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Mortality amongst HIV-infected young people following transition to adult care: an HIV Young Persons Network (HYPNet) audit.

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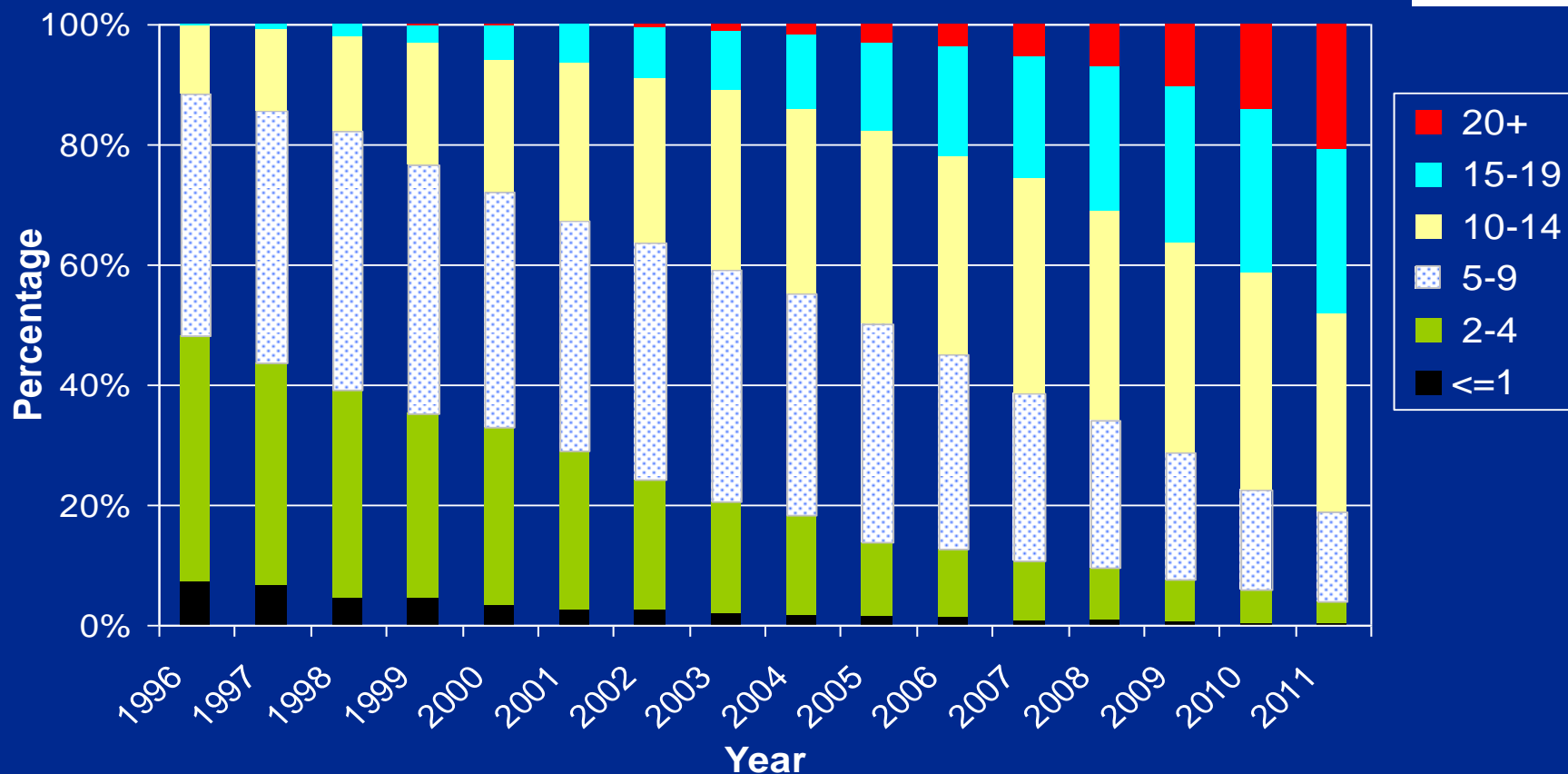
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Background

