



IDENTIFYING KNOWLEDGE GAPS THAT MAY HINDER TRANSITIONS: THE CF R.I.S.E. TRANSITION PROGRAM KNOWLEDGE ASSESSMENT MODULES

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Introduction

- Attaining the necessary knowledge about CF and its management is an essential part of the transition process and readiness evaluation.
- Only 40% of children receive guideline-based transition services and few of these services offer formal readiness assessments (1,2).
- The CF: Responsibility, Independence, Self-care, Education transition program (CF R.I.S.E.) is flexible, yet comprehensive, and targets issues specific to CF (3).
- CF R.I.S.E. includes 12 knowledge assessment modules (KAMs), 6 skills checklists, a progress tracker and educational resources.
 - KAMs target topics experts reported as essential to facilitate transition.

Objectives

To evaluate which Knowledge Assessment Modules (KAMs) are administered most often and provide data on the knowledge level on various CF topics.

Methods

- 12 knowledge assessment modules (KAMs) were developed for individuals age 16-25 years (see Table for list).
- The KAMs are available to all care centers enrolled in CF R.I.S.E. via an online portal (www.cfrise.com).
- A person with CF is registered by the center who then select which KAM(s) to administer.
- This sample is a de-identified, convenience sample of all individuals who completed one or more KAM between January 1, 2014 and August 31, 2017.
- If a person completed a single KAM more than once, only the first administration was included in the analyses.
- Only individuals age 16-25 years with submitted assessments were included in the analyses.
- The sample represents 50 pediatric and 38 adult U.S. CF care centers.
- Each individual completed a median of 4 KAMs

References

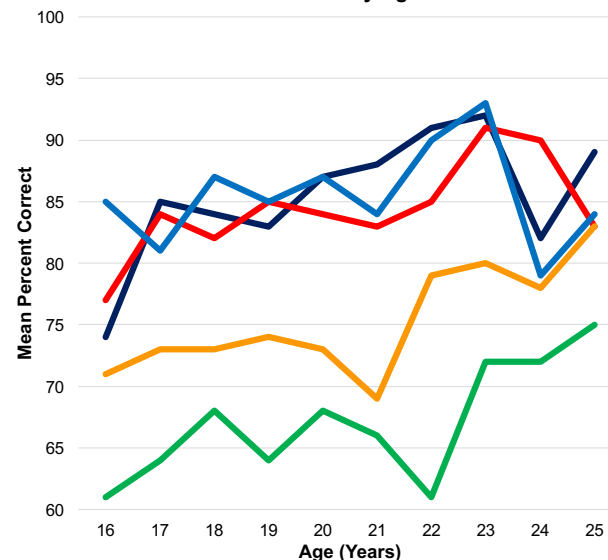
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Results

Table. Descriptive Data for Knowledge Assessment Modules.

Knowledge Assessment Module (Number of items)	N Modules Completed	Mean	SD	Median	Min	Max
Lifestyle (17)	218	86	13	91	27	100
General Health (10)	367	85	17	90	20	100
Equipment Maintenance & Infection Control (9)	164	87	12	89	22	100
Female Sexual Health (9)	124	85	12	89	33	100
Lung Health & Airway Clearance (16)	349	83	15	88	12	100
Screening & Prevention (8)	141	78	14	88	38	100
CF Related Diabetes (14)	115	86	11	86	36	100
Male Sexual Health (7)	93	77	19	86	29	100
College & Work (11)	183	78	16	82	18	100
Pancreatic Insufficiency & Nutrition (16)	245	74	14	75	19	100
Insurance & Financial (17)	102	67	14	71	18	94
Liver Disease (6)	91	60	23	67	17	100

Select Knowledge Assessment Modules Mean Scores By Age



■ General Health ■ Lung Health & Airway Clearance
■ Pancreatic Insufficiency & Nutrition ■ CF Related Diabetes
■ Insurance & Financials

Conclusions

- While there is a general trend for knowledge to increase with age, there are individuals with clear knowledge gaps at all ages.
- Knowledge of general health and lung health were administered most often
- Most people missed 0-2 items per KAM except for:
 - Pancreatic Insufficiency & Nutrition
 - Insurance and Financials
- The subpar nutritional knowledge was surprising given the focus on nutrition education during many clinic visits.
- Other knowledge areas in need of increased attention to support transition readiness include college & work, and liver disease.
 - These KAMs are less frequently administered, suggesting either they are not a topic focused on in clinic visits or care teams only administer these KAMs to verify preexisting concerns about knowledge gaps.
- Limitations
 - While this was a national sample of youth and young adults with CF, it is unknown how modules were selected for administration. If selected based on suspected knowledge gaps, these results may reflect lower knowledge than the general CF population
 - Because the sample was de-identified, we cannot make within person interpretations.
- CF R.I.S.E. KAMs are a comprehensive tool which may help CF centers determine knowledge gaps that may hinder successful transition.
 - There are now comparable modules for 10-15 year olds.
- These results can inform not only individual education and transition planning, but can help care teams systematically evaluate the efficacy of their ongoing education process.

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