Managing adherence in adolescents and young adults: The Liver Transition Service

Anna Hames (Clinical Psychologist) & Marianne Samyn (Consultant Paediatric Hepatologist)
Overview

• Liver services at KCH
• Non-adherence in young people post-transplant
• What makes young people vulnerable to non-adherence?
• The Liver Transition Service
• Role of psychology
Liver Services at KCH

• Paediatric Liver Service:
  – 1 of 3 specialist centres in the UK
  – Specialist care for a range of childhood liver conditions
  – Approx 4600 attendances a year
  – Approx 40 transplants a year (2/3 under 5 yrs)
  – Dedicated liver ward

• Adult Liver Service:
  – Supra-regional expert centre
  – Specialist care for a range of liver conditions
  – Approx 200 transplants year
  – Dedicated liver wards and LITU
Adherence

“The extent to which a person’s behaviour – taking medications, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider”

_The World Health Organization, 2003._
Adherence in liver

• Post-transplant:
  – Daily immunosuppressant medication for life
  – Routine bloods and hospital appointments
  – Lifestyle changes

• Other liver conditions:
  – Often require daily medications and follow-up
  – Lifestyle changes
  – Poor adherence may lead to transplant
Non-adherence in adolescents post-transplant ≥ 50%

Dobbels et al. (2005)
Pediatric Transplant; 9(3): 381-390
Deceased Donor Patient Survival

Deceased Donor Graft Survival

OPTR/SRTR 2010 Annual Data Report
Unexpected graft loss

Watson (2000)

- 20 young adults (11m, 9f)
- Kidney transplant at mean age 14.3 years
- Transferred to 3 adult units at mean 17.9 yrs
- 35% unexpected loss of graft, most within 2 years of transferring
- Of the 7 who lost grafts, 5 had ‘adverse psychosocial circumstances’

Pediatr Nephrol; 14; 469-472
Annunziato et al. (2007)
- 14 Paediatric liver transplant recipients
- Significant decrease in adherence after transfer to adult services

Kiberd, Acott & Kiberd (2011)
- 247 kidney transplant recipients
- Graft loss: aged 11-18 = 18-25 > 25-35
- Adolescents/young adults a vulnerable population
Adolescence and Adherence

• Findings replicated in other chronic illness groups. E.g.:
  – Neurology (Tomlinson & Sugarman, 1995)
  – Diabetes (Kipps et al. 2002)

DoH - Transition: getting it right for young people
Transition

‘a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated healthcare systems’

- Blum, Garell & Hodgman (1993)
### Differences between paediatric and adult units

<table>
<thead>
<tr>
<th>Paediatrics</th>
<th>Adult</th>
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</thead>
<tbody>
<tr>
<td>• Family consultation</td>
<td>• Individual consultation</td>
</tr>
<tr>
<td>• Multidisciplinary team &amp; psychosocial support</td>
<td>• Limited team support (especially psychosocial)</td>
</tr>
<tr>
<td>• Fewer patients</td>
<td>• Large patient numbers</td>
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<tr>
<td>• Specialist knowledge about rare genetic conditions</td>
<td>• Lack of experience with rare ‘paediatric’ conditions</td>
</tr>
<tr>
<td>• Shorter waiting lists</td>
<td>• Longer waiting lists</td>
</tr>
<tr>
<td>• Peer support</td>
<td>• No ‘young adult’ clinic</td>
</tr>
<tr>
<td>• Medications usually free</td>
<td>• Payment for medications</td>
</tr>
</tbody>
</table>

Transfer to the adult service

Tossed out

Cut off

Hurtling into a void

Lost in the shuffle

Sudden

Dumped

Abandoned

Thrown out

Shaw, Southwood & Mcdonagh (2004)
Scott et al. (2005)
Morris (1999)
Adolescence

- Physical changes
- Cognitive development
- Social and emotional development

AND

Interaction of illness & treatment with all of the above
## Tasks of adolescence clash with tasks of adherence