- Increasing numbers of young adults transitioning from paediatric to adult care - outcomes unreported in the UK
- Annual prospective follow up in paediatric care in UK/Ireland in CHIPS cohort ceases at transfer to adult care
- By March 2011 CHIPS cohort: 305/1603 were in adult care

Age* of children including those transferred to adult care by year, 1996-2011



N 357 413 492 557 654 756 866 1001 1116 1219 1317 1400 1451 1475 1446 1284

*Age is taken to be age at start of the year, or age at presentation if child presented during that year.
 Note: Data are for all children and young people in CHIPS (excluding those who have died or who are lost to follow-up) as well as young people in CHIPS who have transferred to adult care (assuming no deaths or losses to follow-up in adult care).

Methods



- A proforma disseminated via HYPNet to 15 participating adult HIV/voluntary sector services
- Identified cause of death and factors associated with mortality, including adherence, co-morbidity and mental health.
- Retrospective reporting of deaths in childhood acquired HIV up to 30.09.11
- Deaths were matched to the CHIPS database to ascertain clinical profile at transfer to adult care

Results

- 11 deaths reported Sept 2003 - March 2011
- 9 black African, 6 female, 9 born abroad
- median age at transfer: 17 yrs (range 15-21)
- median age at death: 21 yrs (range 17-24)
- Causes of death:
 - suicide (2)
 - end stage AIDS (3)
 - respiratory infections (2)
 - PML (1)
 - cerebral lymphoma (1)
 - ICH cerebral toxoplasmosis (1)
 - missing (1)

Results -VL/CD4



Death: CD4 median 27 cells/ul (range 0-630), 9/11 CD4 <200
2 had VL<50; suicide CD4 630, LRTI bronchiectasis CD4 270

Transition: CD4 median 120 cells/ul (range 0-651),
7/11 with CD4 <200, 2 had VL<50.

Resistance: 8/11 had any ART resistance
1 with triple class, two 4 class resistance
however all had potentially suppressive regimens available.

Adherence

- 9/11 had a history of poor adherence in paediatrics, 4/11 ever achieved VL<50 in adult care
- All those with poor adherence were offered multiple modes of support including: specialist and community nurses, health advisors, psychology
- 3 had gastrostomies to aid adherence
- 9/11 attended peer support.

Psychosocial

- Psychiatric Diagnoses: Depression (6), Psychosis (2) eating disorder (1)
- 4 lived with parents, 3 fostered/adopted, 4 lived alone.
- 6 in education, 1 employed, 4 unemployed.
- 6 ever involved with social services: 2 youth offending
- Drug use (4) never smoked (6) sexually active (6)

Results - Statistics

Mortality rates by age group (per 100 person years) from 2006-10*

Age	Person years	Deaths	Mortality rate /100 person yrs (95% CI)
<17	1746	5	0.29 (0.12 - 0.69)
>17	1253	8*	0.64 (0.32 – 1.28)

Poisson regression analysis

Age (years)	n	Mortality rate /100 person yrs (95% CI)	IRR	95% CI
13-15	3	0.22 (0.07-0.67)	1.0	
16-20 pre transition	2	0.30 (0.07-1.22)	1.39	0.21-8.3
16-20 post transition	4	0.63 (0.24-1.67)	2.87	0.64-12.8
21+	4	1.2 (0.45-3.2)	5.49	1.2-24.5

Conclusion

- Small number of deaths from selected clinics (15/~45)
- Due to AIDS diseases of adult populations
- Associated with poor adherence in paediatric care
- High burden of mental health disorders

Planning

- UK Register of HIV Seroconverters
- Flagged to ONS/NHS Information Centre mortality data
- AALPHI - Adolescent and Adults Living with Perinatal HIV Cohort
- Novel adherence interventions - P85, P225

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