

INTRODUCTION

- Paediatric rheumatic diseases can negatively affect the quality of life of patients
- Juvenile idiopathic arthritis (JIA) accounts for most cases of paediatric rheumatic disease while juvenile dermatomyositis (JDM), juvenile systemic lupus erythematosus (jSLE) and juvenile scleroderma (jSc) occur less frequently
- Parents and children need to understand the disease well in order to make informed treatment decisions
- Therefore, parents and children need easily understood, plain-English information
- Recommended readability for this information is:
 - Flesch-Kincaid reading ease score >70
 - 5th-8th grade Flesch-Kincaid reading level
 - No passive sentences

AIM & METHODS

- Assess the readability of freely available online information for parents of children with JIA from reputable English-language websites using standardised tools for measuring reading ease
- Focused search performed in Google Search using "parent information" and combinations of "juvenile", "childhood" and each of the disease names
- Information from advocacy groups, healthcare providers, health-related charities and universities was reviewed
- Results from personal blogs or websites were excluded
- Reading ease, grade, and percentage of passive sentences measured using the Flesch-Kincaid Score in MS Word
- Results recorded in Microsoft Excel to determine average readability for each paediatric rheumatic disease

RESULTS

- 79 information leaflets on childhood rheumatic diseases were analysed
 - 40 JIA
 - 6 JDM
 - 27 jSc
 - 6 jSLE
- Results are summarized in Figure 1
- Only 3/79 leaflets had a reading ease score >70
- No leaflets had a reading grade below 6th grade with the majority above 8th grade
- **No information leaflet met all the recommendations for plain English information**

CONCLUSIONS

- **Plain English parent information for paediatric rheumatic diseases does not meet the recommended standards for reading ease**
- However, it is easily accessible online
- There is a clear need to develop additional easily understood information aimed at parents of children with childhood rheumatic diseases
- **There is an opportunity to co-design such resources in collaboration with families**

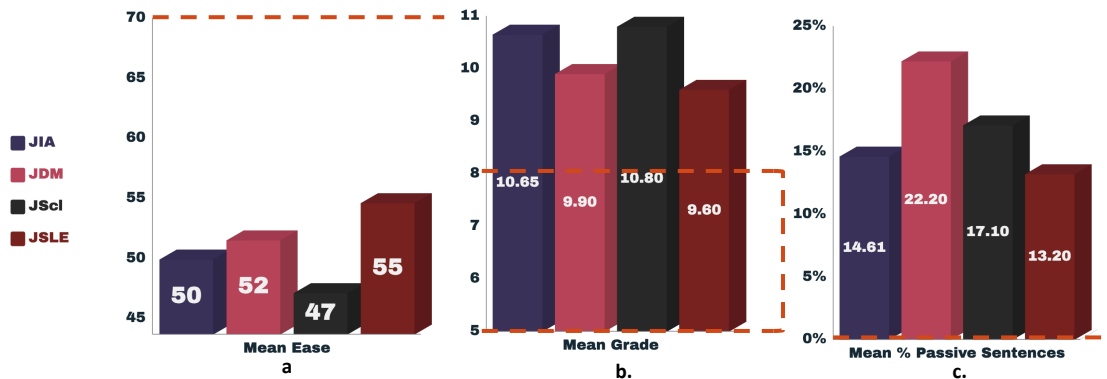


Figure 1
a. Flesch-Kincaid Reading Ease, b. Flesch-Kincaid Reading Grade, c. %passive sentences
— indicates recommended level

References:

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