**Table 1** Reciprocal effects of chronic illness or disability and adolescent development

<table>
<thead>
<tr>
<th>Effects of chronic illness or disability on development</th>
<th>Effects of developmental issues on chronic illness or disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Biological</strong></td>
<td>Biologically</td>
</tr>
<tr>
<td>Delayed/impaired puberty</td>
<td>Increased caloric requirement for growth may negatively impact on disease parameters</td>
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<tr>
<td>Short stature</td>
<td>Pubertal hormones may impact on disease parameters (e.g. growth hormone impairs metabolic control in diabetes)</td>
</tr>
<tr>
<td>Reduced bone mass accretion</td>
<td><strong>Poor adherence and poor disease control due to:</strong></td>
</tr>
<tr>
<td></td>
<td>Poorly developed abstract thinking and planning (reduced ability to plan and prepare using abstract concepts)</td>
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<td></td>
<td>Difficulty in imagining the future; self-concept as being “bullet proof”</td>
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<tr>
<td></td>
<td>Rejection of medical professionals as part of separation from parents</td>
</tr>
<tr>
<td></td>
<td>Exploratory (risk taking) behaviours</td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td>Associated health risk behaviours</td>
</tr>
<tr>
<td>Infantilisation</td>
<td>Chaotic eating habits may result in poor nutrition</td>
</tr>
<tr>
<td>Adoption of sick role as personal identifier</td>
<td>Smoking, alcohol and drug use often in excess of normal population rates</td>
</tr>
<tr>
<td>Egocentricity persists into late adolescence</td>
<td>Sexual risk taking, possibly in view of realisation of limited life span</td>
</tr>
<tr>
<td>Impaired development of sense of sexual or attractive self</td>
<td></td>
</tr>
<tr>
<td>Impaired development of cognitive functions and information processing</td>
<td></td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td></td>
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<tr>
<td>Reduced independence at a time when independence is normally developing</td>
<td></td>
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<tr>
<td>Failure of peer relationships then intimate (couple) relationships</td>
<td></td>
</tr>
<tr>
<td>Social isolation</td>
<td></td>
</tr>
<tr>
<td>Educational failure and then vocational failure; failure of development of independent living ability</td>
<td></td>
</tr>
</tbody>
</table>

*Suris, Michaud & Viner (2004) Arch Dis Child;89:938-942*
Young adulthood

• Multiple other transitions:
  – Leaving school, leaving home, starting work/college/university, intimate relationships
  – Other services (e.g. physical health, mental health, social services)
Factors associated with (non)adherence

• Wide range of potential factors, including:
  – Treatment demands
  – Illness demands
  – Social factors
  – Psychological factors
  – Developmental factors
  – Health care provider
To improve adherence....

In context of adolescent development and multiple transitions, we need to foster:

• Positive patient/provider relationships
• Collaborative decision-making
• Satisfaction with medical care

Try to reduce the burden of illness and treatment demands

Attend to psychosocial needs
Doing things differently...

Harden, Walsh, Bandler et al. (2012, BMJ)

- Adult transfer model: 67% graft loss within 5 years (n=9)
- Young adult model: 0% graft loss within 5 years (n=12)

One size does not fit all...
- Cohort size
- Geographical barriers
- Service variations
- Cultural differences
High level vision for the provision of Transition services in Transplantation at King’s College Hospital

Management within paediatric services 12-16 yrs

Post Transplant referral
Paediatric Liver clinic
Checklist of key milestones to manage a gradual transition from paediatric to adult services. Aim to refer to transition service by 16 years. Can no longer admit to a paediatric ward after 18 yrs. Identify MDT who will be involved in patients’ care through transition Development of information pack and EPR referral

Hepatology referral

Transition services 16-18 yrs

Transition clinic – first visit
Suitable environment as per DH guidelines
Confirm checklist
First visit with parents
MDT core Team
-Paed physician
-Adult physician
-Surgeon
Others available such as transplant co-ordinator/Social worker/Sexual health/Clinical psychologist/dietician/pharmacist

Transition clinic: 2-4 visits per year
Visits may be yearly/six monthly or more frequent dependant on patient to be defined by guidelines
MDT available at all clinics as required

Transition clinics can flag up more complicated patients before transferred to adult services

Auto-immune clinic - MH

New adult clinic for specific diseases

This clinic would be run by the same physician in the transition clinic and cover specific diseases where there is no current specialisation

Adult services 18+

Post Transplant clinic
Transition Service

• Outpatient clinics
  – Pretransition/adolescent clinic (12-16yrs) - POD
  – Transition clinic (16 yrs +) – LOPD
  – Specialist psychology/social work/cns input

