

## QUESTION

### Should counselling or therapy vs. none or anti-anxiety prescription be used for anxiety patients with Friedreich ataxia?

<b>POPULATION:</b>	anxiety patients with Friedreich ataxia
<b>INTERVENTION:</b>	counselling or therapy
<b>COMPARISON:</b>	none or anti-anxiety prescription
<b>MAIN OUTCOMES:</b>	Less anxiety; Better coping/ outlook; QOL;

## ASSESSMENT

### Problem

Is the problem a priority?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<ul style="list-style-type: none"> <li><input type="radio"/> No</li> <li><input type="radio"/> Probably no</li> <li><input checked="" type="radio"/> Probably yes</li> <li><input type="radio"/> Yes</li> <li><input type="radio"/> Varies</li> <li><input type="radio"/> Don't know</li> </ul>	<p>In cohort of 650 individuals with FA 20/560 (3.1%) reported anxiety. Within the subset of those in the typical age of onset group (n=540), 3.3% reported anxiety (Reetz et al, 2018). Notably, 60% of individuals with anxiety had co-morbidities related to visual disturbance.</p>	<p>The Friedreich's ataxia Clinical Management Guideline Patient and Parent Advisory Panel were interviewed on the consequences, urgency and priority of anxiety.</p> <p>4/6 indicated that the problem was serious, 2/6 indicated probably serious.</p> <p>4/6 indicated that the problem was urgent, 1/6 indicated probably urgent, 1/6 indicated probably not urgent.</p> <p>4/6 indicated that the problem was a priority, 2/6 indicated probably a priority. (Aug 2020)</p>

### Desirable Effects

How substantial are the desirable anticipated effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<ul style="list-style-type: none"> <li><input type="radio"/> Trivial</li> <li><input type="radio"/> Small</li> <li><input type="radio"/> Moderate</li> <li><input checked="" type="radio"/> Large</li> <li><input type="radio"/> Varies</li> <li><input type="radio"/> Don't know</li> </ul>	<p>A search of five databases (CENTRAL, MEDLINE, EMBASE, CINAHL, PsycINFO) identified no randomized, non-randomized controlled, cohort and case studies published from 2014 through to 29 July 2020. No further published evidence meeting the search criteria was identified in the Consensus Clinical Management Guidelines for Friedreich's ataxia, 2014.</p>	<p>If counselling is efficacious then the desirable effect on individuals who are anxious would be large.</p>

### Undesirable Effects

How substantial are the undesirable anticipated effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS

<ul style="list-style-type: none"> <li>○ Large</li> <li>○ Moderate</li> <li>● Small</li> <li>○ Trivial</li> <li>○ Varies</li> <li>○ Don't know</li> </ul>	<p>A search of five databases (CENTRAL, MEDLINE, EMBASE, CINAHL, PsycINFO) identified no randomized, non-randomized controlled, cohort and case studies published from 2014 through to 29 July 2020. No further published evidence meeting the search criteria was identified in the Consensus Clinical Management Guidelines for Friedreich's ataxia, 2014.</p>	<p>Need to consider issues of physical accessibility of services in regards to possible undesirable effects of counselling</p>
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## Certainty of evidence

What is the overall certainty of the evidence of effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<ul style="list-style-type: none"> <li>○ Very low</li> <li>○ Low</li> <li>○ Moderate</li> <li>○ High</li> <li>● No included studies</li> </ul>	<p>No published evidence.</p>	

## Values

Is there important uncertainty about or variability in how much people value the main outcomes?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS												
<ul style="list-style-type: none"> <li>○ Important uncertainty or variability</li> <li>○ Possibly important uncertainty or variability</li> <li>● Probably no important uncertainty or variability</li> <li>○ No important uncertainty or variability</li> </ul>	<table border="1" data-bbox="518 1138 1419 1437"> <thead> <tr> <th>Outcomes</th> <th>Importance</th> <th>Certainty of the evidence (GRADE)</th> </tr> </thead> <tbody> <tr> <td>Less anxiety - not measured</td> <td>CRITICAL<sup>a</sup></td> <td>-</td> </tr> <tr> <td>Better coping/ outlook - not measured</td> <td>IMPORTANT<sup>b</sup></td> <td>-</td> </tr> <tr> <td>QOL - not measured</td> <td>CRITICAL<sup>a</sup></td> <td>-</td> </tr> </tbody> </table> <p>a. Identified as critical (3/6) and important (3/6) by people with FA and</p>	Outcomes	Importance	Certainty of the evidence (GRADE)	Less anxiety - not measured	CRITICAL <sup>a</sup>	-	Better coping/ outlook - not measured	IMPORTANT <sup>b</sup>	-	QOL - not measured	CRITICAL <sup>a</sup>	-	
Outcomes	Importance	Certainty of the evidence (GRADE)												
Less anxiety - not measured	CRITICAL <sup>a</sup>	-												
Better coping/ outlook - not measured	IMPORTANT <sup>b</sup>	-												
QOL - not measured	CRITICAL <sup>a</sup>	-												

