

Psychosocial complexity and limited preparation for transition to adult services for young people living with Type-1 Diabetes results in care fragmentation: a multi-method study

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INTRODUCTION:

Young people living with Type 1 Diabetes (T1D) must transition from paediatric to adult health care.

Transition is often associated with sub-optimal glycaemic control as young people learn to engage with a new team of clinicians and take greater independent responsibility for managing their T1D.

There are excellent examples of integrated models of care focussed on successful transition and the provision of care in age-appropriate young adult clinics (1,2,3). However, international evidence suggests that young people encounter many barriers:

- ❖ limited preparation
- ❖ unclear referral pathways
- ❖ limited age-appropriate services in the adult sector
- ❖ limited age-appropriate health information (3).

AIMS:

To understand the experiences of Australian young people living with T1D and transitioning to adult health services including the following:

1. Preparation for transition and increasing independence
2. Level of care continuity during transition
3. Psychosocial support needs at the time of transition

METHODS:

We conducted a multi-methods study to understand the experiences of young people transitioning from paediatric to adult health care services across Australia according to a published protocol (4). Our methods included the following:

1. **A national survey** of young people with T1D transitioning to adult services.
126 participants; 86F/39M; aged 15-18 years;
32 (25%) regional/rural areas; six Australian states
2. **Interviews with 15 young people** who had transitioned to adult services.
15 young people; 10M/5F; 5 Australian states; 2 in rural areas
3. **Survey of 32 clinical services leaders.**
All Australian states and territories represented: 16 metro; 16 regional
4. **Interviews with 7 clinical service leaders.**
4 Australian states represented; 2 from regional services

RESULTS:

1. Preparation for transition (Services N=32)

- 50% of services routinely assessed readiness for transition
- 50% had a structured pathway for transition
- 30% has used transition plans

2. Preparation for Transition (Young people N=126)

- 23% felt well prepared for transition
- 8% said transition had never been mentioned
- 24% had a written transition plan
- 47% “very involved” in discussions about their healthcare after transition compared with (38%) before transition (P<0.01)

3. Care continuity and communication: Three of the 7 services leaders interviewed, said that they routinely followed-up with adult colleagues about the young person’s engagement with the adult clinic.

CONCLUSIONS:

- Need to improve care continuity through greater integration of paediatric and adult health services
- Structured, integrated inter-disciplinary models of care have been implemented and provide services through Adolescent and Young Adult clinics in age-appropriate environments – greater adoption and scaling-up is needed
- Embedding routine psychological support into T1D care models is a priority

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Seven principles for successful transition to adult care

PRINCIPLE 1  A formal transition process	PRINCIPLE 2  Early preparation	PRINCIPLE 3  Empower, encourage and enable young people to self-manage
PRINCIPLE 4  Identify a local transition coordinator or facilitator	PRINCIPLE 5  Good communication and shared responsibility	PRINCIPLE 6  Individual transition plan
	PRINCIPLE 7  Follow-up and evaluation	NSW Health Agency for Clinical Innovation (ACI)

RESULTS:



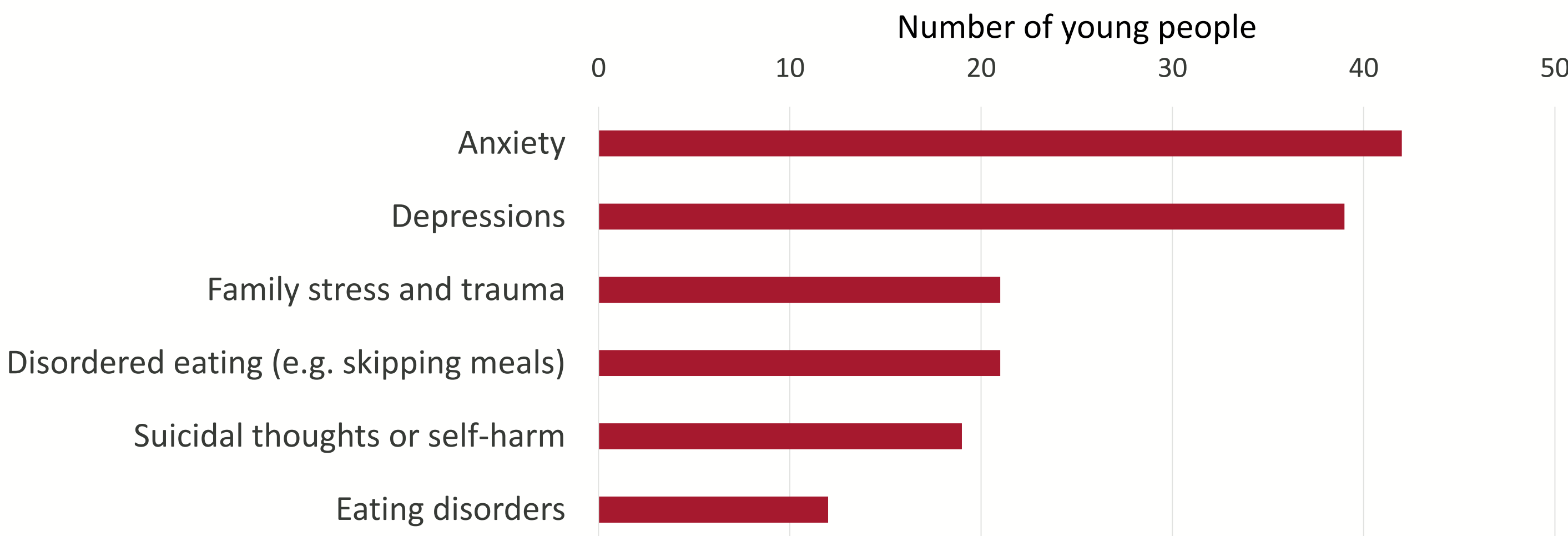
"I just want a bit more certainty... I just want to know that every time I go to my appointment [in the adult clinic], I will have an appointment." (T2)

"I found like it was really inconsistent when I was going through like the public system when I was going to the hospital because I kept getting a different doctor [in the adult clinic]. That's kind of why, like, I wanna stay with one doctor or one team." (T8)

"Umm and basically a doctor came in and was telling me that I shouldn't be eating as much as I am and that, yeah, and that I should only be eating strictly 3 meals a day. No snacks in between and limited and, and I was like, whoa! And my dad actually, like, yelled at him. Like, why would you say that to a teenage girl?" (T10)

Psychological issues identified by young people and services available

Psychological issues for which young people accessed services N=48 (38%)



Nine (28%) of services had access to a psychologist in their clinic
Health professionals young people accessed:

- Psychologists (28; 22%)
- Social workers/councillors (28; 22%)
- GPs (25; 20%)
- Psychiatrists (18; 14%)

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