Transition in other chronic diseases

Janet E McDonagh
Senior Lecturer in Paediatric and Adolescent Rheumatology
Transition in other chronic diseases

• Young Person
• Need for common language
• Evidence base
Living with Arthritis

Systematic review of qualitative literature
27 studies, 542 participants
Main themes:
• aversion to being different
• striving for normality
• stigma and misunderstanding
• suspension in uncertainty
• managing treatment
• desire for knowledge

Tong A et al 2012
# Areas of impact to be addressed within a programme of transitional care as perceived by young people

<table>
<thead>
<tr>
<th>Area of Impact</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Condition (JIA)</td>
<td>Disease education</td>
</tr>
<tr>
<td>Treatment</td>
<td>eg rationale, health care utilisation</td>
</tr>
<tr>
<td>Functional ability</td>
<td>Strategies to maximise independence</td>
</tr>
<tr>
<td>Psychological health</td>
<td>eg invisibility, body image</td>
</tr>
<tr>
<td>Social issue</td>
<td>eg peer and valued activities; bullying</td>
</tr>
<tr>
<td>Parental issues</td>
<td>eg facilitating independence of YP</td>
</tr>
<tr>
<td>Education</td>
<td>eg rights and resources</td>
</tr>
<tr>
<td>Vocation</td>
<td>eg disclosure, rights and resources</td>
</tr>
<tr>
<td>Independent living</td>
<td>eg driving and life-skills</td>
</tr>
<tr>
<td>Adult relationships</td>
<td>eg Sexual and reproductive health</td>
</tr>
</tbody>
</table>

*Shaw KL et al 2004*
Generic approach

• Young people first and foremost
• Same issues – variable consequences
• Core components

• Multisystem disease, complex disability
• Need for coordination
• Potential efficiencies of scale
## Adolescent Transitions

<table>
<thead>
<tr>
<th>Developmental stage</th>
<th>Transitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Adolescence 10-13</td>
<td>Pubertal Social Health self-management Primary to secondary school</td>
</tr>
<tr>
<td>Mid Adolescence 14-16</td>
<td>Pubertal Social Health self-management School to college</td>
</tr>
<tr>
<td>Late Adolescence 17-19</td>
<td>From parental home Paediatric to adult health care Health self-management College to HE/Employment</td>
</tr>
<tr>
<td>Emerging adulthood 20-24 years</td>
<td>Independent living Health self-management Parenthood HE to employment</td>
</tr>
</tbody>
</table>
Conditions for successful health transition from perspective of young people

- Level of knowledge and skills
- Environment
- Transition planning
- Meaning given to transition by young people
- Expectations about transition and the adult centred care environment

Lugasi T et al 2011
Transition in other chronic diseases

Objectives

• Young Person
• Need for common language
• Evidence base
What do we mean by… transition?

- **Institutional:** Negotiation of the structural boundaries between child and adult services

  - **Mid Adolescence 14-16**
    - Pubertal
    - Social
    - Health self-management
    - School to college

  - **Late Adolescence 17-19**
    - From parental home
      - Paediatric to adult health care
    - Health self-management
    - College to HE/Employment

- **Developmental transitions of young people**

  - **Emerging adulthood 20-24 years**
    - Independent living
    - Health self-management
    - Parenthood
    - HE to employment
Vocational Transitions

Poor health in adolescence associated with:
• poorer education
• poorer employment outcomes in adulthood

Hale DR et al, 2015

Transitional Care programme significantly improved
- vocational readiness
- documentation of vocational issues

McDonagh JE 2007; Robertson L 2006
What do we mean by...developmentally appropriate?

- A qualitative multi-site ethnographic study
- 3 hospitals in England, 192 participants
- Wide range of definitions!

Five conceptual dimensions:

(i) bio-psycho-social development and holistic care
(ii) acknowledgement of young people as a distinct group
(iii) adjustment of care as the young person develops
(iv) empowerment of the young person by embedding health education and health promotion
(v) interdisciplinary and inter-organizational work

Farre A et al 2015 (in preparation)
What do we mean by…. a Transition clinic?

- Ad hoc “transition” clinic
- Paediatric and adult teams present
- Rest of care provided in “all age” clinics
- No prior preparation
- ? Youth-friendly service/institution

23 clinics representing 14 specialties
- 14/23 “transition programme”
- 5/14 met “holistic” definition of transition
AND had significantly greater levels of YP satisfaction

Shaw KL et al 2014
What do we mean .... By Youth-Friendly Health Care

Systematic review core indicators:
- Accessibility of health care
- Staff attitude
- Communication
- Medical competency
- Guideline-driven care
- Age appropriate environments
- Youth involvement in health care
- Health outcomes

Ambresin AE et al 2013
Transition in other chronic diseases

- Young Person
- Need for common language
- Evidence base
(i) Assessment of Transition Readiness

- Integral part of a transitional care programme
- Checklists
- Useful trigger
- Identify YP at risk
- Promote and facilitate opportunities for increasing self-management
- Track YP through transition process
Transition Tools

- Assessment of mastery?
- Skills promoting environments?
- Resilience promoting staff?
Transferable Skills in the Healthcare Setting

