Transition to adulthood for patients with intestinal failure

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Case Study 1

- Patient with functional intestinal failure from childhood
  - PN dependent > 20 years
  - Possible super-imposed Crohn's disease
  - Advanced liver disease
  - Recommended combined liver-intestinal transplant

- Transition issues
  - Functions as a pediatric patient
  - No defined primary care provider
  - Inconsistent f/u with a number of adult care-providers
  - Difficult decision making
    - Who is responsible - patient or parent?
    - Who should the care-team focus on?

Case study 2

- Patient with very long-segment HD
- On PN for > 24 years
- Recurrent fungal infections
- Recommended intestinal transplant
- Currently, undergoing intestinal rehab
  - Parent-patient conflict and issues of autonomy
    - ‘I came because she made me do it!’
  - Currently preparing for transition
    - Different geographical location
    - Adult care-provider
    - Patient directing transition!

Case study 3

- Truck driver with short bowel on PN for > 2 years
- Recurrent episodes of ‘slurring, drunkenness, near-coma’
- Seen by multiple adult neurologists, tested extensively
- Contacted our team via Oley!
  - Multiple atresias/dilated bowel/d-Lactic acidosis
  - Bianchi intestinal lengthening
  - Off PN > 1 year

Defining transition

- Transition consists of two processes:

1. Transitioning from pediatric to the adult care settings
2. Transition in health care management from adult caregivers to patients

Possible problem points during transition to the adult health care system

1. Shift occurs before transition in health care management accomplished
2. Difficulties transitioning health care management
3. Factors associated with difficulties transitioning are not addressed
4. Patients are apprehensive about leaving pediatrics
5. Adult providers may not be oriented towards the needs of transitioning patients

Introduction

- Historically, intestinal failure was fatal.
- PN and transplantation has changed a fatal illness into a chronic, life-long condition.
- Long-term care of patients includes:
  - Specialized nutrition support
    - Patchy medical/nutrition expertise
    - Home care companies not uniform in adult/pediatric expertise
  - Medications
  - Follow-up at specialized centers of excellence

Transition in care location

- Among Coronary Heart Disease (CHD) patients, increased mortality post transition (Somerville, 1997).
- Among kidney transplant recipients, Watson (2000) found that graft loss markedly increased after transition.
  - Nonadherence to medications?

Transition to the adult health care system

- Adherence significantly decreased after transition.
- Transitioned patients exhibited poorer adherence than patients in two control cohorts over time.
- Nonadherence among transitioned cohort even prior to transition.

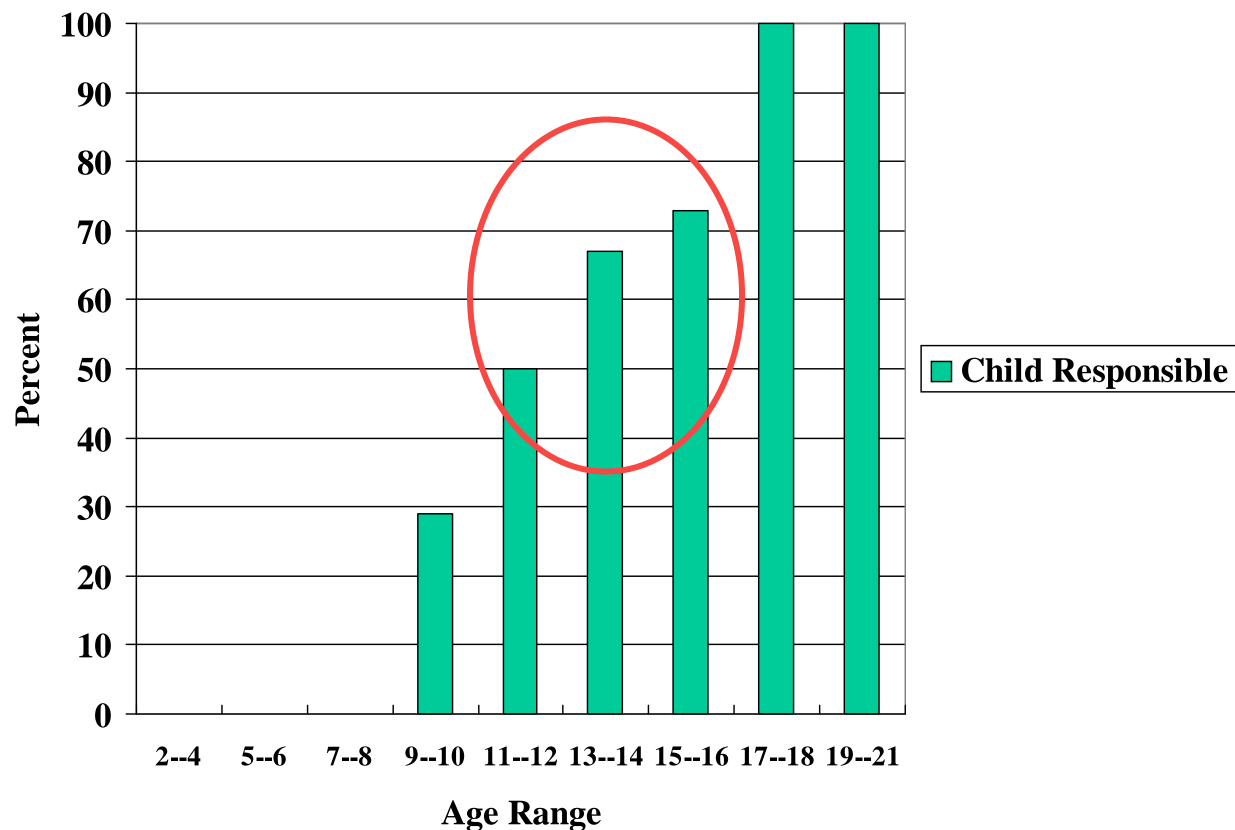
Annunziato et al, 2007

Nonadherence in adolescence

- Nonadherence to health care recommendations is very common!
  - Across diagnoses (Kyngas, 2001)
  - Transplant recipients
  - Risk factors
    - PTSD
    - Abuse
    - Inadequate transition in health care management?

