



Assessing the impact of Coronavirus (COVID-19) on those living with a rare disease

Essential Thrombocythemia report

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Investigating the **impact** of COVID-19 on Caregivers and patients.

**Do you have cancer or a pre-cancerous condition?
Do you have a rare disease?
Are you a caregiver?**

Tell us how the coronavirus (COVID-19) pandemic is affecting you by clicking on the link below:

<https://www.surveymonkey.co.uk/r/IMPACCTsurvey>

This data is extracted from a larger project – the IMPaCCT study:

The IMPaCCT of the COVID-19 pandemic on people with a rare disease

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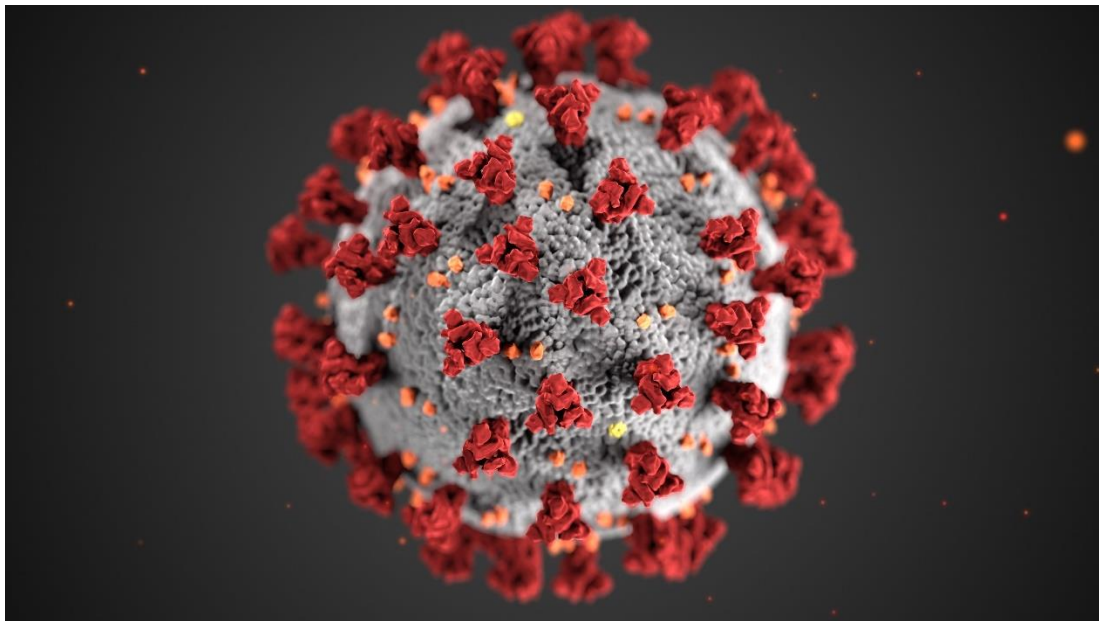
Email contact: raredisease@qub.ac.uk

Background

Coronavirus disease (COVID-19) is an infectious disease caused by a virus which affects the lungs and airways. It first emerged in Wuhan City in China at the end of 2019. From there the virus spread to other countries worldwide with the World Health Organisation declaring it a pandemic on 12th March 2020.

The virus placed enormous pressure on health services which were faced with an increasing number of patients requiring respiratory assistance. As a result, normal care pathways were altered. In the UK, and many other countries, routine primary care and hospital appointments were delayed.

Rare diseases are defined by the European Union as those affecting fewer than 1 in 2,000 individuals, cumulatively affecting 1 in every 17 persons at some point in their lives. It is estimated that 350 million people globally have a rare disease. The ongoing COVID-19 global pandemic has disrupted many sources of support and care for those affected by rare diseases, bringing a range of impacts on healthcare, mental and physical health, social life and work life. The pandemic has highlighted the already too prevalent problems faced by our rare disease community.



General Survey

An online survey was conducted in Spring 2020 to assess the health, healthcare and psychosocial impact of coronavirus (COVID-19) on patients with rare diseases. The survey queried:

- Experience of isolating/self-isolating;
- Substantial life changes and reasons for such changes;
- How difficult these life changes have been;
- Challenges experienced when speaking to medical professionals;
- Concerns about the impact of COVID-19;
- Further information/services/support that would be useful;
- Improvements required to the support available;

The data was anonymised and analysed Thematically. Specific questions which provided written accounts on the impact of isolation and impact on care due to COVID-19 were selected for analysis. The responses given were searched for similarities and differences as well identifying the meaning of the answers given. Keywords and similar opinions were denoted categorical “codes”. The coded responses were then categorised into overarching Themes that captured all variable “codes” for a given question.

