

Psychological Interventions for People with Huntington's Disease: A Call to Arms

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Introduction

Huntington's disease (HD) is a chronic neurodegenerative disorder that can cause several significant psychological difficulties, even before the onset of the symptoms required to make a formal diagnosis.

Among psychological issues, the most frequently reported are depression, mood extremes, irritability and aggressiveness, anxiety, agitation, compulsions, apathy, as well as obsessive-compulsive and perseverative behaviours. Recent evidence also suggests that psychological difficulties may represent more significant determinants of quality of life in people with HD (pwHD) compared to motor symptoms or pain.

However, little is currently known on the ways and areas in which psychological approaches can be best implemented in pwHD, and no literature review has ever been carried out on the range of psychological interventions which may be adopted. Thus, the present study aimed to review the psychological interventions which have been explored and adopted so far with pwHD.

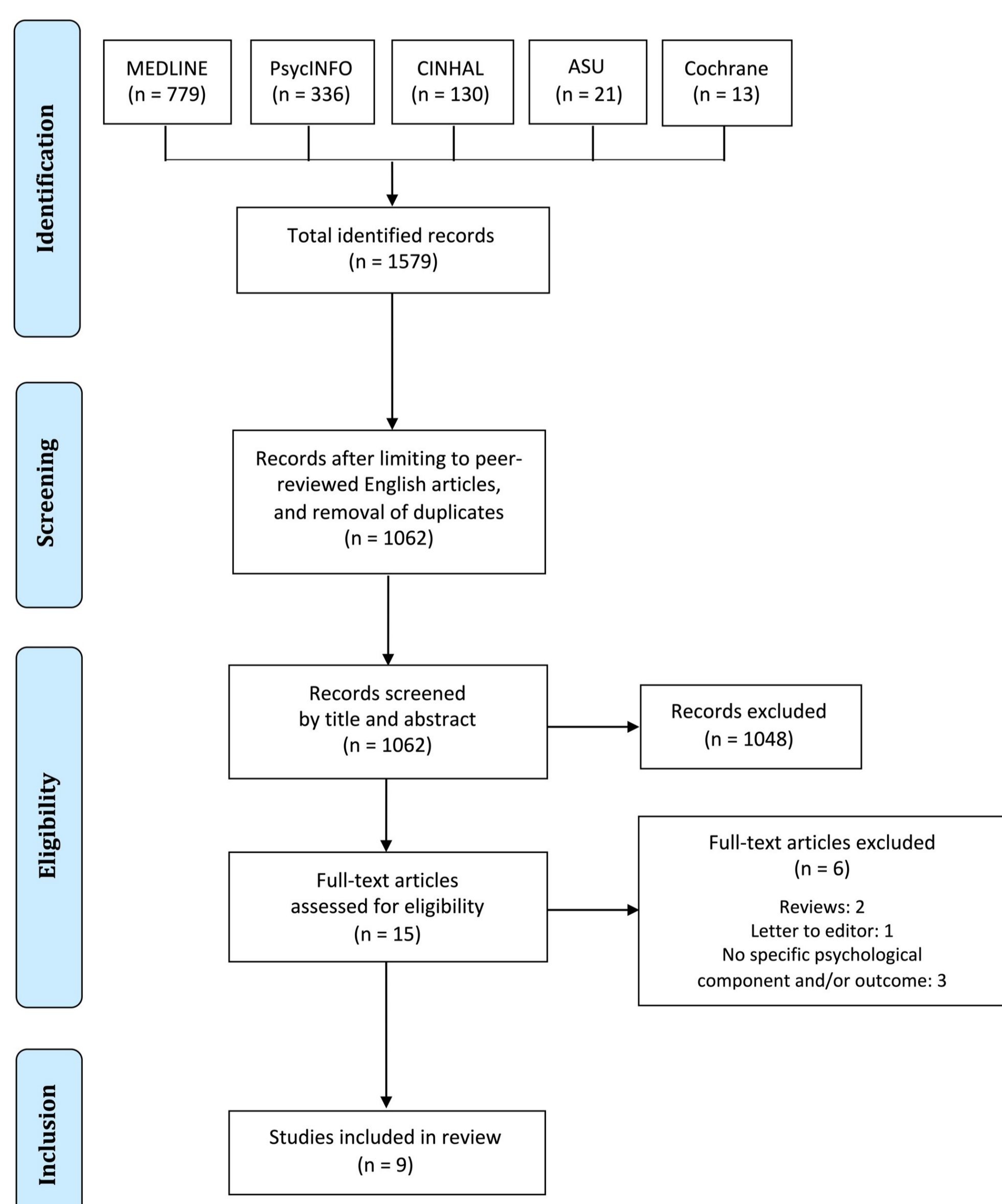
Methods

A systematic scoping review was adopted, following the guidance outlined by the Joanna Briggs Institute. A combination of free text terms was used to perform a comprehensive search across MEDLINE, PsycINFO, CINAHL, Academic Search Ultimate, and Cochrane Library up until March 1st 2020. Hand-searches were also performed to identify further relevant citations.

The study inclusion criteria were: a) being related to people with premanifest or symptomatic HD; b) involving participants aged 18 or above; c) describing the delivery of any form of psychological intervention with pwHD. Systematic reviews, reviews, commentaries, conference proceedings, editorials, letters, and studies not published fully in English were excluded.

As the focus of this review was on psychological interventions for specific psychological outcomes in the people experiencing HD themselves, interventions developed solely for family members and/or carers, or directly targeting only cognitive functions were also excluded.

PRISMA Diagram



Results

- From an initial return of 1579 citations, only 9 papers were eventually identified as eligible for review.
- These included a qualitative investigation, 3 case studies, 2 case series, 2 uncontrolled pretest-posttest designs, and only 1 randomised control trial (RCT).
- The range of adopted psychological interventions included cognitive behavioural therapy (CBT), behavioural activation (BA), psychoeducation, remotivation therapy (RmT), multi-sensory environment (MSE), and behavioural relaxation training.
- These interventions only accounted for 5 main psychological outcomes: anxiety, apathy, depression, irritability, and coping.
- Limited preliminary positive evidence was identified for the use of CBT and psychoeducational interventions to treat anxiety and depression and improve coping strategies in pwHD.
- No studies addressed psychological difficulties such as psychotic experiences (e.g., delusion, hallucinations) or obsessive-compulsive and perseverative behaviours.

Conclusions

- Given the general severe paucity of research on psychological interventions for pwHD, no specific conclusions can be offered yet as to which psychological therapy may benefit this specific population.
- Until further evidence is produced, practitioners are advised to refer to general guidance for more common psychological difficulties published by national and international public health bodies (e.g., NICE in the UK).
- As the current view of psychological difficulties in HD is mainly neuropsychiatric, further adoption of psychological models for behavioural and affective difficulties should also be promoted.
- Ultimately, this review hopes to act as a call to arms for HD researchers worldwide to help find the most effective way to translate psychological theory into practice for the benefit of pwHD.

Full Text



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