

Comparing health-related quality of life in chronic diseases: the importance of analyzing references

Christine Maynié-François and Stéphane Burtey

In their comprehensive article about sickle cell disease (SCD; Sickle cell disease. *Nat. Rev. Dis. Primers* 4, 18010 (2018))¹, Kato and colleagues included a discussion on the negative effect of the disease on patients' quality of life. In Figure 7, the authors compared the health-related quality of life (HRQOL) of paediatric and adult patients with SCD to that of patients with other chronic diseases, including cystic fibrosis, cancer and asthma, and patients on dialysis.

HRQOL was measured in adults using the 36-Item Short Form Health Survey (SF-36)². In this figure, SCD ranked at an intermediate place for HRQOL compared with other diseases, and patients on dialysis had the lowest SF-36 score of ~45 out of 100. After analysing Figure 7, we found that the conclusions that might be drawn from it have limitations and bias.

First, as stated in the figure legend, HRQOL in Figure 7 only includes the physical functioning score from the SF-36 (REF.¹). However, this score is only one of the eight subscales of the SF-36, along with physical role functioning, emotional role functioning, bodily pain, vitality, general health, mental health and social function². It might have been more-appropriate to compare HRQOL in chronic diseases using complete SF-36 measures. Figure 7 was based in part on data from a 2005 paper by McClish and colleagues, who compared the SF-36 scores of patients living with SCD with data from other

studies on asthma, cystic fibrosis and haemodialysis³. The SF-36 physical functioning score of the SCD cohort was significantly higher than that of the dialysis cohort. However, patients with SCD had the lowest score (39.2 ± 22.1 , mean \pm standard deviation) in the general health subscale, and patients on haemodialysis had a significantly higher score (50.0 ± 22.4).

Second, the mean age in the SCD cohort was 33 years³, compared with 58 years in the haemodialysis cohort⁴. Furthermore, the article on the haemodialysis cohort was published in 1997, based on data from 1994–1995 (REF.⁴). Thus, the comparison was based on two cohorts of patients with a mean age difference of 25 years and on data published 10 years apart. Comparing these two cohorts seems difficult: younger individuals may have fewer comorbidities or disease complications, and in 10 years the medical progress in the field of dialysis had improved the HRQOL⁵.

Patients living with chronic diseases such as SCD or chronic kidney disease have an altered HRQOL, and the improvement of HRQOL must be a major objective in health care and research on any chronic disease. Thus, partial, old or hard-to-compare data should be assessed carefully, as the way they are presented might alter the understanding and seriousness of the message. References should always be verified and critically analysed, even if — especially if — they corroborate our findings or our beliefs.

When designing schematic visualizations, we should bear in mind that these items are easy to use by media or patients' associations⁶. Thus, we should be careful to integrate only comprehensive and good-quality evidence, especially on matters such as HRQOL, which are of great concern for patients.

There is a reply to this letter by Panepinto, J. A., Kato, G. J. & Smith, W. R. *Nat. Rev. Dis. Primers* <https://doi.org/10.1038/s41572-019-0080-5> (2019).

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Competing interests

All authors declare no competing interests.