

Self-Injurious Behaviour in Cornelia de Lange Syndrome

The term self-injurious behaviour refers to any non-accidental behaviour (i.e., accidentally bumping your head on the wall would not be classed as self-injury whereas intentionally hitting your head on the wall would) that has the potential to cause some kind of damage such as reddening, bruising, bleeding, hair loss, etc.

An example of self-injurious behaviour in Cornelia de Lange syndrome can be seen in the clip above. In the clip you will see Kieran hitting his chest while Penny tries to talk to him.

Prevalence and frequency of self-injurious behaviour in Cornelia de Lange syndrome

Cornelia de Lange syndrome has generally been known as a syndrome in which self-injury frequently occurs and it has often been argued that the behaviour may have a biological cause. However, our research shows that while self-injurious behaviour is certainly more frequent in individuals with Cornelia de Lange syndrome compared to other individuals with intellectual disability the association is not as strong as was at first thought and self-injury is certainly not an inevitable consequence of Cornelia de Lange syndrome.

Researchers at the University of Birmingham conducted a study that compared 54 children and adults with Cornelia de Lange Syndrome with 46 people with other intellectual disabilities. It was found that 56% of those with Cornelia de Lange syndrome showed self-injurious behaviour compared to 41% with other kinds of intellectual disability. This showed that in people with Cornelia de Lange syndrome, self-injurious behaviour is more likely to occur than for people of the same age, gender and degree of disability who do not have the syndrome. However, this difference in occurrence is not big enough to suggest that the self-injurious behaviour is associated with the syndrome.

Forms and sites of self-injurious behaviour in Cornelia de Lange syndrome

These findings showed that there were no differences in severity of self-injurious behaviour between Cornelia de Lange syndrome and comparison group of individuals with intellectual disability without the syndrome.

It was found that people with Cornelia de Lange syndrome showed more self-biting compared to people with

intellectual disability without the syndrome. This was the only difference that was found regarding the type of self-injurious behaviour. [See Box 1 here.](#)

It was also found that people with Cornelia de Lange syndrome were more likely to show self-injurious behaviour directed towards their hands compared to individuals with intellectual disability without the syndrome. We think that this might be related to the [peripheral sensory neuropathy](#) that is common in the syndrome. [See Box 2 here.](#)

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