• Inpatient support

• Pathways into adult services
  – Ongoing transition MDT input as needed
Multidisciplinary team

- Consultant Paediatric Hepatologist
- Transplant coordinators (Adult & Paediatric)
- Clinical Psychologist (12–25 yrs)
- Specialist social worker (Adult; 16 yrs +)
- Liver CNS (Paediatric)
- Pharmacist
- Liver transplant surgeon
- Sexual Health consultant
Liver transition service activity

*Patient visits

08-'09 09-'10 10-'11 11-'12 12-'13 *

109 389 419 375 448

*Predicted activity Jan 2013
Key components

- Early preparation, proactive approach
- Treating the young person as a young person
- Individualised and flexible
- Holistic: psychosocial, educational & vocational needs
- Communication within and between agencies
- Include family, friends and partners
- Routine adherence management
Emphasis on:

- Stance of assumed non-adherence: Routine Ax and management

- Increasing:
  - Understanding of condition and treatment
  - Skills in communication, decision-making and assertiveness
  - Sense of autonomy and self-care

- Harm minimisation approach
- Sex, drugs, smoking, alcohol
- Other life transitions
<table>
<thead>
<tr>
<th><strong>Home</strong></th>
<th>(parents, siblings, other residents, accommodation, family life etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education/Employment</strong></td>
<td>(school, subjects, teachers, peers, grades, attendance, goals, work etc.)</td>
</tr>
<tr>
<td><strong>Activities</strong></td>
<td>(social life, sport, exercise, hobbies, past-times, driving, police etc.)</td>
</tr>
<tr>
<td><strong>Drugs</strong></td>
<td>(smoking, alcohol, illegal drugs etc.)</td>
</tr>
<tr>
<td><strong>Sexuality</strong></td>
<td>(relationships, sex, sexual health, contraception, abuse, menstruation, self-examination etc.)</td>
</tr>
<tr>
<td><strong>Suicide &amp; Depression</strong></td>
<td>(eating, sleeping, feelings, mental health etc.)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Clinical Examination</strong></td>
<td></td>
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<tr>
<td><strong>Plan</strong></td>
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Role of Clinical Psychologist

• Direct work
  – Assessment (inc cognitive Ax)
  – Intervention: Individual, Couple, Family
  – Joint clinic consultations
  – Liaison with services

• Indirect work
  – Weekly MDT meeting
  – Staff consultation
  – Teaching & training

• Service development

• Research
IT’S EASIER IF WE ALL PULL TOGETHER
Thank you for listening!
Challenges for adherence management

• No widely accepted standard method for assessment of adherence
• Combination of measurements may increase diagnostic accuracy (practical in routine care?)
• Validity of self-report?
• Subjective vs objective

• Useful to consider:
  – Pattern of adherence
  – Intentionality
Tips for adherence management…

• Never assume you know whether someone is adherent; very few people are adherent all of the time. People can change - do not label them.

• Someone is never too young or too old

• Be aware of cultural differences

• Do not tell your patient off or try to terrify them – this is very unlikely to change their adherence behaviours, but is likely to teach them not to tell you again!

• Do not assume you know why someone is non-adherent - there are an infinite number of reasons why someone struggles to take their medications or attend appointments.

• Focus on prevention
  – Identify risk factors
  – Understand the pattern of adherence
What our patients say....

‘Its good that she (Consultant) asked if I was taking my medication, because I wouldn’t have told her otherwise. She almost scared me. It was bad, but that’s what I needed to give me a kick up my backside. She said it in a positive way though - even though I clocked that she was saying that I might die if I didn’t take my medication, she made it sound like I could fix it. If she hadn’t been positive, it would have been a real blow and I probably would have just given up.

She also told me that it wasn’t just me who struggled with my medicines, and she never trivialised it or patronised me. I always thought it was stupid that I didn’t take my medication, but now I realise that it’s a hard thing to do.

She made me feel like we could change it together. At first I thought I could do it on my own, but I kept on slipping up. She kept on reminding me that I could come and see you (psychology). At first I wasn’t sure, but it has really helped and I’ve never been able to take my medication so well for so long.’
‘There’s not just good things about taking meds, there are bad things too... but the doctors only ever talk to you about the good stuff. My mum doesn’t listen, she thinks it’s easy. The most important thing that helped was that you understand how hard it is for me to take my meds; you listened and felt my pain.’