- Joy / happiness → increases during intermediate stages and stabilises over time
- Relief → progressively increases with longer disease trajectories
- Anxiety / residual pain → higher in early stages and decreases over time

FIGURE 3. Agency and identity and positioning model



Source: Author's own elaboration based on the Cetlu multicentric study (2022–2026).

FIGURE 4. From exercise adherence to agency and affective regulation and emotional wellbeing

Aquatic participation	Emotion	Repositioning	Collective agency
• Swimming • Shared practice • Collective space • Embodied action	• Joy • Relief • Reduced anxiety • Calmness • Hope	• Bodily confidence • New self-image • Sense of capability • Resignification of illness	• Visibility • Advocacy • Collective belonging • Participation • Mutual support

Source: Author's own elaboration based on the Cetlu multicentric study (2022–2026).

References:

- Ahearn, L. M. (2001). Language and agency. *Annual Review of Anthropology*, 30, 109–137.
- Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. *Journal for the Theory of Social Behaviour*, 20(1), 43–63.



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