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# Tetraplegia Complications: A Practical Management Guide for Patients and Caregivers

**Topic:** Disability Studies

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## BACKGROUND

This study developed a patient-centered, Arabic-language guide for managing tetraplegia-related complications, aligned with the Health Literacy Skills Framework (HLSF), to address chronic health issues that significantly impair health-related quality of life (HRQoL).

## METHODS

A mixed-methods approach was employed, combining: A Cross-sectional data from 22 tetraplegic participants (assessing chronic complications, demographic factors, and HRQoL via the WHOQOL-BREF questionnaire). Qualitative feedback from focus groups (8 patients, 6 caregivers, and 8 healthcare professionals), analyzed using frequency analysis.

## RESULTS

The most frequent complications were pain (68%), UTIs (59%), pressure sores (55%), and spasticity (50%). Less common complications included respiratory issues (41%), autonomic dysreflexia (36%), and cardiovascular problems (18%). These complications correlated with reduced HRQoL: pressure sores significantly lowered physical HRQoL ($r = -0.45$), while good financial situations improved environmental HRQoL ($r = 0.42$), and easy access to healthcare enhanced physical HRQoL ($r = 0.31$).

Feedback from patients/caregivers highlighted challenges with terminology (e.g., "autonomic dysreflexia"), cultural barriers (e.g., gender-specific care), and gaps in strategies (e.g., hygiene routines, intimate health). Healthcare professionals identified evidence gaps (e.g., misalignment with International Continence Society [ICS] catheterization guidelines) and oversimplification of protocols (e.g., autonomic dysreflexia management).

Revisions prioritized: Simplifying language, incorporating visuals, and integrating cultural context (e.g., stigma reduction). Additionally, strengthening alignment with clinical guidelines (e.g., International Classification of Functioning, Disability and Health [ICF]/ICS) and addressing feasibility concerns (e.g., low-cost solutions).

## CONCLUSION

This study produced a concise, practical "What-Why-How" guide, addressing both individual health literacy skills and external contextual factors. However, the small sample size and reliance on self-reported data limit generalizability. Future research should validate the guide in larger, more diverse population, and address socioeconomic disparities in healthcare access.

**Statement of Disclosures**

*Informed consent was obtained from all participants (tetraplegic patients, caregivers, and healthcare professionals). Participants were informed of their right to withdraw at any stage without consequence.

*For participants with limited mobility, caregivers or legal representatives assisted in the consent process.

*All data were anonymized to protect participant privacy.

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