PhenX Pediatric Development
Working Group
Caregiver Mental Health

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Caregiver mental health

- **Definition:** Psychological health of child’s caregiver
  - Related concepts determined to be outside scope
    - trauma/stress exposures, (parenting) stress, cognitive functioning
- **Concepts:** Psychological health is a very broad area. Most commonly, caregiver mental health refers to psychological/psychiatric symptomatology and/or clinical diagnoses. Symptomatology can refer to specific types of symptoms (e.g., depression) or broader characterization of mental health (e.g., general distress; total symptoms across diagnostic domains).
Caregiver mental health

• Considerations: There are many ways of measuring mental health, with each method presenting different strengths/considerations:

  – Clinical interview
    • Pros: can provide full range of current/lifetime psychiatric diagnoses
    • Cons: training required; cost; time for administration and scoring

  – Diagnostic screener
    • Pros: shorter than full interview; can guide which areas to probe further
    • Cons: limited use on its own; requires follow-up decision-making, interviewing
Caregiver mental health

- **General symptom scale**
  - Pros: can provide rating of overall psychological health; measures available that can be completed as questionnaire and easily scored
  - Cons: if lacks specificity, may diminish usefulness for many research questions

- **Specific disorder symptom scale**
  - Pros: can be used to focus on domains of interest; available as questionnaires; some provide “clinical cut-offs”
  - Cons: may need to give many questionnaires to get coverage of all areas of interest; some domains have better established measures than others
Caregiver mental health

- In many instances, caregiver mental health can be assessed using general (i.e., not specific to caregivers) measures.
- There may be special mental health considerations during pregnancy and the postpartum period.
  - Depression and anxiety in particular identified as frequently presenting/intensifying in perinatal period and having specific and significant, persistent impact on a range of child outcomes.
  - Depression and anxiety may present differently/need to be assessed differently in pregnancy and/or postpartum period.
Existing measurement protocols in PhenX Toolkit

There are many measures in the PhenX Toolkit that address adult mental health.

- Clinical/diagnostic interview
  - SCID-5
    - full range of DSM-5 diagnoses

- Diagnostic Screener
  - Broad Psychopathology: The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) Level 1 Cross-Cutting Symptom Measure
    - 23-item questionnaire assessing 13 psychiatric domains
Existing measurement protocols in PhenX Toolkit

• General symptom scales
  – Emotional Distress
    • Emotional Distress from PROMIS item bank
      – Covers anxiety (7 items), depression (8 items), sleep disturbance (8 items)
    • General Distress Screener: K6
      – 6 questions to assess nonspecific psychological distress during the last 30 days
  – Emotional State
    • PANAS
      – 60 items of emotions over past few weeks
      – 4 subgroups/scales: general dimensions (negative affect, positive affect), basic negative emotions (fear, hostility, guilt, sadness), basic positive emotions (joviality, self-assurance, attentiveness), other affective states (shyness, fatigue, serenity, surprise)
    • General Well-being
      – 18 items across 6 dimensions over prior month: positive well-being, self-control, vitality, depression, anxiety, and general health
Existing measurement protocols in PhenX Toolkit

Specific disorder symptom scales

- **Depression**
  - Screener
    - CIDI-SC 5.0-Depression
  - Symptom questionnaire
    - The Quick Inventory of Depressive Symptoms

- **Anxiety**
  - Screener
    - CIDI-SC 5.0-Anxiety
  - Symptom questionnaire
    - SCL-90 Anxiety Subscale
Existing measurement protocols in PhenX Toolkit

• PTSD
  – PCL-5

• Other Disorders
  – ADHD, Eating Disorders, Sleep Disorders, ASD, Substance Abuse, Schizophrenia/Psychosis/Psychotic Disorders, Psychopathy

• Caregiver specific
  – Edinburgh Postnatal Depression Scale (EPDS)
    • Specifically designed for use in pregnancy and/or postpartum period
Missing elements

1. Minimal coverage of mental health in pregnancy/postpartum period
   - Anxiety
     1. related to many maternal and child outcomes
     2. prenatal and postpartum distinct risk periods for mother and child
     3. symptoms may not assessed by general anxiety scales due to
        a) specific anxieties during these periods (e.g., health of fetus/newborn)
        b) not distinguishing typical anxiety symptoms from common symptoms result of pregnancy/caring for a newborn (e.g., somatic symptoms)
     4. poor correlations/overlap found between measures of general vs. pregnancy anxiety
     5. pregnancy anxiety shown to have impact on maternal and child outcomes separate from measures of general anxiety, depressive symptoms
2. Absence of questionnaires that provide adequate coverage of range of mental health difficulties/psychopathology domains

- Comorbidity common
- Range of caregiver mental health problems associated with poorer child outcomes
- Need for broad measure that captures psychological functioning across domains
- Limitations of relevant measures in PhenX Toolkit
  - requires clinical interview (screener + follow-up or full interview)
  - too general (e.g., focus on distress or negative and positive emotions)
  - not matching standard psychiatric domains/diagnoses
  - too focused on depression/anxiety
1. Anxiety in perinatal period