- Communication
- Negotiation
- Goal setting
- Problem solving
- Decision-making
- Self-management
- Organisational
- Information seeking
- Health care utilisation
- Disclosure
Transition Readiness and Autonomy

48% of total variance in transition readiness explained
• Perceived self-efficacy in skills for independent hospital visits
• Perceived independence during consultations
• Attitude towards transition
• Discussion re transition

Van Staa A et al 2011
Transition – HEADSSSSS
Routine Psychosocial Screening

H – Home
E – Education/Exercise
A – Activities/Ambitions
D – Drugs/alcohol
S – Sleep
S – Safety
S – Sex
S – Suicide/affect

T – Transfer to adult services

Adapted from Goldenring & Rosen 2004

- Suboptimal screening in tertiary hospital settings Boisen KA et al 2015
- Improved significantly following implementation of the transitional care programme Robertson LR 2006
(ii) Transition “coordinator”

- Recognition
  - Betz CL 2005, DH guidance
- Potential of role
  - Annunziato R 2013
  - Crowley R 2011; van Walleghem N 2008
- Rheumatology:
- Young people preference
  - McDonagh JE 2006
- ↑ YP satisfaction
- ↑ Transfer success
  - Jensen PT 2015 (social worker)
(iii) Importance of a team-based approach

(i) Transitional Care Provider characteristics > important than:
- Physical environment
- Process issues

Shaw KL 2007, 2014

(ii) Team climate and changes in team climate predicted the quality of transitional care delivery

Cramm JM 2014

(iii) Successful engagement of young people requires team-based approach

Van Staa AL 2015

(iv) Main determinant of positive transfer experience:
Patient centredness of adult provider

Van Staa AL & Sattoe J 2014
Evidence: Most commonly used strategies in successful programmes

- Patient education and skills training
- Specific clinics:
  - Combined paediatric & adult clinic: 8 studies, only 3 successful
  - Young adult clinic:
    - 4 studies, 3 successful

Crowley R et al 2011

NB Joint out-patient clinics
- considered less useful transfer methods by rheumatology practitioners (n=138, 55.2% response rate)
  Hilderson D et al 2012
# Key Elements of Successful Transition

<table>
<thead>
<tr>
<th>Key element</th>
<th>Essential (%)</th>
<th>Essential + v important (%)</th>
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<tbody>
<tr>
<td>Coordination between paediatric and adult professionals</td>
<td>97</td>
<td></td>
</tr>
<tr>
<td>Early start</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>Self-management discussions</td>
<td>74</td>
<td></td>
</tr>
<tr>
<td>Young person involvement</td>
<td>74</td>
<td></td>
</tr>
<tr>
<td>Independent visits if developmentally appropriate</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Identification of adult provider</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Individualised transition planning</td>
<td>57</td>
<td>91</td>
</tr>
<tr>
<td>Identification of transition manager/coordinator</td>
<td>46</td>
<td>91</td>
</tr>
<tr>
<td>Written health and biopsychosocial summary</td>
<td>63</td>
<td>89</td>
</tr>
<tr>
<td>Written transition protocol</td>
<td>54</td>
<td>89</td>
</tr>
<tr>
<td>Adult appointment in place prior to transfer</td>
<td>60</td>
<td>89</td>
</tr>
<tr>
<td>Adolescent health trained staff</td>
<td>49</td>
<td>89</td>
</tr>
<tr>
<td>Parental involvement</td>
<td>37</td>
<td>89</td>
</tr>
<tr>
<td>Primary care kept informed</td>
<td>63</td>
<td>86</td>
</tr>
<tr>
<td>Tracking mechanism</td>
<td>46</td>
<td>83</td>
</tr>
<tr>
<td>Discussion re differences between paediatric and adult care</td>
<td>37</td>
<td>77</td>
</tr>
<tr>
<td>Discussion re risk behaviours and influence on health</td>
<td>40</td>
<td>71</td>
</tr>
</tbody>
</table>
NIHR Programme Grant
Pl. Prof Allan Colver, Newcastle University
http://research.ncl.ac.uk/transition/

Diabetes, cerebral palsy, autism

Includes IDAHO study:
Implementation of Developmentally Appropriate Healthcare in Organisations
BUT….still gaps…. 

Process areas most in need of improvement:
- Guidelines
- Protocols
- Coordination

Sonneveld H 2013 (Netherlands)

Health system strategies
• Flexibility
• Funding
• Cross-sectoral collaboration
  (including communication and coordination)
  Moore Hepburn C et al, 2015
Coming Soon!

Interventions to improve transition of care for adolescents from paediatric services to adult services (Protocol)
Campbell F, O'Neill PM, White A, McDonagh J

And.....NICE guidance Transition from Children’s to Adult Services (due 2016)
6 Principles to shape our thinking about Young People’s Health

PHE 2015
Transition in other chronic diseases

“It’s not about [arthritis], it’s about living with it”  
Shaw KL 2004

25-26 February 2016, Manchester  
A New Look at Young People’s Health  
AYPH/YPHSIG/RCP/RCGP conference & YPHSIG Clinical Symposium

janet.mcdonagh@manchester.ac.uk