

Development of a Patient Acceptable Symptom State (PASS) Question for Children with Consistent, Long-Term Disability

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Students: Meagan Dahl, Maddy St. John, Nicole Nelson,
Kat Olennikov, Tara Paddock, Lisa Watson & Garth West

Advisor: Dr. Ryan Jacobson

INTRODUCTION

Patient Acceptable Symptom State (PASS) is a single Yes/No question where a “yes” response indicates the minimal level of symptoms and function above which a person considers their current condition satisfactory.

- PASS has shown validity as an anchoring question for important health outcomes in adults with various diagnoses and in children with JIA (*Strand 2011; Kvien 2007; Tubach 2012; Filocamo 2012; Consolaro 2012; Roos 2019*). However, it has not been researched in children with consistent, long-term disability.



PURPOSE

- ★ To seek child and family insights to develop a potentially useful version of a single patient-reported question on acceptable/not acceptable state (PASS or PASS-like) of health, wellbeing, and/or diagnosis-referenced quality of life for children with consistent, long-term disability and their families.
- ★ Final version of a PASS question might be used in subsequent research in these populations for clinical decision making and *outcomes benchmarking*.



THREE VERSIONS OF THE PASS QUESTION:

Version 1) Taking into account all your child's activities, any pain he/she experiences, and also his/her abilities and challenges, do you consider his/her **current state to be satisfactory?** *(modified from Tubach et al 2005 and Kvien et al 2007)*

Version 2) Taking into account your child's physical and mental health, his/her social life, and also his/her challenges and aspirations, do you consider his/her **current state of wellbeing to be satisfactory?** *(modified from Tubach 2005 et al and Kvien et al 2007)*

Version 3) Considering all the ways your child's diagnosis affects him/her, would you be satisfied if his/her condition remained stable/unchanged for the **next few months?** *(per Consolaro et al 2012 and Filocamo et al 2012 JIA articles).*



METHODS

- **Semi-structured interviews** with child and caregivers.
- **Quantitative Variables:** age, gender, ethnicity, primary diagnosis and classification, insurance coverage, Gross Motor Function Classification System (**GMFCS**) level and Patient-Reported Outcomes Measurement Information System (**PROMIS**) Pediatric Global Health 7. Three PASS question versions.
- Interviews were audio recorded, transcribed, then analyzed using **thematic analysis**.



Semi-structured Interview Questions - PASS for Kids

Domain of Inquiry

- Family/child perspectives on what is referenced in deciding "acceptable" or "satisfactory" state—particularly related to health status, wellbeing, and diagnosis.

Categories of the Topic

- Physical, mental, emotional, and social functioning, symptom burden, and QoL
- Capabilities, activities and relationships
- Valuation of the above

Question Stems

- Which **words or phrases** in these three questions are **most important to you** in deciding whether to answer **yes or no**?

***Want to focus on words/ideas/cues within the questions, not on whether or not PASS itself is important to the interviewees.

- In what way...? Tell me about that...? Such as...?

- **What do you think about** when deciding whether to answer yes or no for each of these three questions?

- In what way...? Tell me about that...? Such as...?

- Are there **differences in how you interpret** for each question? Tell me more about those differences.

- The first 2 questions attempt to **distinguish "health status" versus "wellbeing"**...as being different. What are your thoughts about this?

- The last question asks you to **take into account your diagnosis/disability specifically** when deciding whether to answer "yes" or "no." What are your thoughts about this?

We've touched on some of these next questions already, but I want to hear more about how some specific things impact whether you answer yes or no for these three questions.

- In what ways do **physical, mental, emotional, and social functioning** impact your answer?***

- In what way does **your overall health** (current health, and over past years) impact your answer?***

- In what way does **your level of participation in life's activities** (home, play, community, school, relationships) impact your answer?***

- Are there **any other things we haven't talked about** that impacted your answers on any of these three questions?***

***In what way...? Tell me about that...? Such as...?

RECRUITMENT & PARTICIPANTS

- **7 semi-structured interviews** were conducted between May and Aug 2020.
 - Included parents or caregivers
 - 5 out of 7 interviews also the child
- **Age range:** 12-15 years (mostly female)
- **Primary diagnoses:** spina bifida (2), cerebral palsy (1), genetic syndromes (3), and leukodystrophy (1).
- All caucasian families (in OR, SW WA)
- 5 of 7 families on private health insurance

...sample *not representative*



Research Study Family Focus Group

**PLEASE
VOLUNTEER**

Who: Children with disabilities & their families

What: 30 - 45 minute focus group/interview

Why: Our study is developing a family-centered question pediatric therapists might use to understand what really matters in your life. We need your input and opinions! **...YOU are the experts!**

Contact: Ryan Jacobson, DPT
rjacobson@georgefox.edu
503-504-3247



Study approval #: 2192014

So, what were the **FINDINGS** from our Thematic Analysis of these Semi-Structured Interviews?



