Type 1 diabetes and adolescence: An exploration of lived experiences

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The problem of T1D in adolescence

- Type 1 diabetes (T1D) is the third most common chronic disease in childhood
- Absolute lack of insulin in the body
- Self-management: insulin injections, blood glucose self-monitoring, diet, exercise
- Aim: HbA$_{1c}$ of <7.5% to reduce the risk of complications in later life (damage to eyesight, nerves, kidneys, cardiovascular system) (DCCT, 1993)
- Evidence of deteriorating metabolic control in adolescence
  - e.g. Only 15% of under-15’s with T1D in the UK were maintaining the recommended HbA$_{1c}$ levels of 7.5% (Diabetes UK, 2005)
Literature review

- Biopsychosocial determinants of blood glucose control
  - Hormone imbalances during puberty
  - Psychological disorders
  - ‘Adolescence’
  - Psychological theories of identity development
  - Personal models of illness
  - Psychological stress in parents
  - Family relationships
  - Theories of family adaptation and coping with chronic illness
  - Systematic reviews: finger-stick blood testing not beneficial to HbA$_{1c}$ (Chetty; Golicki, 2008)
Systematic review


Findings

- Teenagers’ abilities to be independent in diabetes management are embedded within relationships with parents, peers, health professionals and teachers
- Need for rigorous qualitative research in the UK, underpinned by epistemological tradition and novel theoretical frameworks
- Need to explore both parents’ and adolescents’ perspectives
Theoretical background: Complexity science

- The world is a network of **COMPLEX ADAPTIVE SYSTEMS**
- Criticism of reductionist scientific model: unpredictable outcomes (eg. weather patterns, biochemical reactions, human organisations)
- Multiple interacting elements (connectivity)
- Complex systems move between states of DISORDER and ORDER to adapt and survive within their environment
- Difference between ‘complicated’ and ‘complex’

**Behaviour of a complex system** (adapted from Mitleton-Kelly, 2003)

- FAR-FROM-EQUILIBRIUM
- EXPLORE SPACE OF POSSIBILITIES
- POSITIVE FEEDBACK
- SELF-ORGANISATION
- CONNECTIVITY
- EMERGENCE
- CO-EVOLUTION
- SPACE OF POSSIBILITIES
- NEGATIVE FEEDBACK

ESSENTIAL FOR ADAPTATION AND FITNESS OF THE SYSTEM
Complexity science and diabetes

- Human illness and behaviour are NOT PREDICTABLE
- Neither can be modelled in a simple cause and effect system

This is recognised in biopsychosocial approach to chronic illness management.
However, the biomedical model constrains the implementation of this approach to diabetes care.

Adolescent diabetes management as a complex system

Blood glucose tests

Blood Glucose

Friends

Family

Independence & autonomy

Puberty

Lifestyle

School

Body image

Health & illness

Insulin

Exercise

Diet

Emotions

Alcohol

Adolescent diabetes management as a complex system
Criticisms of complexity science

- Purely metaphorical
- Yet to be integrated:
  - (i) as a basis for empirical qualitative research (Kovandzic & Cooper, 2009)
  - (ii) for the study of diabetes in adolescence
- In need of assimilation and validation by academic philosophy (Heyleighen, 2007) and empirical evidence (Fuller & Moran, 2000)
- Need for an underpinning epistemological approach to ‘uncover’ the complexity of adolescent diabetes
Study aims

1) Explore the lived experiences of adolescents with T1D and their parents

2) Investigate the applicability of complexity science as a theoretical framework for understanding adolescent T1D management
Epistemology

Interpretive (hermeneutic) phenomenology to ‘access’ complexity

- Study of taken-for-granted lifeworld
- Knowledge is a product of interpretation, influenced by individual context and history (the lifeworld), and instrumented by language
- The researcher plays an active role in the research process and the formation of knowledge
  - Participants give meaning to their own experiences
  - Instrument this through language to the researcher
  - The researcher interprets their description based on their life experience
Methodology

**PARENT HERMENEUTIC INTERVIEWS**
*Function:* Context data (Family relationships)

**CASI DIARY TOOL**
*Function:* Context data (Self-management behaviour in relation to biomedical definitions of diabetes)

**ADOLESCENT HERMENEUTIC INTERVIEWS**
*Function:* Explore the lifeworlds of adolescents with Type 1 diabetes

**FOCUS GROUPS**
*Function:* Validation of the researcher’s interpretations of lived experiences situated in context

**BACKGROUND CLINIC DATA**
*Function:* Context data (Bio-medical definitions of diabetes)

Maximum variation sample:
- 20 adolescents aged 13-16 & their parents
- HbA1c, gender, age, duration of diabetes
Data analysis

1. Contact summary
2. Thematic analysis of adolescent interview focusing on individual experience
3. Thematic analysis of parent interview focusing on individual experience
4. Exploration of adolescent interview data in relation to context data (background, CASI and parent interview data)
5. Synthesis of adolescent, parent and context data
6. Data organisation: NVIVO
7. Extract final categories, themes and sub-themes
1. NORMALISATION
• Blood glucose control influenced by the level of normalisation of T1D within spatial environments
• Diagnosis disrupts family functioning and adaptation is necessary and meaningful within the family
• Barriers exist to self-management at school and in the social environment as T1D is not always meaningful to others
• Adolescents maintain invisibility of diabetes to facilitate social acceptance

2. EMBODIMENT
• T1D disrupts the taken-for-granted functioning of the body
• Redefinition of the self and identity to ‘fit’ new bodily existence
• Psychosocial adjustment problems in newly-diagnosed adolescents
• ‘Parental embodiment’ of a child’s diabetes when diagnosed at a young age can restrict independence in adolescence

3. LEARNING THROUGH EXPERIENCE
• Learning becomes meaningful through past experiences and future orientation
• Meaningful learning often occurs after serious events
• Education must be meaningful in relation to individual adolescents’ social worlds

4. RELATIONSHIPS WITH SIGNIFICANT OTHERS
• Family structure and relationships with peers, teachers and health professionals affect self-management and blood glucose control
• Positive communication with health professionals and parental support is instrumental for structured education, to support experiential learning
Conclusions

- Living with T1D in adolescence is an on-going process of adaptation, underpinned by social interactions within various environments; past experience and future orientation.

- These aspects make self-management behaviour meaningful.

- Complexity science provides a framework for understanding adolescent diabetes management:
  - Individuality
  - Order and disorder
  - Connectivity between the four lived experience themes
  - Living with T1D is an emergent process.
Blood glucose control is underpinned by complex interactions within the adolescent system and feedback from these.

Disruptions are a normal part of life - a system has to be pushed to its limits in order to change.

Adaptation to disruptions improves the overall fitness of a complex system, and therefore ‘mistakes’ are essential to the process of experiential learning.
Implications for practice

- Complexity science shifts the interpretation of the meaning of living with T1D from a developmental process with an end-point (ie. control), to an on-going journey of highs and lows underpinned by rich and individualised learning processes.

- Current ‘top down’ approach to education – no room for health professionals to acknowledge individual meanings.

- Need for **continuing needs-assessed education**.
Aim: to design a computerised, interactive tool created by young people (age 13-18) for young people, to assess individual learning needs with a view to promoting greater independence for diabetes self care
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