

Genetic Counsellor-led Helpline Service based in the Voluntary Sector: A Service Evaluation

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Introduction

With public awareness of genetic disorders increasing and more genetic testing taking place in a wider range of settings, there is a growing need for those who can offer guidance and support to affected individuals and their families [1]. In the UK there are around 300 practicing genetic counsellors (GC) [2], with most genetic counselling taking place through the NHS, as well as increasingly through the private sector [2]. The national charity Genetic Disorders UK (GDUK) has been operating a free genetic counsellor-led helpline for all genetic conditions for more than six years [3]. The telephone and email service can be accessed by anyone at the time they need it. An independent service evaluation was conducted to assess how well the helpline service was performing and meeting the needs of its enquirers. The University of Exeter's Research Ethics Framework was followed for this project.

Aims

- Assess helpline enquirers' satisfaction levels
- Observe how anxiety levels changed following contact
- Assess how informed and supported enquirers felt by GDUK

Methods

- Mixed methods approach: surveys and interviews.
- Links to surveys were sent via text or email to enquirers before and after contact with the helpline GC, from 29.11.19 to 04.10.20.
- The survey design was informed by the Genetic Counselling Outcome Scale [4] and the answers were based on a 5-step Likert scale.
- Exclusion criteria for interviews included: sensitive situation; support ongoing; uncontactable.
- Interview transcripts were analysed using thematic analysis [5], with all interviewees given pseudonyms.

Results

Surveys:

- 154 pre-contact surveys sent, 23 responses.
- 139 post-contact surveys sent, 44 responses.
- 95% would recommend GDUK.
- 95% said the experience was helpful.
- Significant reduction in anxiety and confusion, and a significant increase in feeling supported and informed ($P < 0.001$).

Interviews:

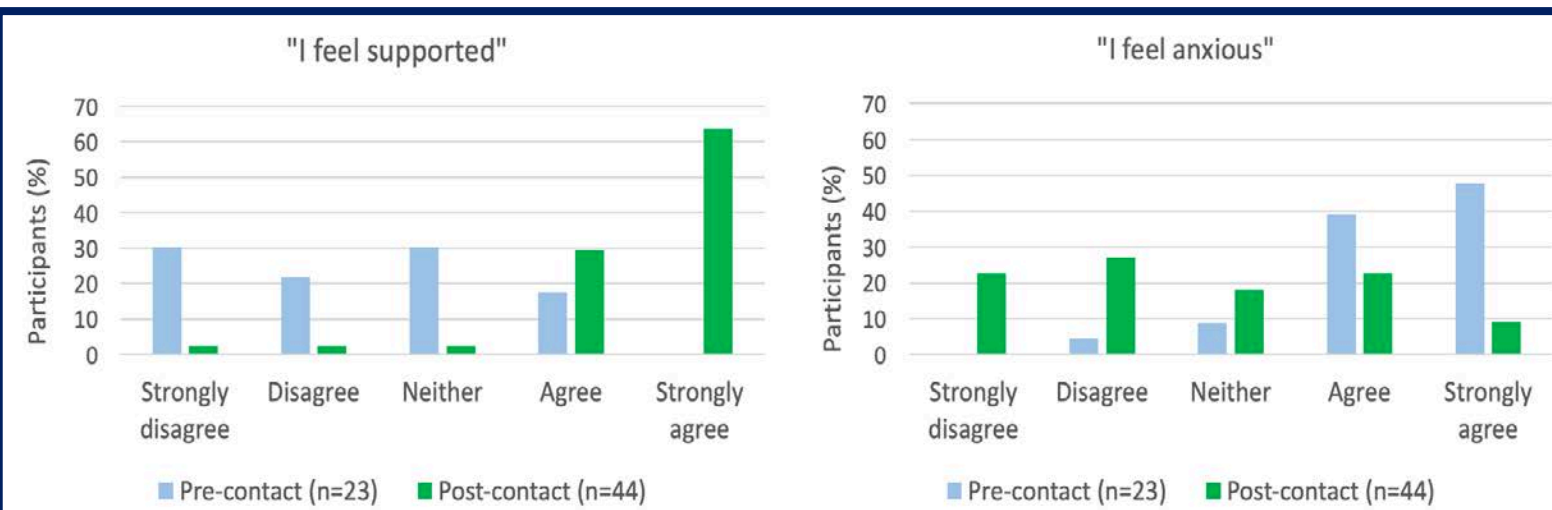
- 82 people who enquired between 09.01.19 and 06.04.20 were invited. 15 responded and were all interviewed.

Interview key themes:

- GDUK complemented NHS genetic services.
- Contact with GC-led helpline made a tangible difference.
- GC qualities were highly valued.
- Lack of signposting towards GDUK; enquirers discovered GDUK online whilst looking for help.

"I feel informed"

Pre-contact: 35%
Post-contact: 82%



"Can you imagine walking through a dark tunnel... and then you suddenly talk to someone on the end of the phone and you can actually see a light there."

'David'

"The support and information I received was not only excellent it was encouraging and reassuring."

Survey comment

Results from the electronic surveys, where n is the number of respondents, showing level of participant agreement with the statements "Regarding the condition I am enquiring about, I feel..." Due to the difference in numbers, responses are graphed using percentage of respondents. All participants answered all questions. Data were collected between 29.11.19 and 04.10.20.

"That was really helpful to have that level of expertise and someone who knows that area."

'Rosa'

"I feel like if, like, doctors could signpost people, it would be a lot more useful."

'Lauren'

"Just the fact that I know you're [GDUK] there helps, it really does help."

'Jess'

CONCLUSIONS

Results from the interviews and surveys were consistent, suggesting that GDUK and the GC-led helpline provide effective support to a broad range of people concerned about a genetic situation or condition. The majority of respondents felt supported by GDUK and were less anxious following contact. The service appears to fulfill an unmet need in the UK in a manner that complements and supports clinical services. With increased capacity the service could benefit more people and further develop as a key part of the landscape of supportive care for the whole genetic disorders community.

References: [1] Dragojlovic, Nick, Kennedy Borle, Nicola Kopac, Ursula Ellis, Patricia Birch, Shelin Adam, Jan M Friedman, Amy Nisselle, Alison M Elliott, and Larry D Lynd. 2020. 'The composition and capacity of the clinical genetics workforce in high-income countries: a scoping review', *Genetics in Medicine*, 22: 1437-49. [2] Abacan, MaryAnn, Lamia Alsubaie, Kristine Barlow-Stewart, Beply Caanen, Christophe Cordier, Eliza Courtney, Emeline Davoine, Janice Edwards, Niby J Elackatt, and Kate Gardiner. 2019. 'The global state of the genetic counseling profession', *European Journal of Human Genetics*, 27: 183-97. [3] Genetic Disorders UK. 2016. 'Financial Statements for the Year 1 April 2015 to 31 March 2016', Accessed 08.03.2020. [4] McAllister, Marion, Alex M Wood, Graham Dunn, Shoshana Shiloh, and Chris Todd. 2011. 'The Genetic Counseling Outcome Scale: a new patient-reported outcome measure for clinical genetics services', *Clinical genetics*, 79: 413-24. [5] Braun, Virginia, and Victoria Clarke. 2006. 'Using thematic analysis in psychology', *Qualitative research in psychology*, 3: 77-101.