How to Define Successful Transition

23rd Annual Chronic Illness and Disability Conference:
Transition from Pediatric to Adult-Based Care

Bethany Coyne, PhD, CPNP-PC, RN

October 28th, 2022

University of Virginia

Objectives

At the end of this session, the audience will be able to describe:

1. Previous definitions of successful transition
2. Medical and non-medical metrics to define successful transition
3. Considerations in standardizing a definition of successful transition

HOW WOULD YOU DEFINE TRANSITION SUCCESS?

Go to www.menti.com

code: 8180 2290

Objective #1: Describe previous definitions of successful transition

Quadruple Aim	Expert opinion	Review of existing literature
• Improve population health • Enhance the patient experience of care • Reduce cost of care • Improve work-life for providers	• Delphi methodology	• Domains of Health Care Quality

Prior et al (2014)

Used the Triple Aim to categorize transition related outcome measures

- Majority only measured outcomes in one domain
- Seldom used the same measure consistently
- Population Health most reported domain
  - Few used standardized/validated instruments
  - QOL and self-care were the exception
  - Most on self-care and knowledge vs disease specific measures
- Patient Experience
  - Satisfaction using the Got Transition® instruments
- Cost
  - Utilization
  - Gaps in care

Suris and Akre (2015)

Delphi methodology to determine international consensus for transition program.

37 experts identified 8 indicators for successful transition

1. Patient not lost to follow-up
2. Attendance of scheduled visits in adult care
3. Development of a trusting relationship with adult provider
4. Continuing attention to self management
5. First visit to adult care no later than 3-6 months after transfer
6. Number of emergency room visits for regular care
7. Patient and family satisfaction
8. Maintain/improve standard for disease control

Fair et al (2016)

Delphi methodology to refine a list of health care transition outcomes

Interdisciplinary group identified 10 final outcomes:

- Individual
  - Quality of life
  - Knowledge of conditions and complications
  - Knowledge of medications
  - Self management
  - Adherence to medications
  - Understanding health insurance
- Health service outcomes
  - Attending medical appointments
  - Having a medical home
  - Avoidance of unnecessary hospitalizations
- Social outcomes
  - Having a social network

Coyne et al (2017)

Integrative review to identify measurable patient-level outcomes for transition

Disease specific patient-level outcomes

Non-disease specific patient level outcomes

Timing of outcome measurement

Frequency of outcome measurement

Bailey, et al (2022)

- Identified quality indicators for transition across physical, mental, and development conditions.
- Classified quality indicators using the IOM Domains of Health Care Quality and categorized according to the Donabedian Model.

Donabedian's Quality Framework. Available from: https://www.ncbi.nlm.nih.gov/books/NBK44008/figure/A25995/

Bailey, et al (2022)

- 9 studies, identified 169 quality indicators
  - 72 patient level
    - Satisfaction
    - Self-management/self efficacy
  - 50 provider level
    - Transition education
    - Transition planning
  - 30 health system level
    - Continuity of care
    - Transfer documentation
  - 14 caregiver level
    - Caregiver roles and responsibilities

- IOM Domains
  - Patient-centered (87, 51%)
  - Safe (41, 24%)
  - Effective (21, 13%)
  - Efficient (15, 9%)
  - Timely (5, 3%)
  - Equity (0)

- Donabedian Model
  - Process (75, 44%)
  - Outcomes (56, 33%)
  - Structure (38, 23%)

Objective #2: To describe medical and non-medical metrics to define successful transition

Medical

- Disease specific measures
- Self-management and knowledge
- Adherence
- Health care utilization
- Medical home

Non-Medical

- Quality of life
- Vocational outcomes
- Self-efficacy
- Satisfaction
- Social development

OBJECTIVE #3: TO DISCUSS CONSIDERATIONS IN STANDARDIZING A DEFINITION OF SUCCESSFUL TRANSITION

Medical Metric: Disease-Specific Measures

- HgA1C
- Retinopathy
- Hypoglycemic episodes
- Creatinine
- Acute rejection episodes
- Hypertension
- Graft survival/loss
- Mortality
- Transfusion need

Medical Metric: Self-Management

- Developmentally Based Skills Checklist
- Denyes Self-Care Practice Instrument
- Transition Readiness Assessment Questionnaire (TRAQ)
- Self-Care Inventory R

Medical Metric: Adherence

- Medication
  - Drug levels
  - Prescription refills
  - Electronic monitoring
  - Patient, caregiver, provider report
- Recommended screenings

Medical Metric: Health Care Utilization

- Appointment attendance
  - Primary Care
  - Subspeciality Care
- Hospitalizations
- Emergency room visits
- Gaps in care

Medical Metric: Medical Home

- Provision of a medical home that is:
  - Accessible
  - Family-centered
  - Continuous
  - Comprehensive
  - Coordinated
  - Compassionate
  - Culturally Effective

American Academy of Pediatrics, 2022

Non-Medical Metric: Quality of Life

- Pediatric Quality of Life Inventory ™ (PedsQL™)
- Child Health and Illness Profile (CHQ)
- KIDSCREEN
- Child Health Questionnaire
- Young Adult Quality of Life (YAQOL)

Non-Medical Metric: Quality of Life

- Short Form 36
- Quality of Life Instrument for Chronic Disease (QLICD)
- Duke Health Profile
- WHOQOL-BREF

Non-Medical Metric: Vocational Outcome

- Completion of HS or equivalent
- Post-HS education
- Job attainment and retention

Non-Medical Metric: Self-Efficacy

- General Self-Efficacy Scale
- Self-Efficacy Survey (SES)
- Chronic Illness Self-Management Scale (CISM)
- Perceived Medical Condition Self-Management Scale (PMCSMS)

Non-Medical Metric: Satisfaction

- Patient, caregiver, provider
- Mind the Gap Scale

Non-Medical Metric: Social Development

- Social network
  - Adolescent Social Network Assessment (ASNA)
  - Young Adult Social Network Assessment (YASNA)
- Independent living
- Healthy relationships

Conclusions

- Measures to determine transition success should include:
  - Medical outcomes
  - Non-medical outcomes
  - Patient, parent, provider perspectives
- Further work need to develop consistency in measurement using valid and reliable instruments

References

- Bailey, K., et al. (2022). Quality Indicators for Youth Transitioning to Adult Care: A Systematic Review. *Pediatrics*, 150 (1), e2021055033.
- Coyne, B., et al. (2017). Measurable Outcomes After Transfer From Pediatric to Adult Providers in Youth With Chronic Illness. *Journal of Adolescent Health*, 60 (1), 3–16.
- Fair, C., (2016). International and Interdisciplinary Health Care Transition Research Consortium. International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatr*, *170*(3), 205-211.
- Prior, M., et al. Measuring the 'Triple Aim' in Transition Care: A Systematic Review. *Pediatrics*, 134 (6), e1648-1661.
- Suris, J. & Akre, C. (2015). Key Elements for, and Indicators of, a Successful Transition: An International Delphi Study. *Journal of Adolescent Health*, 56 (2), pp. 612–18.

UNIVERSITY of VIRGINIA