Respondents

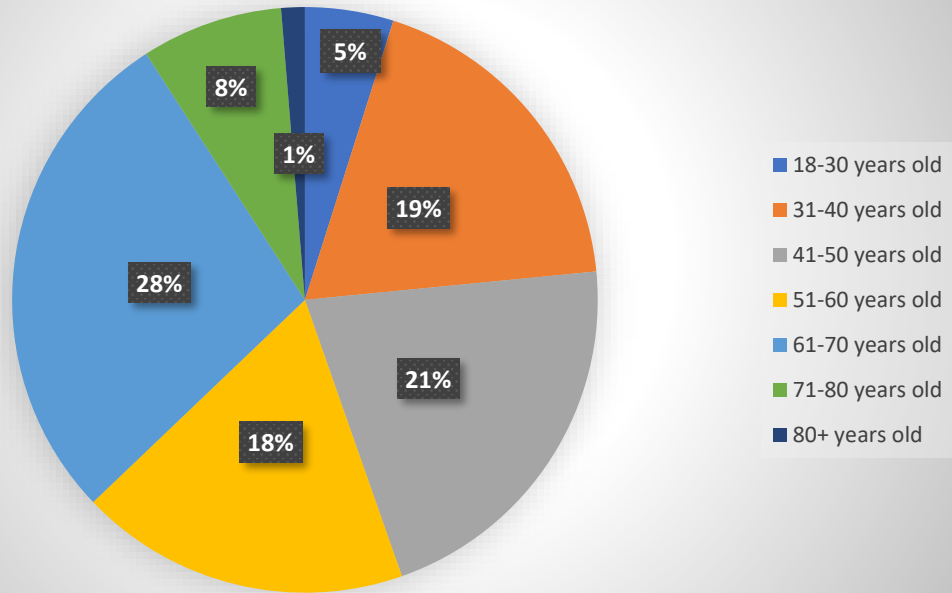
Rare disease respondents

- 424 people with a rare disease (rare disease/rare cancer) responded to the survey.
- The largest number of respondents were 61-70 years old.
- 294 respondents reside in United Kingdom, 57 of those were from Northern Ireland.

Caregivers respondents

- 165 caregivers responded to the survey (8 cancer and rare disease / 157 rare disease)
- The largest number of respondents were 41-50 years old.
- 148 respondents reside in the United Kingdom, 6 of those were from Northern Ireland.
- Carer results were not sub-grouped by disease.

Age range of rare disease respondents



Essential thrombocythemia

Essential thrombocythemia is an uncommon disorder caused when the body produces too many platelets. Around 90% of those with the condition have a gene mutation contributing to the disease. It can cause fatigue and feelings of light-headedness which can result in headaches and vision changes. Risk of blood clots is also increased with this condition.

This condition is more common in those over 60 years old but can occur in younger people. It is also more common in woman.

Symptoms of this condition are not always noticeable, but the development of a blood clot can be one of the first indicators. Clots can develop anywhere in your body but with essential thrombocythemia they most often occur in the brain, hands, and feet.

Essential thrombocythemia is has no cure. Those with a mild form of the disease may not need treatment, however those with severe symptoms may need medicine that lowers platelet count, blood thinners or both.

Essential Thrombocythemia specific results

Forty-nine individuals (36 England, 3 Scotland, 2 Wales, 3 Channel Islands, 2 USA, 1 Spain, 2 Australia) with Essential Thrombocythemia responded to the survey

Social experience

- Respondents reported feelings of loneliness as a result of isolation.
- No longer able to rely on family.
- Miss work life and the independence this provides.

Psychological experience

- Worry and anxiety were commonly reported.
- Worry regarding other family members and the inability to visit them.
- Relying solely on themselves caused much stress.

Impact of COVID-19 on daily lives

- Worry felt about the future implications of furlough, this was a particular issue for those who were self-employed.
- Missing dancing, dining out, holidays and hobbies which previously played a huge role in their lives.

Communication and support

- Lack of disease specific awareness and information – blanket information does not take account of individual circumstances.
- Requested clarity around shielding.
- Individuals reported conflicting information about the level of risk they are at due to COVID-19.

Access to healthcare and support

- Concerns expressed about the impact of COVID-19 on their care, such as cancellations and receiving treatment in a timely manner.
- Nervousness around attending hospital appointments due to fear of contracting COVID-19.
- Long term implications for healthcare was a worry.
- Specific information on Haematological effects on Covid 19 was requested.
- Disease specific information would be welcomed.

Essential Thrombocythemia Summary



- Loneliness as a result of isolation.
- No longer able to rely on family.
- Miss work life and the independence this provides.



- Worry and anxiety were common.
- Worry about family and the inability to visit them.
- Relying solely on themselves caused much stress.



- Worry felt about the future implications of furlough.



- Lack of disease specific awareness and information.
- Requested clarity around shielding.
- Conflicting information about the level of risk.



- Concerns expressed about the impact of COVID-19 on their care.
- Nervousness attending hospital appointments.
- Worry about long term implications for healthcare was a worry.
- Disease specific information would be welcomed.

Conclusion

Like many other individuals living with a rare disease, those with Essential Thrombocythemia missed the support and company of family and friends. They reported missing work life due to the independence this provides and worried about the longer-term implications of the furlough scheme. Hobbies which provided them with some very much need respite were also sorely missed. Those with Essential Thrombocythemia would welcome disease specific information, in particular, information on the Haematological effects on Covid 19 was requested.

Restrictions and regulations to fight COVID-19 have ultimately exacerbated long-established challenges faced by the rare disease community as well as creating new issues that will have long-lasting effects. There was a wide and varied experience of lockdown reported by those who have rare disease. Both positive and negative responses were included, though there was a predominance of negative and challenging experiences. The diverse range of answers gives an important insight into what these challenges are. The main topics raised through the survey responses were information, long term uncertainty, the lack of practical support, missed social interactions, the changes in healthcare and the impact that is having on wellbeing, and the experience of dealing with healthcare professionals.

Going forward, the mental health aspects of living with a rare disease should be highlighted as equally important to physical aspects, as they often go hand in hand in maintaining patient wellbeing. Mental health services should be treated as a priority and should resume as soon as possible to deal with mental health issues faced by the rare disease community. Also, disease-specific or tailored advice for more vulnerable individuals would also serve to reduce stress and anxiety, and to reassure patients of their safety when attending hospital appointments, returning to work and shopping. These failures to address rare disease issues should be used as a learning curve to ensure problems are met not only in the extreme possibility of a future pandemic but especially under normal circumstances.