

DIFFERENCES BETWEEN CARRIERS AND NON-CARRIERS OF HD, MJD AND FAP TTRV30M REGARDING PSYCHOLOGICAL ISSUES

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Psychological issues are important for genetic counselling and psychosocial intervention in late-onset diseases, as Huntington disease (HD), Machado-Joseph disease (MJD) and familial amyloid neuropathy (FAP) TTR V30M.

A protocol of genetic counselling and psycho-social evaluation and support, for pre-symptomatic testing in those diseases, is thought to be important to a healthy adjustment to the results of the test, whatever these may be.

Our aim was to evaluate psychological well-being and health perception in persons coming for pre-symptomatic testing after disclosure of the results, in carriers and non-carriers.

Our hypothesis was that carriers could be more concerned about their health and show more adverse indicators regarding their psychological well-being, once they are pressed by the knowledge of later developing an incapacitating disease. Subjects included 11 non-carriers and 26 carriers for HD, FAP and MDJ.

We applied the Psychological General Well Being (PGWB) schedule and the Health Perception Questionnaire (HPQ), 3 weeks after results disclosure.

There were significant differences regarding general psychological well-being, namely, in anxiety, depressive mood and auto-control; there were also significant differences in health perception, namely, prior and current health, doctor visits and feeling ill.

Carriers presented less anxiety, less depressed mood and more auto-control, and showed better well-being indicators than non carriers. Carriers also presented better health perception regarding prior and current health, and doctor visits; however, carriers feel significantly more that they will get ill, as expected.