The perception of professionals in the socio-health field about the support services provided for families with a member with neurodegenerative disease

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Abstract

Background: In the Spanish case, the social organization of care is characterized by being family oriented. This means that the involvement of the family in the care of its members is high in relation to the participation of other social actors, such as the State, the market, or the community. Neurodegenerative diseases (ND) significantly affect the quality of life of the person, but also that of their family, precisely because of their high involvement in care. Families require support services to increase their well-being, and several studies have shown the impact that the absence of support services has on the Family Quality of Life (FQoL). Considering this, the main objective of this study is to find out the perception of professionals working in the socio-health field about the adequacy and sufficiency of the services available to people with ND and their families in the Spain-Portugal cross-border area.

Method: This research has been developed through qualitative methodology. Three focus groups were held. They involved: 1) public social services personnel; 2) public health services staff; 3) workers in the services offered by private initiatives. All of them carried out their work in the cross-border area studied. With the support of the Atlas.ti software and following a deductive coding model, the data obtained were systematically coded and interpreted.

Results: Initial research results suggest that professionals in the socio-health field agree on their perceptions of the adequacy and sufficiency of support services provided for families with a member with ND. They consider that:

1) most support services are aimed solely at the needs of the person with a ND and therefore contribute little to improving the FQoL;

2) support services considered very adequate for the improvement of the FQoL are very insufficient;

3) the characteristics of the environment (small population, geographical dispersion, etc.) significantly limit support services in rural areas

Conclusion: The support services provided for families with a member with ND are scarce and inadequate, and therefore contribute little to improving the FQoL. There is a need to improve access and adapt support services to the needs of families.