Supporting CYP with a 'High HbA1c'

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Knowledge

Are there gaps in knowledge? Ie. Carb counting, what HbA1c is, why testing important. Who has knowledge? Eg. Parent very knowledgeable but child has less understanding

Motivation

Does the young person/family see high HbA1c as a problem? What is their understanding of the number? Do they want to make changes or reduce their levels? How confident are they about making changes?

What do they see as obstacles to making change? Are they ambivalent about making changes?

School/Education/Peers

Are there issues at school impacting on diabetes? Eq. Exams, difficulties with school's understanding of diabetes, bullying, lack of understanding in peers, reluctance to inject at school or worries about managing hypos in school/exams. Are there difficulties at school with learning/behaviour?

What contributes to high HbA1c?

Safeguarding concerns

Are there concerns about levels of supervision of diabetes management? Other matters of concern in family eq. Domestic violence, neglect, abuse.

Medical **Factors**

Psychological Factors

Are there difficulties with low leading to avoidance (particularly anxiety about hypos)? Are there any concerns about misuse of insulin ie. Self-harm or controlling weight?

depressed/anxious? Is esteem? Did the family experience diagnosis as traumatic?

Factors Influencing a

High HbA1c

Social factors

Are there obstacles for the family aettina to appointments or prioritising diabetes? Eq. Housing, financial, ill health in other family members, employment

Developmental factors

Are they able to understand long term consequences? Are they becoming more independent and therefore more difficult to supervise? Is normal adolescent behaviour impacting on managing diabetes?

- -Diabetes 'burnout'
- -Fear of hypos
- -Negative life events
- -Frequent DNA's? Higher incidence of DNA in adolescents

Emotional/

mood, anxiety about diabetes

Is the parent diabetes impacting on self-

Factors within Family

Are there different view within the family on how to manage diabetes effectively, for instance between parents or between parent and child? Is there agreement about who takes responsibility for diabetes? Are parents struggling to hand over responsibility to young person or does young person feel they are having to take responsibility too soon?



Factors that affect Blood Glucose

FOOD

11

- ↑ ↑ 1 Carbohydrate quantity
- A 2 Carbohydrate type

 2 Carbohydrate type

 3 carbohydrate type

 4 carbohydrate type

 5 carbohydrate type

 5 carbohydrate type

 5 carbohydrate type

 6 carbohydrate type

 6 carbohydrate type

 6 carbohydrate type

 7 carbohydrate type

 8 carbohydrate type

 8 carbohydrate type

 9 carbohydrate type

 9
- → ↑ 3 Fat
- 4 Protein
- Caffeine
- Alcohol
- 7 Meal timing
 - 8 Dehydration
 - ? 9 Personal microbiome

MEDICATION



- → ↓ 10 Medication dose
- ◆ ↑ 11 Medication timing
- 12 Medication interactions
- ↑↑ 13 Steroid administration
 - 14 Niacin (Vitamin B3)

ACTIVITY



- → 4 15 Light exercise
- ◆ ↑ 16 High-intensity & moderate exercise
- → 4 17 Level of fitness/training
- 18 Time of day
- \$\ldot\ \frac{\pha}{\pha} \quad 19 \quad \text{Food and insulin timing}

The arrows show the general effect these 42 factors seem to have on blood glucose based on scientific research and/or our experiences at disTribe. However, not every individual will respond in the same way, so the best way to see how a factor affects you is through your own data: check your blood glucose more often with a meter or wear a GGM and look for patterns.

BIOLOGICAL



- 20 Too little sleep
- ♠ 21 Stress and illness
- 22 Recent hypoglycemia
- → ↑ 23 During-sleep blood sugars
 - 24 Dawn phenomenon
 - 25 Infusion set issues
 - ♠ 26 Scar tissue / lipodystrophy
- 4 4 27 Intramuscular insulin delivery
 - 28 Allergies
 - 29 A higher BG level (glucotoxicity)
- \$\ldot\ \frac{\pha}{\pha} \quad 30 \quad Periods (menstruation)
- ↑↑ 31 Puberty
- ◆ ↑ 32 Celiac disease
 - 33 Smoking

ENVIRONMENTAL



- ↑ 34 Expired insulin
- 4 4 35 Inaccurate BG reading
- \$\ldot\ \frac{\pha}{\pha} \quad 36 \quad \text{Outside temperature} \]
 - 37 Sunburn
 - ? 38 Altitude

BEHAVIOR & DECISIONS

- 39 More frequent BG checks
- 4 40 Default options and choices
- → ↑ 41 Decision-making biases
- 42 Family and social pressures



How does it make everyone feel? And what does that have us doing?

Young person: numb, angry, frustrated, low, scared

Parent/s carer/s: frustrated, angry, scared, embarrassed

MDT: frustrated, worried for YP & professionally, helpless

Psychologist: frustrated, worried, helpless

Psychology's role?

- * Variations across teams dependent on psychology time, focus and interests of team.
 - Individual appointments with YP
 - * Supporting MDT
 - Developing pathways and paperwork
- * E.g. Stepping Hill: High HBA1c pathway extra nursing clinics, referral from team to psychology, consultation to team.
- * Tameside: High HbA1c 'tool' (based on MI principles), focus on trying to gain holistic view of why sugars are high and patient-centred decision re: what support they'd find helpful (in theory!!)
- * South Manchester: recently started psychology-led clinics to provide initial assessment (Solution Focussed booklet)

What's the evidence that Psychology input is effective?

- * 2016 systematic review of interventions to improve outcomes for YP with T1. Concludes the effectiveness of interventions on clinical, behavioural and psychosocial outcomes among young adults is inconclusive. Evidence for the role of structured transition programmes.
- * 2020 systematic review of psychological interventions to improve glycaemic control no significant improvements found in 18 studies reviewed.
- * Diabetes UK 2010 document –Emotional and Psychological Support and Care in Diabetes Report MI & CBT improved HBA1c.
- * Motivational interviewing seems to be most researched evidence when used by trained prof can improve glycaemic control (Channon SJ et al. 2007)
- * Dr Mann Sunderland's audit of their pathway (2015-17) fortnightly contact, clinic every 6 weeks. 62% of patients improved within 6 months to come off pathway (HBA1c <69) Essential factors early contacts with team and access to Psychology (18% of data set received Psych).

What works?

- * Evidence for the role of structured transition programmes (multiple refs Pyatak EA et al , 2017)
- * Language matters (2018)
- * Motivational interviewing(Channon SJ et al, 2007)
- * Solution focussed approaches Ormskirk model
- * Parental support focus on parental transfer of self management (Trudeau,B et al, 2019), using language that is collaborative and engaging
- * Persuasion and confrontation regarding risks of nonadherence was associated with poorer glycemic control and adherence (Caccavale LJ et al, 2019)

Ideas for discussion

- * How do your teams support CYP and families with high HbA1cs?
 - * How do you get involved?
 - * What terminology gets used?
- * Have you found things that 'work'?
 - * Anecdotally?
 - * Research?
 - * Magic wand?!
- * Do you notice pushes/pulls from the different feelings in the system? How have you managed these?

References

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