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QUEEN ELIZABETH II CONFERENCE CENTRE
LONDON



Evolving Models of Care for the 21st Century: An update on clinical networks and multi-professional aspects of care

Peer Support & Transitional Care
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Demographics

- Total number of patients = 12
- Median age 15.5 years (range 2.3 – 17)
- Team members – 1xFTE NHS consultant, 1 x academic, 1 x CNS HIV, HIV pharmacist, no dedicated social worker, psychology or dietetic input
- 8 HIV clinics per year
- MDT meeting before each HIV clinic
- No family clinic



Disclosure / Peer support

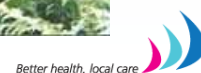
- Full disclosure in 11 of 11 (100%)
- Peer support activities offered to all children age >13 years (n=8)
- CHIVA camp / body and soul (London)/ remote mentoring / local activities (Positive Action)
- 6 of 8 (75%) actively engaging
- 1 has developmental delay secondary to HIV encephalopathy, 1 about to engage in local activities

Peer Support where did it all start?

- 2011: Increasing number of cohort 13yrs+
- Joint bid for funding with voluntary sector (Positive Action) to Southampton City Council (SCC)
- Bid successful: £3,800 given by SCC
- Funding held by voluntary sector
- Multiagency team to plan activities
- F2B Evaluation from Summer Camp 2011
- 2012 Funding built in to Positive Action contract to provide peer support for young people accessing HIV care in Southampton



Go Ape



Evaluation

- The future
- Learn how to talk to others about HIV
- Discuss issues around disclosure of HIV status
- Only talked to doctor and nurse at clinic about HIV
- Meet other young people with HIV



Results

- Similar to F2B 2011 report
- Positive feedback: all enjoyed meeting and wanted to meet again
- Demonstrated high level of isolation



What next?



- Local meetings at Positive Action
- Group visits to Body & Soul
- Activity day ½ term
- Applications to CHIVA Summer Camp
- Young people becoming members Executive Youth Committee CHIVA
- Maintain what was started!

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Remote mentoring: Beyond boundaries pilot

- Opportunity for young people with HIV to speak to a trained mentor (HIV +ve) using Skype
- During clinic hours
- No set agenda or time limit for conversation
- All mentors have completed a 4 week training course in mentoring
- All mentees age ≥ 18 years
- Strict supervision measures in place to ensure safeguarding of patients
- Pilot to run for 12 months – August 2013 - July 2014

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Beyond boundaries pilot: rationale

- 1,117 HIV +ve 16-24 year olds (YPHIV) living outside London (HPA 2011)
- Statistically, YPHIV are:-
 - Less likely to have undetectable VL
 - More frequent hospitalised
 - More likely to miss clinic appointments
- Vulnerable group where positive interventions may improve health outcomes in adulthood



Beyond boundaries pilot

- Body and Soul have been providing face-to-face mentoring in London clinics since 2010
- Feedback from mentees and HYPNet survey
 - 69% of participants found it helped adherence
- But geographical inequality exists
- Pilot sites across the UK (outside London):-
 - Southampton, Nottingham, Leeds and Newcastle
 - Will recruit children ≥ 14 years
 - Informed consent from mentee (and parent if age < 16 years)
 - 1 year funding (Gilead)





Beyond boundaries pilot: evaluation

- Monitoring and evaluation embedded into the pilot
- Data collected from mentees, mentors and healthcare professionals
 - Health efficacy
 - Psychological wellbeing
- Is remote mentoring effective in meeting health outcomes and reducing costs?



Beyond boundaries pilot: evaluation

- Southampton and Leeds have piloted the project
- Logistical issues
 - Finding a clinic room for Skype conversation
 - Juggling bloods/clinic review/mentoring





Beyond boundaries pilot: patient feedback

- Mentoring was good – mentor told me about his experiences and how he dealt with HIV
- Mentor and I had to go through the pressures of not telling friends about not being positive and just keeping it in the family
- Mentoring has made a difference as I'm able to speak to someone my own age – it's like talking to a friend



Beyond boundaries pilot: patient feedback

- Getting to talk to different people that I don't know – getting the confidence
- At first was nervous but then felt OK
- She made me feel comfortable talking to her





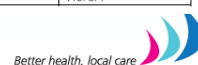
Beyond boundaries pilot: patient feedback

- I feel uncomfortable speaking to someone I haven't met before – I prefer to speak to them face to face. It's weird talking about myself to a stranger.
- Didn't find it useful, not made a difference
- Was fun speaking to mentor



HAD – Hospital Anxiety and Depression Form (Zigmond and Snaith 1983)
Please circle the one answer that best describes how you feel

A	I feel tense or wound-up	Not at all	From time to time, occasionally	A lot of the time	Most of the time
D	I still enjoy the things I used to enjoy	Definitely as much	Not quite so much	Only a little	Hardly at all
A	I get a sort of frightened feeling as if something awful is about to happen:	Not at all	A little, but it doesn't worry me	Yes, but not too badly	Very definitely and quite badly
D	I can laugh and see the funny side of things:	As much as I always could	Not quite so much now	Definitely not so much now	Not at All
A	Worrying thoughts go through my mind:	Only occasionally	From time to time, but not too often	A lot of the time	A great deal of the time
D	I feel cheerful:	Most of the time	Sometimes	Not Often	Not at all
A	I can sit at ease and feel relaxed:	Definitely	Usually	Not Often	Not at all
D	I feel as if I am slowed down:	Not at all	Sometimes	Very often	Nearly all the time
A	I get a sort of frightened feeling like 'butterflies' in the stomach:	Not at all	Occasionally	Quite Often	Very Often
D	I have lost interest in my appearance:	I take just as much care as ever	I may not take quite as much care	I don't take as much care as I should	Definitely
A	I feel restless as I have to be on the move:	Not at all	Not very much	Quite a lot	Very much indeed
D	I look forward with enjoyment to things:	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
A	I get sudden feelings of panic:	Not at all	Not very often	Quite often	Very often indeed
D	I can enjoy a good book or radio or TV programme:	Often	Sometimes	Not very often	Very Seldom
POINTS ALLOCATED FOR EACH ANSWER		0	1	2	3
Scoring (add the As = Anxiety. Add the Ds = Depression). The norms below will give you an idea of the level of Anxiety and Depression. 0-7 = Normal, 8-10 = Borderline abnormal, 11-21 = Abnormal					
Total Score for As:				Refer?	
Total Score for Ds:				Refer?	



