

Study Summary Report

1. Study Title

Loss-adjusting: Young people's constructions of a future living with Complex Regional Pain Syndrome.

2. Authors

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3. What we did

This study examined how young people who have Complex Regional Pain Syndrome (CRPS) think about their future. Fifty young people aged 14-25 who have CRPS took part in the study. These young people answered some questions about themselves (e.g. age) and about their CRPS (e.g. how long they have had CRPS), before writing a story about what they think their future will be like. Out of the 50 people who took part online, we asked ten of these young people to talk more about their responses to the story in an interview.

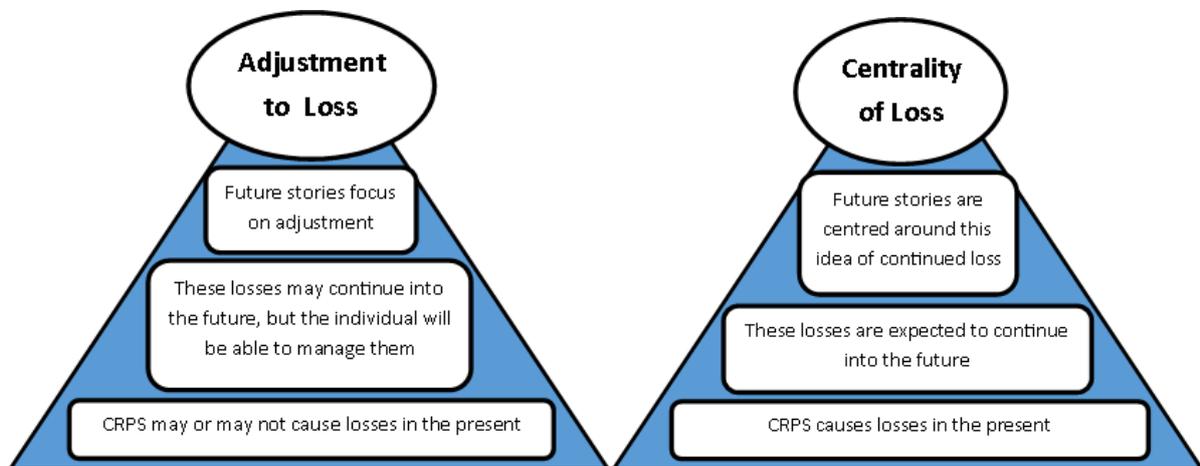
4. What we found

In this study we were really interested to see how much hope and fear the young people included in their stories. Whilst our results showed that there was some fear in the stories, young people wrote more often about hope. We then took these hopes and fears about the future and looked at them in more detail alongside the information from the interviews. By doing this, we developed two ways to categorise how young people talked about their future. These different ways of categorising the data are called themes.

The first theme was called "Centrality of Loss" because some of the stories focused on the losses that CRPS creates in young people's lives. These stories talked about how some young

people felt that losses they had already experienced due to CRPS (e.g. not being able to go to university to pursue a particular career) will continue in the future.

The second theme was called “Adjusting to Loss” because other stories focused on young people’s ability to adapt to the losses that CRPS creates. Some of these stories didn’t mention CRPS at all, and some mentioned CRPS in a way that suggested it would no longer be a problem for the young person in their future. However, some stories talked about how hard CRPS is at present and will be in the future, but focused on how the participant will be able to manage this to live the life that they want to live (e.g. having adaptations at home or at work to facilitate independent living).



5. What these results mean

These two themes show us that different people have different ideas about how CRPS will impact their future. There may be ways in which healthcare professionals can use this new information to help people to move from a loss-focused way of thinking about their future, to an adjustment-focused one. We suggest that other studies look at ways that we can help people to feel more positive about their future. This may involve making sure that people get the right support, and that they are able to talk about how they think CRPS will impact their future.