RESULTS

Different categories of codes emerged during the thematic analysis process....

1. Values/Beliefs/Priorities of the children and families
2. What respondents consider when answering Y/N on PASS
3. Which parts of the PASS questions stand out as important & how words are interpreted

LET'S DIVE DEEPER INTO THESE THEMES...



Values, Beliefs & Priorities of the Children & Families

The *most common codes (values)* mentioned across families that were driving factors when deciding yes or no on PASS:

- ★ **INDEPENDENCE**
- ★ **QUALITY OF LIFE**

Other important values mentioned include:

- Health/Medical Status
- Social Interaction & Personal Relationships
- Capabilities of Daily Life
- Development/Growth
- Faith

Differences between child and parent-proxy answers...

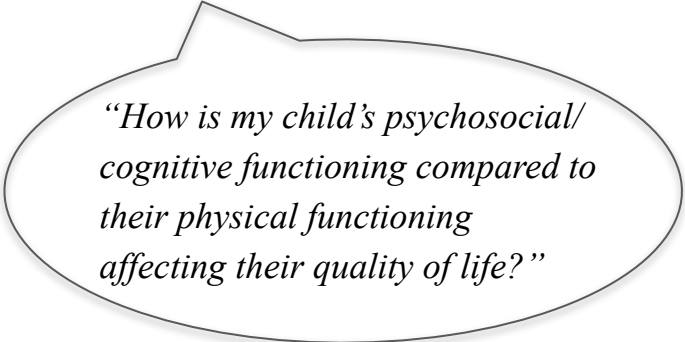
- Parents tend to compare their child to typical-developing children; children did not



What respondents consider when answering Y/N on PASS

- ★ **OUTLOOK (reference of time):** *future*-oriented, *present* state, or *trajectory*?
 - Impacts how PASS is answered
 - Parents/caregivers tended to be more future-oriented than children with goal of “normalcy” and independence.

- ★ **Type of disability...** what is important/relevant to the child and how to weigh each aspect.
 - Physical/mobility-related
 - More readily able to accommodate for
 - Psychosocial/mental
 - More challenging to interact with peers; harder to accommodate for in daily life



“How is my child’s psychosocial/ cognitive functioning compared to their physical functioning affecting their quality of life?”

Which parts of the PASS questions stand out as important & how words are interpreted

★ “*Satisfactory*”

- Very subjective term
- What is the threshold?
- Parents want better for their child

■ Satisfactory may not be the goal... what about THRIVING?

★ Questions 1 and 2 tend to be interpreted as being interconnected and draw similar things into consideration when answering Y or N. Whereas **Question 3 stands out as very different.**

- Children did not tend to offer insight to depict differences in PASS questions



THEMES

Values, Beliefs, & Priorities of the Children & Families



- **INDEPENDENCE**
- **QUALITY OF LIFE**
- Health/Medical Status
- Social interaction & personal Relationships
- Capabilities of daily life
- Development & growth
- Faith

What Respondents Consider When Answering Yes or No on PASS



- *Outlook*: Future vs. Present vs. Trajectory of the child's status
- *Physical* (mobility-related) vs. *psychosocial/mental* aspects of disabilities

Which Aspects of the PASS Questions Stand Out as Important & How Words are Interpreted



- “*Satisfactory*” → subjectivity
 - What is the **threshold**?
 - Satisfactory/acceptable may not be the goal... what about thriving?
- **PASS Q1 and Q2 are very similar, whereas Q3 stands out as different.**

WHY IT MATTERS

- Children base their answers more on their ability to interact with their peers and *not on typical-development*
- Understanding what factors play into a PASS yes or no can help guide direction of further treatment
- Valid PASS-like question could open the door to more *meaningful conversations* with child and family
- Helps to **align child and family goals with physical therapy goals** to guide *person-centered care!*



FUTURE RESEARCH!

- Correlating PASS question #3 with PROMIS and other subjective outcome measures to determine clinical viability.
- Allowing child and parents to answer separately
- Utilizing a Likert scale for answers rather than a “yes” or “no”
 - Range from “strongly disagree” to “strongly agree”



