

Psychometric properties of the Arabic-validated Severe Respiratory Insufficiency Questionnaire for the assessment of Health-Related Quality of Life (HRQL) in patients on home mechanical ventilation

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Informed consent

Validation of the Arabic Severe Respiratory Insufficiency Questionnaire American University of Beirut

You are invited to participate in a research study that will involve 150 patients aiming to validate the Arabic version of the Severe Respiratory Insufficiency (SRI) Questionnaire; this questionnaire assesses the quality of life of patients with chronic respiratory insufficiency who receive mechanical ventilation at home. The study is being conducted by Drs. Salah Zeineldine and Mohamad Khatib from the Faculty of Medicine and Drs. Lilian Ghandour and Abba Sibai from the Faculty of Health Sciences at the American University of Beirut, as well as Mr. Marwan Alawieh from the Inhalation Therapy Department at the American University of Beirut Medical Center. The study's findings will allow to generate an Arabic-validated tool that helps assess the quality of life and better address patients' needs in future studies. Your name and contact number have been provided to our research team by your attending physician who has authorized his/her secretary to call you and obtain an initial oral consent to participate in the study.

What will be involved if you participate? Your participation is completely voluntary. If you decide to participate in this research study, you will be asked to fill out a questionnaire. Your total time commitment will be approximately 30 minutes. The survey will ask you about some personal information (e.g., gender, age, living arrangements, etc.), and past medical history (e.g. how many times did you visit the emergency room during the previous year?).

Are there any risks or discomforts? There are no known risks, nor are there any costs for your participation in this research study. If at any time and for any reason, you would prefer not to answer any questions, please feel free to skip them. You also have the right to withdraw your consent and discontinue your participation at any time for any reason. If you are tired from the

interview, a short break will be taken; another interview can be scheduled on another day if you feel very exhausted.

Are there any benefits to yourself or others? Participation has no personal benefits. Direct benefits to you may not be clear, but your participation is essential to help the research team in studying factors that affect the quality of life in patients using home mechanical ventilation in order to draw on future recommendations for a better delivery of this therapy at home. Once achieved, new patients requiring home mechanical ventilation will benefit from these recommendations.

If you change your mind about participating, you can withdraw at any time. If you choose to withdraw, your data will be withdrawn as well. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with AUB, AUBMC or your attending physician.

We will protect your privacy and the data you provide by coding the survey, and thus no one will be able to identify you. The information gained from you and other participants in this study will be analyzed and may be published in a professional journal, and/or presented at a professional meeting.

Records will be monitored and may be audited by the Institutional Review Board at AUB while assuring confidentiality of your contact information and information you have provided.

If you have questions about this study, please contact Dr. Salah Zeineldine at AUB ext. 4526 (sz01@aub.edu.lb), or Mr. Marwan Alawieh at AUB ext. 6680. If you have questions about your rights as a research participant, you may contact the American University of Beirut Institutional Review Board by phone +961 1 350 000 ext. 5445 or by emailing (irb@aub.edu.lb). A copy of the consent will be kept with you.

The American University of Beirut's Institutional Review Board has approved this document for use.

Having read the information above, you must decide if you want to participate in this research project.