

QUESTION

Should customized assistive technology (personal care technology, environmental control (iPad, home apps, smart watches), Alexa/Siri) vs. non-use be used for subjects with impaired upper limb functionality who use digital and assistive technology with Friedreich ataxia?

POPULATION: subjects with impaired upper limb functionality who use digital and assistive technology with Friedreich ataxia

INTERVENTION: customized assistive technology (personal care technology, environmental control (iPad, home apps, smart watches), Alexa/Siri)

COMPARISON: non-use

MAIN OUTCOMES: Independence in daily activities; Quality of life; Physical devices; Social and occupational participation ;

ASSESSMENT

Problem

Is the problem a priority?

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 		<p>The Friedreich's ataxia Clinical Management Guideline Patient and Parent Advisory Panel were interviewed on the consequences, urgency and priority of digital and assistive technologies.</p> <p>4/6 indicated that the problem was serious, 2/6 indicated they didn't know if serious.</p> <p>2/6 indicated that the problem was urgent, 1/6 indicated probably urgent, 1/6 indicated probably not urgent, 2/6 indicated they didn't know if urgent.</p> <p>3/6 indicated that the problem was a priority, 1/6 indicated probably a priority, 2/6 indicated they didn't know if 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"> <input checked="" type="radio"/> Trivial <input type="radio"/> Small <input type="radio"/> Moderate <input type="radio"/> Large <input type="radio"/> Varies <input type="radio"/> Don't know 	<table border="1"> <thead> <tr> <th>Outcomes</th> <th>No of</th> <th>Certainty of</th> <th>Relative</th> <th>Anticipated absolute effects* (95% CI)</th> </tr> </thead> <tbody> <tr> <td> </td> <td> </td> <td> </td> <td> </td> <td> </td> </tr> </tbody> </table>	Outcomes	No of	Certainty of	Relative	Anticipated absolute effects* (95% CI)						
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	participants (studies) Follow-up	the evidence (GRADE)	effect (95% CI)	Risk with non-use	Risk difference with customized assistive technology (personal care technology, environmental control (iPad, home apps, smart watches), Alexa/Siri)
Independence in daily activities assessed with: Canadian Occupational Performance Measure	1 (1 observational study) ¹	⊕○○○ Very low ^{a,b,c,d}	-		A 60-year old man with Parkinson's disease was assessed using an eating-adaptive device during feeding tasks for 70 sequential days. The COPM was used to identify changes in the individual's perception about their performance in occupations that are important in their daily routine. The study participant was evaluated in relation to the variables of interest during three phases: baseline (A: evaluating the performance and satisfaction outcomes during the feeding task using a conventional spoon), intervention (B: same outcomes were evaluated with the participant using the adaptive eating device without any filled cavity), and intervention (C: using the adaptive eating device with one cavity filled with water). In phase A, the value of the participant's average score in relation to the satisfaction outcome was 6.57 (SD = 1.72), range 4-9. In stage B of the intervention, the mean score was 7.81 (SD = 1.14), range 5-10 points. In the phase C of the intervention, the mean score for satisfaction was 7.83 (SD = 1.34), range 5-10.
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Undesirable Effects

