KNOWLEDGE, AWARENESS, PREPAREDNESS AND EDUCATIONAL NEEDS REGARDING RARE DISEASES AMONG NURSING UNDERGRADUATES IN SRI LANKA

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Abstract

Rare diseases (RDs) affect <1 in 2, 000 people and represent a growing global health challenge. Low prevalence, diagnostic complexity, and limited treatment options contribute to poor patient outcomes, while inadequate healthcare professional knowledge may result in prolonged diagnostic delays. This study assessed knowledge, awareness, preparedness, perceived barriers, and educational needs regarding RDs among final-year nursing undergraduates in Sri Lanka. A descriptive, cross-sectional study was conducted among 251 of final-year nursing undergraduates in six state universities and a defense university in Sri Lanka, where admission is determined through national university entry Z-score system. Sample size was calculated using Cochran's formula adapted to known population, and participants were recruited through proportionate stratified random sampling. Data were collected using a pre-tested, content-validated, self-administered questionnaire. The 20-item knowledge section demonstrated acceptable internal consistency (Cronbach's α=0.711). Knowledge was assessed using composite score, while all other domains were assessed using structured items. Data were analyzed using SPSS v29.0. Mann-Whitney U and Kruskal-Wallis tests were performed for non-normally distributed knowledge scores with Bonferroni-adjusted significance at $p<0.002$ for 21 pairwise university comparisons. The mean age was 24.96±1.25 years, and 76.5% were female. The median knowledge score was 5(IQR 3-7) (range: 0-17). The majority were unaware about the definition (76.5%), prevalence (91.2%), affected age group (74.5%), diagnostic duration (89.2%), and treatability (82.1%) of RDs. 56.6% identified genetic factors as the main cause, and 62.1% recognized RDs as a serious public health issue. Significant differences in knowledge scores were observed among universities ($p<0.001$). Only 43.3% felt prepared to care for RD patients. 83.3% expressed interest in further learning. Major barriers included limited curriculum coverage (60.2%) and insufficient clinical exposure (58.3%). Final year undergraduates demonstrated gaps in RD knowledge and preparedness despite interest in further learning. Strengthening RD-related curriculum content and clinical learning opportunities may enhance preparedness for future nursing practice.

Keywords: educational needs, knowledge, preparedness, nursing undergraduates, rare diseases