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BACKGROUND

The goal of our overall project are to develop meaningful methods of describing a child's course of JIA with respect to 5 variables: changes in pain over time, quality of life, active joint count, medication requirements over time, and medication side effects over time. These variables were determined in a previous study based on results of parent, patient, and health care provider focus groups [1]. In order to use data about a child's use of various medication regimens and occurrence of side effects in a prediction model, a quantitative scale is required.

OBJECTIVE

Solicit input from patients with JIA, parents of patients with JIA, and pediatric rheumatology clinicians in developing weighted scales measuring medication requirements (MedReq) and medication side effects (MedSE).

METHODS

Development of the MedReq and MedSE scales:

Scale items were drawn from data available in ReACCh-Out.

Draft scales were designed by two investigators (LT, JG)

The MedReq scale:

Ordered 11-level scale

Ranges from 0= no medications to 10= Biologic, DMARD, and systemic corticosteroids.

The MedSE scale:

Ordered 11- level scale

Ranges from 0= no side effects to 10= side effect resulting in death or permanent disability.

Evaluation of draft MedReq and MedSE scales: Focus groups

Three separate focus groups were convened:

Youth with JIA (n=3)

Parents of children with JIA (n=3)

Pediatric rheumatology clinicians (2 MD, 1 nurse)

Each items in a scale was printed onto Q cards.

Participants were asked to rank the Q cards independently, without knowledge of the proposed order.

Participants viewed everyone's rankings, and engaged in discussion about their ranking choices.

Rankings could be changed if desired after the discussion.

Notes were taken about the discussion by a research assistant.

Results were summarized.

RESULTS

The draft MedReq and MedSE scales

MedReq Items	Item score	MedSE Items*
No treatment at this visit	0	No side effects
Anti-inflammatory med only	1	One side effect occurring hardly any of the time
Intra-articular corticosteroids only	2	One side effect occurring some of the time
Anti-inflammatory med and intra-articular corticosteroids	3	Two side effects occurring hardly any of the time
DMARD only	4	Two side effects occurring some of the time
DMARD with Anti-inflammatory and intra-articular corticosteroids	5	One side effect occurring 50% or more of the time
Multiple DMARDS	6	Two side effects occurring 50% or more of the time
Multiple DMARDS with Anti-inflammatory and intra-articular corticosteroids	7	Three side effects occurring 50% or more of the time
DMARD and systemic corticosteroids	8	More than 3 side effects present more than 50% of the time
Biologic and DMARD	9	Side effect requiring in hospital treatment
Biologic, DMARD, systemic corticosteroids, with or without other medications	10	Side effect resulting in death or disability

* MedSE reported in JAQQ:

Poor appetite, mouth sores, nausea/vomiting, abdominal pain, heartburn, Diarrhea, constipation, skin rash, pain or discomfort passing urine, headache.

Summary of Focus Group Results

MedReq Scale:

- Overall consensus at either end of scale.
- Some differences in ranking in middle portion of scale.
- Clinicians noted that medications being used for uveitis might not be ranked the same as those used for arthritis.
- Item ranking for parents and youth was dependant on their personal experience of a medication.
- Parents noted that duration, frequency of administration, and method of administration influences ranking; for example, having to take a medication daily was 'worse' than a single intra-articular injection.
 - 4/9 participants ranked IA injection lower than anti-inflammatory medication.
- 5/8 participants ranked biologic treatment lower than combination therapy with DMARD/anti-inflammatory/IA injection.
- Youth described systemic corticosteroids as the 'worst' medication.

MedSE Scale:

- Overall consensus at either end of scale.
- Parents noted that the severity of any single SE needed to be accounted for; i.e. one side effect occurring some of the time might be much worse than 2 or 3 side effects if it resulting in significant discomfort and functional interference.
- Side effects that affect quality of life are most problematic for children and families.
- Youth and parents made special mention of the side effects of methotrexate as problematic.

CONCLUSIONS

- Qualitative methods can be used to incorporate patient and parent input into research design.
- Youth with JIA and parents of children with JIA consider the type of medication required to treat JIA and possible medication side effects a very important issue in their thinking about the impact of JIA on their lives.
- There is a gap in availability of valid and reliable tools to collect this valued information in a useful way.