A qualitative investigation into the role of communication with healthcare professionals in promoting psychological well-being in adolescents with type 1 diabetes

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Field supervisor
The Service Context

- Research took place within a North–West paediatric diabetes team

- Research question jointly identified by myself and field supervisor who was the clinical psychologist within the team.

- Research idea followed conversation with service user around communication
Type 1 Diabetes

- Diabetes is a complex metabolic disorder whereby the individual has higher than normal blood glucose levels due to insufficient insulin being secreted by the pancreas.

- In type 1 diabetes (T1D), the pancreas secretes no insulin at all, and the condition is therefore managed by daily insulin replacement usually administered through injections or an insulin pump.

- There are approximately 31,500 children and young people with diabetes under the age of 19 in the UK, with the majority having a diagnosis of T1D (Diabetes UK, 2015).
Research is well established showing the impact of chronic illness (including diabetes) on adjustment in children and adolescents such as Lavigne and Faier–Routman (1992), whose meta–analytic review indicated children with chronic physical health conditions, are more likely to encounter behavioural and emotional difficulties. This finding seems to be robust and has since been reported in numerous studies (e.g. Blackman & Conaway, 2013).

Role of Communication

- Patient–centred communication, is associated with a greater sense of control in illness management and agreement on treatment goals (Heisler et al., 2003), enhanced glycaemic control (Atkins, Bingham & Piette, 2005) and reductions in blood glucose levels over a 12 month period (Williams, Freedman & Deci, 1998).

- Patient–centred communication specifically looks to build a collaborative partnership between healthcare provider and patient, looking to increase empathy, interpersonal sensitivity and mutual information exchange (Erickson, Gerstle & Feldstein, 2005).

- Adolescents perceptions of support from healthcare providers rated positively for adherence (Drotar, 2009).
Communication and Adolescents with T1D

- PCC shown to lead to increase perceptions of control and beliefs relating to competence (Croom et al., 2010)

- Adolescents shown to want more input into care plan. Furthermore communication harder if healthcare professional judged as judgemental, rushed and controlling (Davidson et al., 2004)

- Freeborn et al (2013) recommended professionals need to address emotional impact of T1D

- Lowes et al., (2015) positive communication can make clinic visits a rewarding experience. Often adolescents feel staff cannot understand what it is like to have T1D and couldn’t understand what they were going through. Emotions such as anger, frustration and sadness expressed, yet did not see clinic as source of emotional support
The BPS (2007) ‘New ways of working for applied psychologists in health and social care: Working psychologically in teams’ recommends psychologists should seek to integrate their work within teams, develop their roles and promote their unique contribution to their work with service users.

The National Institute of Health and Care Excellence guidance (NICE, 2015), National Service Frameworks (DoH, 2001) and the subsequent New Horizons framework (DoH, 2009) recognise the importance of promoting psychological well-being in children with chronic illness.

Kinderman, Schwannauer, Pontin and Tia (2010) suggest there has been a clear evolution in areas of mental health and social care toward enhancing well-being.
“What are adolescents’ experiences of communicating with the paediatric diabetes team and does this relate to psychological wellbeing?”

With the research aims being:
- (i) to explore adolescents’ experiences of communication with paediatric diabetes teams
- (ii) to consider the role of communication with healthcare professionals in promoting psychological well-being
- (iii) to understand how communication can be used to make young people feel confident to express their emotional responses to T1D.
Method

- Inductive thematic analysis (Braun & Clarke, 2006)
- Semi-structured interview
- 6 participants (3 male, 3 female) aged between 14 and 17
- Interviews audio recorded and transcribed
- Interview lasted between 34 and 64 minutes
- Epistemology
- Rigour and validity
Results

- Four main themes with subthemes

The Many Hats of Communication
- The Best Hat
  - Knowledge
  - Honesty
  - Reassuring
  - Praise
  - Collaborative
- The Worst Hat
  - Patronising
  - Authoritative
  - Directive
  - Lack of knowledge

"I live with it every day"
- Context is King
  - Understanding context of everyday life
  - I am more than my diabetes
- Personal matters
  - Importance of communicating personal issues

Adolescent experiences

The Evolving Relationship
- Relationship develops over time
- Easier to communicate openly
- Team know me
- Team know what I know

Invisible Power
- Guilt
- Pride
- Worry
- Motivation
Theme one: The many hats of communication

- Refers to the many facets of communication that participants reported when communicating to the team.