	<p>important by expert authors on this topic</p> <p>b. Identified as critical (2/6), important (3/6) and less importance (1/6) by people with FA and important by expert authors on this topic</p>	
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## Balance of effects

Does the balance between desirable and undesirable effects favor the intervention or the comparison?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<ul style="list-style-type: none"> <li><input type="radio"/> Favors the comparison</li> <li><input type="radio"/> Probably favors the comparison</li> <li><input type="radio"/> Does not favor either the intervention or the comparison</li> <li><input checked="" type="radio"/> Probably favors the intervention</li> <li><input type="radio"/> Favors the intervention</li> <li><input type="radio"/> Varies</li> <li><input type="radio"/> Don't know</li> </ul>	No published evidence.	

## Acceptability

Is the intervention acceptable to key stakeholders?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<ul style="list-style-type: none"> <li><input type="radio"/> No</li> <li><input type="radio"/> Probably no</li> <li><input type="radio"/> Probably yes</li> <li><input checked="" type="radio"/> Yes</li> <li><input type="radio"/> Varies</li> <li><input type="radio"/> Don't know</li> </ul>	No published evidence.	<p>The Friedreich's ataxia Clinical Management Guideline Patient and Parent Advisory Panel were asked if counselling or therapy for people with anxiety was acceptable (weighing up the balance between benefits, harms and costs).</p> <p>3/4 indicated that the intervention was acceptable, 1/4 indicated not acceptable. (Aug 2020).</p>

## SUMMARY OF JUDGEMENTS

	JUDGEMENT						
PROBLEM	No	Probably no	<b>Probably yes</b>	Yes		Varies	Don't know
DESIRABLE EFFECTS	Trivial	Small	Moderate	<b>Large</b>		Varies	Don't know
UNDESIRABLE EFFECTS	Large	Moderate	<b>Small</b>	Trivial		Varies	Don't know

JUDGEMENT							
CERTAINTY OF EVIDENCE	Very low	Low	Moderate	High			No included studies
VALUES	Important uncertainty or variability	Possibly important uncertainty or variability	<b>Probably no important uncertainty or variability</b>	No important uncertainty or variability			
BALANCE OF EFFECTS	Favors the comparison	Probably favors the comparison	Does not favor either the intervention or the comparison	<b>Probably favors the intervention</b>	Favors the intervention	Varies	Don't know
ACCEPTABILITY	No	Probably no	Probably yes	<b>Yes</b>		Varies	Don't know

## TYPE OF RECOMMENDATION

Strong recommendation against the intervention ○	Conditional recommendation against the intervention ○	Conditional recommendation for either the intervention or the comparison ○	Conditional recommendation for the intervention ○	<b>Strong recommendation for the intervention ●</b>
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## CONCLUSIONS

### Recommendation

We recommend counseling or therapy over no counseling for individuals with Friedreich ataxia who present with symptoms of anxiety.

### Justification

While there is no published evidence in FRDA, if counselling is efficacious then the desirable effect on individuals who are anxious would be large. It is important clinicians explore what will work best for an individual with FRDA, particularly in the context of other aspects of their lives (accessibility requirements of face-to-face counselling, time constraints for work/study/family, etc.). The clinician may need to consider treating symptoms of anxiety with both counseling and medication.

## Subgroup considerations

This recommendation is for individuals with Friedreich ataxia and symptoms of anxiety. It may be difficult for a person with severe dysarthria to engage in counseling. Consideration should be given to a possible link between visual disturbance and the emergence of anxiety.

## Research priorities

Finding ways to offer counselling in a manner that is acceptable and user friendly for individuals with FRDA, such as via telephone. Exploration of the impact of visual impairment on mental health.

### Reference

Reetz K, Dogan I, Hohenfeld C, Didszun C, Giunti P, Mariotti C, et al. Nonataxia symptoms in Friedreich Ataxia: Report from the Registry of the European Friedreich's Ataxia Consortium for Translational Studies (EFACTS). *Neurology*. 2018;91(10):e917-e30.