

QUESTION

Should enquiring about lower urinary tract (LUT) symptoms vs. no assessment be used for all patients with Friedreich ataxia?

POPULATION:	all patients with Friedreich ataxia
INTERVENTION:	enquiring about lower urinary tract (LUT) symptoms
COMPARISON:	no assessment
MAIN OUTCOMES:	LUT related quality of life; Lower urinary tract symptoms;

ASSESSMENT

Problem

Is the problem a priority?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<input type="radio"/> No <input type="radio"/> Probably no <input type="radio"/> Probably yes <input checked="" type="radio"/> Yes <input type="radio"/> Varies <input type="radio"/> Don't know	LUT symptoms are common in Friedreich ataxia (Lad, 2017) and therefore this problem is important.	<p>Clinical experience indicates that individuals with Friedreich Ataxia may suffer with LUT symptoms.</p> <p>LUT symptoms may exert an adverse effect on quality of life and presage bladder dysfunction which may be complicated by urinary retention.</p>

Desirable Effects

How substantial are the desirable anticipated effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<input type="radio"/> Trivial <input type="radio"/> Small <input checked="" type="radio"/> Moderate <input type="radio"/> Large <input type="radio"/> Varies <input type="radio"/> Don't know	A search of four databases (CENTRAL, MEDLINE, EMBASE, CINAHL) identified no randomized, non-randomized controlled, cohort and case studies published from 2014 through to 13 July 2020. No further published evidence meeting the search criteria was identified in the Consensus Clinical Management Guidelines for Friedreich's ataxia, 2014.	Treatment options for LUT symptoms exist, so identification is potentially important.

Undesirable Effects

How substantial are the undesirable anticipated effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS

<ul style="list-style-type: none"> ○ Large ○ Moderate ○ Small ● Trivial ○ Varies ○ Don't know 	<p>A search of four databases (CENTRAL, MEDLINE, EMBASE, CINAHL) identified no randomized, non-randomized controlled, cohort and case studies published from 2014 through to 13 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>There are unlikely to be any negative effects from enquiring about LUT symptoms.</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"> ○ Very low ○ Low ○ Moderate ○ High ● No included studies 	<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"> ○ Important uncertainty or variability ○ Possibly important uncertainty or variability ● Probably no important uncertainty or variability ○ No important uncertainty or variability 	<table border="1" data-bbox="520 1138 1415 1365"> <thead> <tr> <th data-bbox="527 1143 999 1222">Outcomes</th> <th data-bbox="1005 1143 1157 1222">Importance</th> <th data-bbox="1163 1143 1409 1222">Certainty of the evidence (GRADE)</th> </tr> </thead> <tbody> <tr> <td data-bbox="527 1227 999 1295">LUT related quality of life - not measured</td> <td data-bbox="1005 1227 1157 1295">IMPORTANT^a</td> <td data-bbox="1163 1227 1409 1295">-</td> </tr> <tr> <td data-bbox="527 1300 999 1369">Lower urinary tract symptoms - not measured</td> <td data-bbox="1005 1300 1157 1369">IMPORTANT^a</td> <td data-bbox="1163 1300 1409 1369">-</td> </tr> </tbody> </table> <p data-bbox="562 1406 1199 1433">a. Identified as important by expert authors on this topic</p>	Outcomes	Importance	Certainty of the evidence (GRADE)	LUT related quality of life - not measured	IMPORTANT ^a	-	Lower urinary tract symptoms - not measured	IMPORTANT ^a	-	
Outcomes	Importance	Certainty of the evidence (GRADE)									
LUT related quality of life - not measured	IMPORTANT ^a	-									
Lower urinary tract symptoms - not measured	IMPORTANT ^a	-									

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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"> <input type="radio"/> Favors the comparison <input type="radio"/> Probably favors the comparison <input type="radio"/> Does not favor either the intervention or the comparison <input checked="" type="radio"/> Probably favors the intervention <input type="radio"/> Favors the intervention <input type="radio"/> Varies <input type="radio"/> Don't know 	No published evidence.	

Acceptability

Is the intervention acceptable to key stakeholders?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
<ul style="list-style-type: none"> <input type="radio"/> No <input type="radio"/> Probably no <input checked="" type="radio"/> Probably yes <input type="radio"/> Yes <input type="radio"/> Varies <input type="radio"/> Don't know 	No published evidence.	

SUMMARY OF JUDGEMENTS

PROBLEM	JUDGEMENT						
	No	Probably no	Probably yes	Yes		Varies	Don't know
DESIRABLE EFFECTS	Trivial	Small	Moderate	Large		Varies	Don't know
UNDESIRABLE EFFECTS	Large	Moderate	Small	Trivial		Varies	Don't know
CERTAINTY OF EVIDENCE	Very low	Low	Moderate	High			No included studies
VALUES	Important uncertainty or variability	Possibly important uncertainty or variability	Probably no important uncertainty or variability	No important uncertainty or variability			

JUDGEMENT							
BALANCE OF EFFECTS	Favors the comparison	Probably favors the comparison	Does not favor either the intervention or the comparison	Probably favors the intervention	Favors the intervention	Varies	Don't know
ACCEPTABILITY	No	Probably no	Probably yes	Yes		Varies	Don't know

TYPE OF RECOMMENDATION

Strong recommendation against the intervention <input type="radio"/>	Conditional recommendation against the intervention <input type="radio"/>	Conditional recommendation for either the intervention or the comparison <input type="radio"/>	Conditional recommendation for the intervention <input checked="" type="radio"/>	Strong recommendation for the intervention <input type="radio"/>
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CONCLUSIONS

Recommendation

We conditionally recommend that clinicians enquire about the presence of lower urinary tract (LUT) symptoms when consulting individuals with Friedreich ataxia.

Justification

Studies have shown that LUT symptoms are common in Friedreich ataxia (Lad, 2017) and clinical experience indicates that LUT symptoms may adversely affect quality of life in individuals with Friedreich ataxia and herald an increased risk of complications.

Subgroup considerations

None.

Research priorities

Examining the acceptability and utility of enquiry regarding LUT symptoms in individuals with Friedreich ataxia.

References

Lad M, Parkinson MH, Rai M, Pandolfo M, Bogdanova-Mihaylova P, Walsh RA, et al. Urinary, bowel and sexual symptoms in a cohort of patients with Friedreich's ataxia. *Orphanet J Rare Dis.* 2017;12(1):158.