• Several pregnancy-specific measures exist
  – 2015 review: Identified 17 scales used to assesses anxiety during pregnancy, 7 specifically for pregnancy-related anxiety
    • Length ranged from 4 to 58 items
    • Concluded none had sound theoretical and psychometric properties or sufficient scope and depth for adequate assessment. Need research.
  – 2016 review: Identified critical areas to cover and reviewed current measures for coverage
    • Concluded best “measure” is mixture from two measures (Pregnancy-Related Anxiety Scale, Pregnancy Outcome Questionnaire)
Filling in the gaps

2. Questionnaire assessing broad psychopathology
   • Adult Self-Report/Adult Behavior Checklist
     – 126 items, multiple types of scales
       • Adaptive Functioning Scales: Friends; Spouse/Partner; Family; Job; Education; Personal Strengths
       • Syndrome Scales: Anxious/Depressed; Withdrawn; Somatic Complaints; Thought Problems; Attention Problems; Aggressive Behavior; Rule-breaking Behavior; Intrusive
       • DSM-oriented Scales: Depressive Problems; Anxiety Problems; Somatic Problems; Avoidant Personality Problems; Attention Deficit/Hyperactivity Problems (Inattention and Hyperactivity/Impulsivity subscales); Antisocial Personality Problems
       • Substance Use Scales: Tobacco, Alcohol, Drugs, mean substance use
Filling in the gaps

2. Questionnaire assessing broad psychopathology
   • Adult Self-Report/Adult Behavior Checklist
     – Pros:
       • normed scales
       • wide-ranging coverage
       • available in many languages
       • reliable, validated
       • can be completed on self or by other reporter (e.g., partner)
       • being used in ECHO
     – Cons:
       • proprietary
       • scoring programs needed for normed scores
Filling in the gaps

2. Questionnaire assessing broad psychopathology

- **SCL-90-R**
  - 90 items, 9 primary symptom dimensions and 3 global indices
    - Somatization; Obsessive-Compulsive; Interpersonal Sensitivity; Depression; Anxiety; Hostility; Phobic Anxiety; Paranoid Ideation; Psychoticism
    - Global Severity Index (overall psychological distress); Positive Symptom Distress Index (intensity of symptoms); Positive Symptom Total (self-reported symptoms)
Filling in the gaps

2. Questionnaire assessing broad psychopathology
   • SCL-90-R
     – Pros:
       • established reliability, validity
       • normed on psychiatric outpatients, inpatients, nonpatients
     – Cons
       • proprietary
       • scoring programs needed
       • psychometric weaknesses noted
       • relatively long
         – short versions, some may perform as well/better than SCL-90-R
           » Brief Symptom Inventory (BSI), Symptom Checklist-27 (SCL-27), Brief Symptom Inventory-18 (BSI-18), Symptom Checklist-14 (SCL-14), Symptom Checklist short version-9 (SCL-K-9)
2. Questionnaire assessing broad psychopathology

- **SDQ17+**
  - 25 items, 5 scales
    - Emotional Problems, Conduct Problems, Hyperactivity, Peer Problems, Prosocial
  - **Pros:**
    - SDQ for children already in PhenX Toolkit
    - SDQ well-established, normed, widely used
    - Copyrighted but freely available
  - **Cons**
    - Appears to be for adults still in need of care/supervision
    - Items do not appear appropriate for independent adults
    - Not clear whether SDQ17+ has undergone rigorous psychometric study
Recommendations to the WG

• Recommendation #1: Perinatal Anxiety Measures
  – Need for measures of anxiety during pregnancy and postpartum period
    • Pregnancy and postpartum period critical periods of concern for anxiety
    • Several measures exist for assessing anxiety in pregnancy
    • Limited measures for postnatal period
    • Measures should be separate due to distinct concerns in each period
    • Existing measures need further research/development to confirm reliability and validity to be added confidently to PhenX Toolkit
      – Many of the measures appear to have been developed outside U.S. with samples not representative of U.S. racial/ethnic diversity
      – Other considerations for choice for Toolkit inclusion: ideal length of measure, subdomains covered
Recommendations to the WG

• **Recommendation #1: Perinatal Anxiety Measures**
  – Request suggestions of well validated, published instruments that measure Prenatal Anxiety and Postnatal Anxiety during community outreach for WG consideration
Recommendations to the WG

  - Current PhenX Toolkit Broad Psychopathology adult measure is a diagnostic screener
  - Non-proprietary options that match the depth, breadth, and psychometric strengths not available
  - CBCL is widely used in literature
    - The ASR/ABCL is “adult” version
    - May be particularly useful in studies using CBCL
      - Longitudinal tracking
      - Caregiver(s) and child
Recommendations to the WG

- Recommendation #3: “Competing” measures
  - Many other mental health measures used to assess caregiver mental health in literature generally and in large cohorts specifically (e.g., ECHO)
  - *Not strong reasons to add these measures to compete with existing PhenX measures*
    - Depression: PROMIS, PHQ-9, CESD-R, BDI-II (proprietary)
    - Anxiety: STAI (proprietary; state/trait)