How substantial are the undesirable anticipated effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS																	
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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>There is very low certainty of evidence as per the Evidence Profile table.</p>	
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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" style="width: 100%; border-collapse: collapse; text-align: center;"> <thead> <tr style="background-color: #d3d3d3;"> <th data-bbox="518 662 1062 773">Outcomes</th> <th data-bbox="1068 662 1192 773">Importance</th> <th data-bbox="1199 662 1419 773">Certainty of the evidence (GRADE)</th> </tr> </thead> <tbody> <tr> <td data-bbox="518 777 1062 899">Independence in daily activities assessed with: Canadian Occupational Performance Measure</td> <td data-bbox="1068 777 1192 899">CRITICAL^a</td> <td data-bbox="1199 777 1419 899">⊕○○○ VERY LOW^{b,c,d,e}</td> </tr> <tr> <td data-bbox="518 904 1062 1026">Quality of life assessed with: Canadian Occupational Performance Measure</td> <td data-bbox="1068 904 1192 1026">CRITICAL^a</td> <td data-bbox="1199 904 1419 1026">⊕○○○ VERY LOW^{b,c,d,e}</td> </tr> <tr> <td data-bbox="518 1031 1062 1097">Physical devices - not measured</td> <td data-bbox="1068 1031 1192 1097">IMPORTANT^f</td> <td data-bbox="1199 1031 1419 1097">-</td> </tr> <tr> <td data-bbox="518 1102 1062 1224">Social and occupational participation assessed with: Canadian Occupational Performance Measures</td> <td data-bbox="1068 1102 1192 1224">IMPORTANT^g</td> <td data-bbox="1199 1102 1419 1224">⊕○○○ VERY LOW^{b,c,d,e}</td> </tr> </tbody> </table> <p style="margin-top: 10px;"> a. Identified as critical (2/5) and important (3/5) by people with FA and critical by expert authors on this topic. b. Individual with Parkinson's disease, not FRDA. c. Selective outcome reporting, pilot study. d. Sample size = 1. e. Single case study. f. Identified as critical (1/5) and important (4/5) by people with FA and important by expert authors on this topic g. Identified as critical (2/5), important (2/5) and low importance (1/5) by </p>	Outcomes	Importance	Certainty of the evidence (GRADE)	Independence in daily activities assessed with: Canadian Occupational Performance Measure	CRITICAL ^a	⊕○○○ VERY LOW ^{b,c,d,e}	Quality of life assessed with: Canadian Occupational Performance Measure	CRITICAL ^a	⊕○○○ VERY LOW ^{b,c,d,e}	Physical devices - not measured	IMPORTANT ^f	-	Social and occupational participation assessed with: Canadian Occupational Performance Measures	IMPORTANT ^g	⊕○○○ VERY LOW ^{b,c,d,e}	
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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 	<p>Expert opinion suggests benefit from the use of such technology</p>	<p>A survey designed to systematically collect expert-based opinions from clinicians involved in developing the recommendations for this topic and providing clinical care for individuals with Friedreich ataxia, was conducted. Clinical experts from Australia, Europe, UK, South America, Canada and the USA were asked to consider the harms/benefits of Customized assistive technology (personal care technology, environmental control [iPAD, home APPs, smart watches], ALEXA/ SIRI) as a management strategy for individuals with impaired upper limb functionality.</p> <p>Reflecting on the impact of Customized assistive technology (personal care technology, environmental control [iPAD, home APPs, smart watches], ALEXA/ SIRI) on <u>Independence in daily activities</u>, 75% (3/4) clinical experts reported a benefit (large, moderate or small), and 0% (0/4) reported observing a harm (large, moderate or small). 1 clinician could not provide any information on this outcome.</p> <p>Reflecting on the impact on <u>Quality of life</u>, 100% (4/4) clinical experts reported a benefit.</p> <p>Reflecting on the impact on <u>Physical devices</u>, 75% (3/4) clinical experts reported a benefit. 1 expert clinician could not provide any information on this outcome.</p> <p>Reflecting on the impact on <u>Social and occupational participation</u>, 100% (4/4) clinical experts reported a benefit.</p>

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 	<p>No published evidence.</p>	<p>The Friedreich's ataxia Clinical Management Guideline Patient and Parent Advisory Panel were asked if customised assistive technology for people with impaired arm and hand function was acceptable (weighing up the balance between benefits, harms and costs).</p>

		4/5 indicated the intervention was acceptable, 1/5 indicated probably acceptable. (Aug 2020).
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SUMMARY OF JUDGEMENTS

	JUDGEMENT						
PROBLEM	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			
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

For individuals with Friedreich ataxia with impaired upper limb functionality, we suggest the use of customized assistive technology for personal care and environmental control (e.g., iPad, home apps, smart watches, Alexa/Siri) to enhance independence in daily activities, quality of life, and social and occupational participation.

Justification

Despite the low level of evidence in only one like condition, expert clinicians who provide clinical care for individuals with Friedreich ataxia agree that customized assistive technology for personal care can benefit independence in daily activities, quality of life, and social and occupational participation in individuals with Friedreich ataxia.

Subgroup considerations

This recommendation is specifically for individuals with Friedreich ataxia with impaired upper limb functionality. The guideline expert panel considers that all individuals with Friedreich ataxia might benefit from the use of digital and assistive technology.

Research priorities

Key research priorities in this area include identifying and evaluating the most appropriate customized assistive technology for individuals with Friedreich ataxia and measuring efficacy against effects on independence in daily activities; quality of life, social and occupational participation.