Rare diseases and mental health in the UK - a quantitative survey and multi-stakeholder workshop

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Rosa Spencer-Tansley
Genetic Alliance UK

Nick Meade
Genetic Alliance UK

Farhana Ali
Genetic Alliance UK

Amy Simpson
Genetic Alliance UK

Amy Hunter
Genetic Alliance UK

amy@geneticalliance.org.uk *Corresponding Author*
ORCID: <https://orcid.org/0000-0001-5076-8761>

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Abstract

Background: Rare disease patients and carers report significant impacts on mental health but this has not been extensively studied. We explored the experiences of UK-based individuals through an online survey, and offer recommendations for policy and practice developed with a multi-stakeholder workshop.

Results: In total 1,355 patients and 571 carers responded to the survey. Due to their rare condition, the majority of respondents had felt worried/anxious (95%); stressed (93%); low/depressed (90%); emotionally exhausted (88%). Thirty-six percent of patients and 19% of carers had had suicidal thoughts. Challenges that are particular to rare conditions and which negatively affect mental health included low knowledge of the condition amongst healthcare professionals (88%), not being believed or taken seriously by healthcare professionals (80%), and lack of available information about the condition (76%). Only 23% of respondents felt mental health was considered by healthcare professionals as equally important as physical health. Almost half of patients (46%) and carers (48%) reported never having been asked about their mental health, or that of the person they care for, by healthcare professionals. Forty-six percent of respondents had received professional psychological support; the most common reason for not having accessed professional psychological support was that it had not been suggested (41%). Fifty-nine percent of respondents had accessed sources of additional emotional support, such as patient groups, with the majority (75%) having found this support themselves. With input from our multi-stakeholder workshop we developed recommendations for healthcare professionals to be supported to effectively and sensitively recognise and address patients' and carers' mental health needs; and for service level coordination of care to integrate professional psychological support with rare disease services.

Conclusions: Living with a rare disease can substantially impact mental health. Many of the drivers of poor mental health reflect issues specific to managing rare conditions. To meet existing UK government commitments, there should be a focus on empowering healthcare professionals who treat rare disease patients and on integration of mental health support with rare disease services.

Full-text

Due to technical limitations, full-text HTML conversion of this manuscript could not be completed.

However, the manuscript can be downloaded and accessed as a PDF.

Figures

Figure 1

Flow chart of study methods