The best hat:
- “honesty is very important… both sides should be very open”
- “I think it’s quite important that you feel sort of praised and like the effort you are putting in is paying off when they are happy for you”
The worst hat:

- “It really bugs me if I’m being patronised because I’d like to think that I’m quite a mature person”

- “I don’t like people telling me what to do so I find it hard when they tell me what to do”

- “I think their approach should maybe, not change automatically, but they should ask you about, they should have input from you about how they should ... it’s probably important that the patient can dictate how the team speaks to them and what they speak to them about”
A strong sense of the value of the relationship between the participants and the paediatric diabetes team. There was a sense that it was easier to communicate to them about a range of issues:

“They understand everything what I have been through and how hard it has been, so it is really easier to talk to them…”

“I feel like I’ve got such a connection with them. Our relationship has developed so much I don’t want to have to go back to starting all over again because I might not like the people as such as I do now”
Theme three: “I Live With It Every Day”

- Strong sense of participants’ narratives around having to live with diabetes every day with their experiences something the team cannot fully understand.

- Participants spoke about the importance of the team understanding that they are more than their diagnosis (*context is king*) and the importance of communication around the personal issues affecting their well-being and this relating to their diabetes management (*personal ‘matters’*).
Context is King:

“Sometimes I feel it needs to be said like, this is how it is, it’s not just my first thought about my diabetes, my first thought might be getting changed from PE and then eating and like the time that I’ve got so. But yes its fine to say it and I don’t ever feel awkward”

Personal ‘matters’:

“It’s all about like how you’re actually doing with control but not with your emotions so I think just taking time out and being like how is everything would probably make a difference, it would make me feel at ease that I can just kind of tell them if I need to”
Within the analysis a strong sense of a power differential between the paediatric diabetes team and participant emerged, which often resulted in strong feelings being inadvertently elicited in the participants such as pride, guilt, doubt, pressure and feeling judged.

“When I first started they would ask me questions and I would feel like I was put on the spot and feel quite anxious about it because I wanted to get the right answer”

“They wouldn’t get angry but I would see the disappointment and I’d feel like I’d let them down... You feel really guilty”

“Knowing like the doctors are proud as well it like makes it feel better, and it makes me want to do it more”
Clinical Implications

- The results seem to tie with the concept of patient-centred communication, and importantly give some specific insight into the types of communication adolescents find helpful (the best hat) and what they find less helpful (the worst hat).

- The results also suggest an emphasis needs to be given on attempting to incorporate an understanding of the young person’s life context and personal issues into appointments.

- Role of the relationship emphasised—similar finding in therapeutic settings (Lambert & Barley 2001)

- How can clinical psychologists make the most of their skills within paediatric diabetes teams?
Role for team formulation?
◦ Team formulation can be defined as the process of facilitating a team of professionals to construct a shared understanding of a client’s difficulties (Johnstone, 2014). It may also be an effective way to shift MDT cultures toward more psychosocial perspectives (Division of Clinical Psychology, 2011).

Role for formulation skills training?
◦ Developing communication around the emotional impact of the condition rather than the implementation of large scale manualised communication interventions

How to manage power?
◦ Clinical supervision and peer supervision

Wider implications:
◦ Communication skills training
◦ Channon et al (2010) varying levels of communication skills training within paediatric diabetes teams

Peer support and staff well–being considerations
◦ Previous research showing impact of staff feeling burned out and disempowered (Gehring, Widmer, Bänziger & Marti, 2002).
SRP reflections

- Self care is important, be kind to yourself. Manage your time, plan ahead, navigate ethics but there will still be bumps in the road.

- During tough times I found it helpful to think about the meaning of the research and the time participants were willing to give you

- Immerse yourself in it—(in-line with self care values)

- Use the foot pedal!
References


