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Psychological status of older patients with hemophilia: results from the multicenter S+PHERA study

Background: Today the management of PWH has dramatically changed, due to the availability of more and safer replacement products and specialized treatment centers attending comprehensively these patients. Accordingly, they have reached a life expectancy close to that of males in the general population.

Methods: Due to the paucity of published data in this field, a prospective, longitudinal, non-interventional study (the S+PHERA study) in elderly patients with severe hemophilia (aged 60 years or older) was designed with the aim of evaluating HrQoL, emotional and functional level in this poorly researched group of patients and comparing with age-matched controls using a battery of generic and specific validated scales.

Results: Out of 102 patients attending 14 Italian hemophilia treatment centers (HTCs) and matched with a group of age-matched men without hemophilia (n=204), chosen randomly from 6 general practices in Italy, only the generic HrQoL VAS index (EQ-5D instrument) was worse in patients than controls according to ($P < 0.001$) while other life dimensions (WHOQOL-Old scale) were equally impacted among the 2 groups with patients showed the highest impairments in the domain "death" ($p = .004$), while controls reported more impairments than PWH in "sensory" ($p = .006$) and "intimacy" ($p = .024$). At the emotional level, the degree of depression (GDS scale) was higher in patients than controls (mean total score 12.5 ± 3.2 for PWH vs 11.3 ± 2.7 for controls, $p = .001$) while pertaining to the functional status for simple activities of daily living as measured by ADL, patients showed slightly lower mean scores (5.5 ± 1.1 vs 5.9 ± 0.4 , $p < .001$), but for the more complex activities of daily living measured by IADL, there were no difference between PWH and controls (PWH mean score 6.4 vs 6.5).

Conclusions: Using an array of psychological tools and a suitable control, we were able to measure that current life status and functional capacities of older hemophiliacs are similar or only marginally lower than those of their age peers without hemophilia. These results emphasize the role that specialized and comprehensive HTCs, as well as specific programs meant to make aging successful in PWH, play to reduce the gap with age-matched peers without hemophilia who receive standard care by their general practitioners.

Max 350 words (excluding title)