Letter to the Editor



Participation and Rehabilitation: The Need for Developing Native Instruments

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Dear Editor-In-Chief

The concept of disability is undergoing a revolution since terms of restriction or lack of "participation in meaningful roles of life" is becoming more widely used instead of the phrase 'handicap' (1). These roles have been defined in an individual, familial, and social levels; In this way, the goal of modern rehabilitation is to remove the burdens and increase the one's participation to the high levels of function and performance, likely after the occurrence of any incident or disorder(2). Therefore, major actions from researchers and leaders of the field have proceeded (3, 4) family members, (5) and health caregivers (6). Since the WHO's ICF conceptualize participation as involvement in real life situations, it can be in the means of having the will and being able to choose, and applying preferences of involvement by the individual himself; it also points out that the function of each individual should be conceptualized through his own socio-cultural context, and needs to carefully consider individual viewpoints of the involvement in his life's situation (7).

Therefore, there has been an increasing agreement on utilizing subjective manners of participation in therapeutic planning, in order to obtain more reliable evidence for researchers, as well as providing scientific documentation and solutions from the perspective of patients who experience "restriction" themselves, rather than observers who just document external observations (8). (Like attending a gym, that represents participation in a social activity with a recreational approach, but it can be challenging for the person with a disability to fulfil this role completely effective in the game, even though this interaction happens in a subjective way in particular.

With regards to searching major domestic and International scientific databases such as SID, PubMed and Google Scholar for the articles including the keywords "participation, rehabilitation services, outcome measurement, tool, instrument" and their relative synonyms, studies considering participation as a rehabilitation outcome have been selected. Ultimately, no evidence was found in concern of an instrument for evaluation of participation in the population of chronic and/or acute patients of Iran which are more prone to participation restriction. Various studies were focused on assessment of concepts such as quality of life in the population of vulnerable minorities (9, 10). Although one component of life's quality was mentioned as participation in meaningful roles of life, seldom attention has been



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paid to subjective interactions and participation of the individual. In response, the absence of a native instrument to evaluate and assess participation-rehabilitation is an emerging challenge for both the caregivers and recipients of rehabilitation services around the world. Therefore, researchers and clinician scientists should make serious efforts to provide native and cultureadapted instruments. In this regard, research for evaluation of rehabilitation-participation has been conducted recently at University of social welfare and rehabilitation sciences of Iran.

The evaluation and conceptualization of participation with regards to exclusive conditions of each community will definitely serve the supreme ideals of rehabilitation and population health, Since the classification of WHO has stressed on defining and applying the concept of participation in proportion with the individualized context which the person lives in, and has not proposed any distinction between activity and participation. Therefore, findings of such researches not only are the scientific capital to better understand the results of health services, but it will also be available to health and rehabilitation politicians and planners as valid and credible evidence that will advance the goals of rehabilitation and prevent the imposition of critical personal and familial costs on society.

Conflict of interest

The authors declare that there is no conflict of interest.

References

 WHO (2001). International classification of functioning, disability and health: ICF: Geneva: World Health Organization.

- VAN DDV, Bracke P, VAN GH, et al (2016). Measuring participation when combining subjective and objective variables: the development of the Ghent Participation Scale (GPS). Eur J Phys Rehabil Med,52(4):527-40.
- Lindberg J, Kreuter M, Person L, Taft C (2013). Patient Participation in Rehabilitation Questionnaire (PPRQ)—development and psychometric evaluation. *Spinal Cord*,51(11):838-42.
- Rauch A, Fekete C, Cieza A, Geyh S, Meyer T(2013). Participation in physical activity in persons with spinal cord injury: a comprehensive perspective and insights into gender differences. *Disabil Health J*,6(3):165-76.
- 5. Lindberg J, Kreuter M, Persson L, Taft C(2014). Family members' perspectives on patient participation in spinal cord injury rehabilitation. *Int J Phys Med Rehabil*,2(05).
- Florin J, Ehrenberg A, Ehnfors M (2006). Patient participation in clinical decisionmaking in nursing: a comparative study of nurses' and patients' perceptions. J Clin Nurs, 15(12):1498-508.
- Lund ML, Fisher AG, Lexell J, Bernspång B(2007). Impact on participation and autonomy questionnaire: internal scale validity of the Swedish version for use in people with spinal cord injury. J Rehabil Med, 39(2):156-62.
- 8. Goodley D, Hughes B, Davis L(2012). *Disability* and social theory: New developments and directions: Springer.
- Shahandeh H, Moradi S, Bavandpour K, Bohlooli F(2012). The quality of life of patients with spinal cord injuries. J Inj Violence Res, 4(3 Suppl 1): 73.
- Tajvar M, Arab M, Montazeri A(2008). Determinants of health-related quality of life in elderly in Tehran, Iran. BMC Public Health,8:323.