

Quality of life of Norwegian adults with primary immunodeficiencies

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A sample of Norwegian adults with primary immunodeficiencies reported poorer physical health than the general population in Norway, and lower quality of life than an Italian sample with CVID.

Objective

- **Expand the limited knowledge** on health-related quality of life (HRQOL) of adults with primary immunodeficiencies (PID) in Norway.
- **Test validated HRQOL instruments**, comparing our PID sample to the general population and to an Italian CVID sample.

Centre for Rare Disorders

Centre for Rare Disorders is an interdisciplinary, nationwide competence centre, which offers information, counselling and seminars on a selected range of rare disorders.

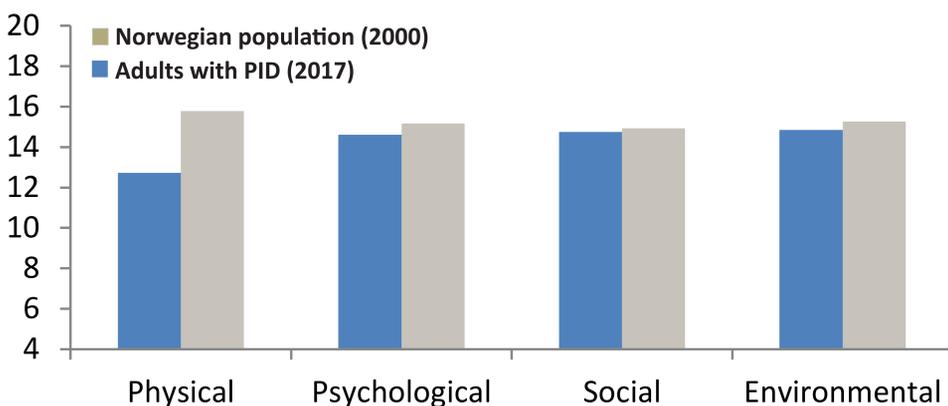
Design and method

- **Adults with PID** participating in a course at the Centre for Rare Disorders in Norway filled out two questionnaires on quality of life: WHOQOL-BREF (WHO 1996) and CVID_QoL (Quinti et al 2016).
- **The sample consisted of 34 persons:** 25 women and 9 men, M= 48.8 years. Thirty-two had antibody deficiencies, with CVID as the largest group (n = 15). Thirty-three were receiving immunoglobulin replacement therapy.

Results

- For WHOQOL and CVID_QoL, there was no difference in our sample between groups based on gender, age, marital status, health region, educational level, and type of antibody deficiency. Participants who were employed reported higher QOL.
- Three of the WHOQOL domains correlated strongly with the global CVID_QoL and two of its three dimensions ($r = 0.74-0.85$).
- Tiredness, fear of worsening health, and cough/phlegm were the items most frequently reported as impacting negatively on the lives of the Norwegian patients.

Adults with PID vs. Norwegian population: WHO quality of life (20 = highest QOL)

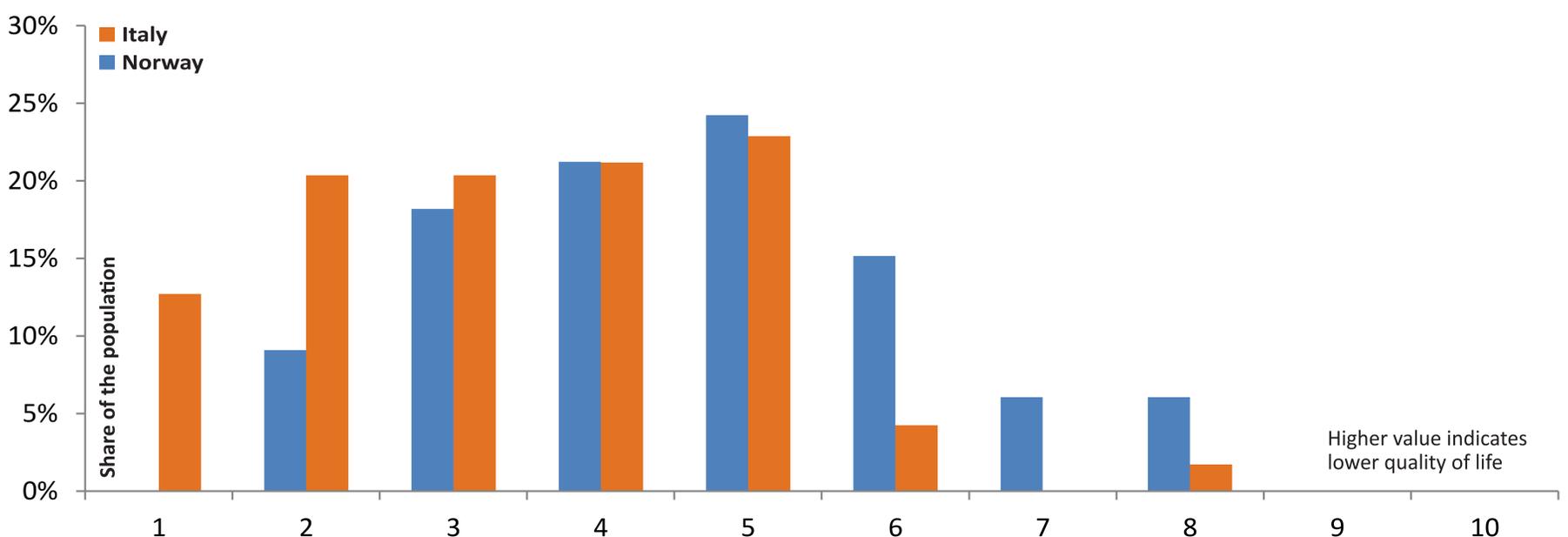


HRQOL was lower than in the general Norwegian population in the physical health domain; no difference was found in the psychological, social relationships, and environmental domains.

Conclusions

- The strong correlation between WHOQOL and CVID_QoL indicates the need to evaluate the utility of using both instruments.
- Our sample reported significantly lower CVID_QoL than the patients in the Italian study. The results point to the need for additional studies, including further evaluations of the instrument's cross-cultural validity.

Norwegian vs. Italian sample: distribution of global CVID_QoL (quality of life)



Our sample reported significantly lower CVID_QoL compared to the Italian sample (Quinti et al 2016). Our data had a normal distribution, in contrast to the Italian sample. Cronbach's alpha of CVID_QoL was identical in the two studies ($r = 0.72-0.90$).