Transition in health care management

- In our clinic, patients assume responsibility for medications on average by age 12.



Transition in health care responsibility: Additional intervention targets

Frequency of engagement in self-management behaviors, patients age 18 and older (N=18)			
Behavior	**Never**	**Sometimes**	**Always**
Discuss diagnosis with parent(s) and medical team	4%	38%	58%
Know chronic illness history	4%	56%	40%
Manage liver disease by myself	12%	46%	42%
Engage in a healthy lifestyle	0%	44%	56%
Keep track of medications	4%	32%	64%
Take medications correctly	0%	8%	92%

Transition in health care responsibility: Additional intervention targets

Frequency of engagement in self-management behaviors, patients age 18 and older (N=18)			
Behavior	**Never**	**Sometimes**	**Always**
Call pharmacy to reorder medications	23%	19%	58%
Know different health care providers	8%	28%	64%
Know dates of appointments	4%	31%	65%
Make own appointments	4%	61%	35%
Know health insurance basics	4%	38%	58%
Understand health insurance	4%	56%	40%

Health care management survey

- Results
  - Health care management improves with age
  - Management, even among older patients, is poor
  - Adherence was a positive
- Next steps
  - Analyze results by diagnosis
  - Incorporate targets in funding application

Transition in health care responsibility: Pilot intervention

- Methods (n = 20 patients, aged 10 - 21)
  - Two module protocol administered in outpatient clinic (typically delivered on the same day)
    - Module 1 - Clinician administered
      - Review disease
      - Review treatments
      - Review medication regimen
      - Discuss importance of adherence
      - Checklist
    - Module 2 - Mental Health professional
      - Introduce idea of transition
      - Identify potential areas of difficulty
      - Problem-solve barriers to transition
  - Patients and caregiver included

Annunziato et al, 2008

Transition in health care responsibility: Pilot intervention

Question	Response
Have you tried to take your medications as directed because of these meetings?	83%
Has your child tried to take his/her medication as directed because of these meetings?	70%
Have you tried to do the things you talked about in the meetings (child)?	89%
Have you tried to do the things you talked about in the meetings (caregiver)?	90%
Since participating in this program, how comfortable do you feel about taking responsibility over taking the medications?	78% more comfortable
Since participating in this program, do you feel that you know enough to make decisions about giving your child the responsibility over taking the medications?	70% more comfortable

Transition in health care responsibility: Pilot intervention

- Conclusions:
  - This simple, brief approach is feasible
  - May be especially useful for families identified as struggling with transition

Miscellaneous…

…rarely as mature…child life, art therapy, music therapy provide support…adult psych only as consultants..body form issues ..

..Less financial help for the adult patient..

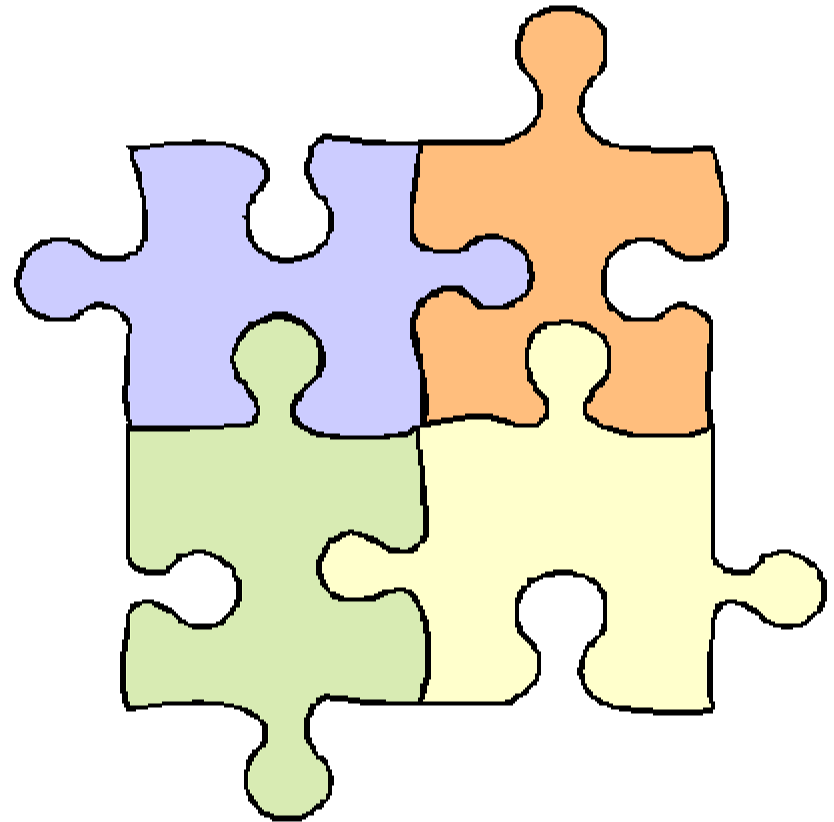
..travel..lodging..fewer services

..insurance..if not working, apply for straight medicaid..if working, ensure adequate insurance coverage..? Consider reducing work hours if needed for medicaid

..don't forget the siblings..psychosocial stressors in family..where is the support?..growth issues..sexual maturity..

Pulling it all together

- **Intervention development**
  - Improving transition in health care management
  - Widening behavioral targets
- **Clinical program**
  - Preparing patients/families for adjustment to new health care providers
  - Organizational change



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