REFERENCES

- Amtmann D, Cook KF, Johnson KL, Cella D 2011 The PROMIS initiative: Involvement of rehabilitation stakeholders in development and examples of applications in rehabilitation research. *Archives of Physical Medicine and Rehabilitation* 92: S12-S19.
- Anderson MR, Baumhauer JF, DiGiovanni BF, Flemister S, Ketz JP, Oh I, Houck JR. Determining Success or Failure After Foot and Ankle Surgery Using Patient Acceptable Symptom State (PASS) and Patient Reported Outcome Information System (PROMIS). *Foot Ankle Int.* 2018 Aug;39(8):894-902.
- Consolaro, A., Bracciolini, G., Ruperto, N., Pistorio, A., Magni-Manzoni, S., Malattia, C., ... & Paediatric Rheumatology International Trials Organization. (2012). Remission, minimal disease activity, and acceptable symptom state in juvenile idiopathic arthritis: defining criteria based on the juvenile arthritis disease activity score. *Arthritis & Rheumatism*, 64(7), 2366-2374.
- DeWalt D.A., et al. (2013). PROMIS Pediatric Peer Relationships Scale: Development of a Peer Relationships Item Bank as Part of Social Health Measurement. *Health Psychology*, 32(10).
- Filicamo, G., et al (2012). Parent Child Acceptable Symptom State in Juvenile Idiopathic Arthritis. *Journal of Rheumatology*. 2019; 38(4).
- Forrest, C.B., et al (2016). Concurrent Validity of the PROMIS Pediatric Global Health Measure. *Qual Life Res.* 2016;25(3).
- Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *Pharmacoeconomics*. 2016 Jul;34(7):645-9.
- Kvien, T. K., Heiberg, T., & Hagen, K. B. (2007). Minimal clinically important improvement/difference (MCII/MCID) and patient acceptable symptom state (PASS): what do these concepts mean?. *Annals of the Rheumatic Diseases*, 66 Suppl 3(Suppl 3), iii40–iii41.
- McIntosh, M. J., & Morse, J. M. (2015). Situating and Constructing Diversity in Semi-Structured Interviews. *Global Qualitative Nursing Research*. Aug 14;2:233339361559767
- Ngamaba KH, Panagioti M, Armitage CJ. How strongly related are health status and subjective well-being? Systematic review and meta-analysis. *Eur J Public Health*. 2017 Oct 1;27(5):879-885
- Noble, P., Fuller-Lafreniere, S., Meftah, M., Dwyer, M. (2013). Challenges in Outcome Measurement: Discrepancies Between Patient and Provider Definitions of Success. *Clinical Orthopaedics and Related Research*. 471:3437-3445.
- Noble, P., Dwyer, M., & Brekke, A. (2013). Commonalities, Differences, and Challenges with Patient-Derived Outcome Measurement Tools: Function/Activity Scales. *Clinical Orthopaedics and Related Research*. 471:3457-3465.
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*. 16:1-13.
- Pontin E, Schwannauer M, Tai S, Kinderman P. A UK validation of a general measure of subjective well-being: the modified BBC subjective well-being scale (BBC-SWB). *Health Qual Life Outcomes*. 2013 Sep 3;11:150.
- Roos EM, Boyle E, Frobell RB, Lohmander LS, Ingelsrud LH. It is good to feel better, but better to feel good: whether a patient finds treatment 'successful' or not depends on the questions researchers ask. *Br J Sports Med*. 2019 Dec;53(23):1474-1478.
- Rumsfeld JS, Alexander KP, Goff DC Jr, Graham MM, Ho PM, Masoudi FA, Moser DK, Roger VL, Slaughter MS, Smolderen KG, Spertus JA, Sullivan MD, Treat-Jacobson D, Zerwic JJ; American Heart Association Council on Quality of Care and Outcomes Research, Council on Cardiovascular and Stroke Nursing, Council on Epidemiology and Prevention, Council on Peripheral Vascular Disease, and Stroke Council. Cardiovascular health: the importance of measuring patient-reported health status: a scientific statement from the American Heart Association. *Circulation*. 2013 Jun 4;127(22):2233-49.
- Strand V, Boers M, Idzerda L, Kirwan JR, Kvien TK, Tugwell PS, Dougados M. It's good to feel better but it's better to feel good and even better to feel good as soon as possible for as long as possible. Response criteria and the importance of change at OMERACT 10. *J Rheumatol*. 2011 Aug;38(8):1720-7.
- Tubach, F., Ravaud, P., Baron, G., et al (2005). Evaluation of clinically relevant states in patient reported outcomes in knee and hip osteoarthritis: the patient acceptable symptom state. *Annals of the Rheumatic Diseases*, 64(1):34–37.
- Tubach F, Ravaud P, Martin-Mola E, Awada H, Bellamy N, Bombardier C, Felson DT, Hajjaj-Hassouni N, Hochberg M, Logeart I, Matucci-Cerinic M, van de Laar M, van der Heijde D, Dougados M. Minimum clinically important improvement and patient acceptable symptom state in pain and function in rheumatoid arthritis, ankylosing spondylitis, chronic back pain, hand osteoarthritis, and hip and knee osteoarthritis: Results from a prospective multinational study. *Arthritis Care Res (Hoboken)*. 2012 Nov;64(11):1699-707.
- Vik MH, Carlquist E. Measuring subjective well-being for policy purposes: The example of well-being indicators in the WHO "Health 2020" framework. *Scand J Public Health*. 2018 Mar;46(2):279-286.



GEORGE FOX
UNIVERSITY

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Thank you
for your time!

