

Publication

Autonomy and social influence in predictive genetic testing decision-making: A qualitative interview study

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Author(s) Zimmermann, Bettina M.; Koné, Insa; Shaw, David M.; Elger, Bernice Simone

Author(s) at UniBasel [Zimmermann, Bettina](#) ; [Koné, Insa](#) ; [Shaw, David](#) ; [Elger, Bernice Simone](#) ;

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Beauchamp and Childress' definition of autonomous decision-making includes the conditions of intentionality, understanding, and non-control. In genetics, however, a relational conception of autonomy has been increasingly recognized. This article aims to empirically assess aspects of social influence in genetic testing decision-making and to connect these with principlist and relational theories of autonomy. We interviewed 18 adult genetic counselees without capacity issues considering predictive genetic testing for cancer predisposition for themselves and two counselling physicians in Switzerland. We conducted a qualitative analysis, building on a grounded theory study about predictive genetic testing decision-making. We found that some participants agreed to predictive genetic testing predominantly because relatives wanted them to do it, with some even acting contrary to their own convictions. Others, in contrast, based their decision on purely individualistic reasons but expressed difficulties in explaining their decision to their social environment. Healthcare professionals had a critical influence on decision-making in many cases without being manipulative, as perceived by counselees. Still, cases of coercion and social pressure occurred within social relationships. In conclusion, predictive genetic testing decision-making includes relational and individualistic aspects, and both are compatible with autonomous decision-making. While the principlist and relational notions of autonomy compete on a theoretical level, they are two sides of the same coin when used as analytical lenses for genetic testing decision-making. Social acceptance of refusal of testing should be improved to mitigate social pressure. Individuals should be encouraged to decide for themselves how much their social environment influences their decision regarding predictive genetic testing.

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