Transition

- “a purposeful, planned process for adolescents with chronic physical & medical conditions as they move from child-centred to adult orientated health care.
- A process that addresses their
 - Medical needs
 - Psychosocial needs
 - Educational/vocational needs
- *Blum et al 1993*



What's important about Transition?

IDDM <i>Kipps et al 2002</i>	94 % attending opd in paediatric services 57% attending opd in adult services @ 2yrs
Congenital heart disease <i>Sommerville 1997</i>	70-80% reach adult life; Mean death 25.4yrs 1:5 premature/avoidable
Hydrocephalus <i>Tomlinson et al 1995</i>	FU 100% paediatrics 40% in adult services 95 pts; 13/95 died – <i>presumed secondary to shunt failure</i>



What do young people want?

- Start transition early
- Honest explanation of adolescent condition and associated health care
- Continuity in health personnel
- Opportunity to see health professional without parents
- Able to express opinions and be involved in decisions
- Address medical, psychosocial, educational/vocational needs
- Non-judgemental
- Correct information
- Confidentiality

CHIVA Conference Adolescent forum 2008[9]



Ready Steady Go: Transition Programme

Knowledge
Self advocacy
Health + lifestyle
Education/future
Psychosocial issues
Transition



www.uhs.nhs.uk/readysteadygo



Ready Steady Go: Transition Plan

Southamptons NHS University Hospitals

Transition plan

Name: _____ Hospital no: _____

Address: _____ DOB: _____

Transition start date: _____ School/college: _____

Home tel no: _____ Mobile no: _____

Email: _____

Diagnosis:

Target date for transfer adult services: _____

Discharge summary completed: _____ Date: _____

Transition booklet for young people: _____

Transition booklet for parent/carer: _____

Other (please specify): _____

Offer copy of this letter: _____ Date: _____

MDT involvement:

Health worker: _____

Social worker: _____

Psychologist: _____

Specialist nurse: _____

Dietsician: _____

Other: _____

Key worker: _____

Adult carer home contact: _____

Date of planned visit to adult unit: _____

www.suht.nhs.uk

Transition plan

(K) KNOWLEDGE

1. Describe condition, effects and prognosis
2. Understand medication purpose and effects
3. Understand treatment purpose and effects
4. Know how to use medication and their side

(S) SELF ADVOCACY

1. Understand how to speak up for their own
2. Know how to make appointments/other appointments
3. Understanding of confidentiality
4. Order repeat prescriptions
5. Take own complete responsibility for medication/other treatment
6. Know where to get help

(H) HEALTH AND LIFESTYLE

1. Understand importance of diet/dietary restriction
2. Understand impact of smoking/alcohol/substance use
3. Understand sexual health/contraception/STIs

(A) ACTIVITIES OF DAILY LIVING

1. Self care/meal preparation
2. Independent mobility
3. Transport/night sleep away from home
4. Budgeting

(V) VOCATIONAL

1. Current and future educational/employment of condition on career plan
2. School attendance and performance
3. Work experience and how to access career advice
4. Create CV and portfolio
5. Disclosure to school/college

(P) PSYCHOSOCIAL

1. Self awareness/confidence
2. Build self image
3. Peer relationship building
4. Support network/peer disclosure to friends
5. Coping strategies

(T) TRANSITION

1. Understand concept of transition
2. Agree transition plan
3. Attend transition clinic
4. Make adult unit of appointment
5. Have GP involvement

Ready: _____ Date: _____ Signature: _____

Steady: _____ Date: _____ Signature: _____

Go: _____ Date: _____ Signature: _____

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Ready Steady Go: Making it happen

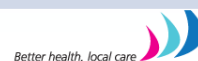
- Ready Steady Go (RSG) documentation
- Information campaign
- Young persons clinic weeks 4 x year
 - Promotes transition
 - MDT, patients and parents
 - Share resources
 - Young person friendly environment



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Ready Steady Go: Snapshot Feedback

Questions	Responses
The "Transition: moving into adult care" helped patients + family understand why they are starting RSG	93/93 agree
The questionnaires were easy to understand	93/93 strongly agree/agree
RSG questionnaires helped focus clinic appt + address difficult issues	90/93 agree
RSG helps ease the process of transition	93/93 strongly agree/agree
RSG improved my practice	21/22
Any questions that would help improve transition? Comments?	All – No Time issues Relevance of some questions especially in patients with learning disabilities



Ready Steady Go: Summary

- A generic programme that works across sub-specialities
- Shifting emphasis to empowering the young person
- **RSG** succeeds because:
 - The staged 'traffic light system' is appealing, it's simple to use, easy to implement and has minimal cost
- **RSG-Hello** continuity from paediatrics to adults
- Contact: Dr Arvind Nagra (Consultant Paediatric nephrologist and Lead for Transitional Care: arvind.nagra@uhs.nhs.uk)



References

- Dodds, C., 2011. *Freedom To Be (F2B) summer camp: outcome evaluation*. Sigma Research: London.