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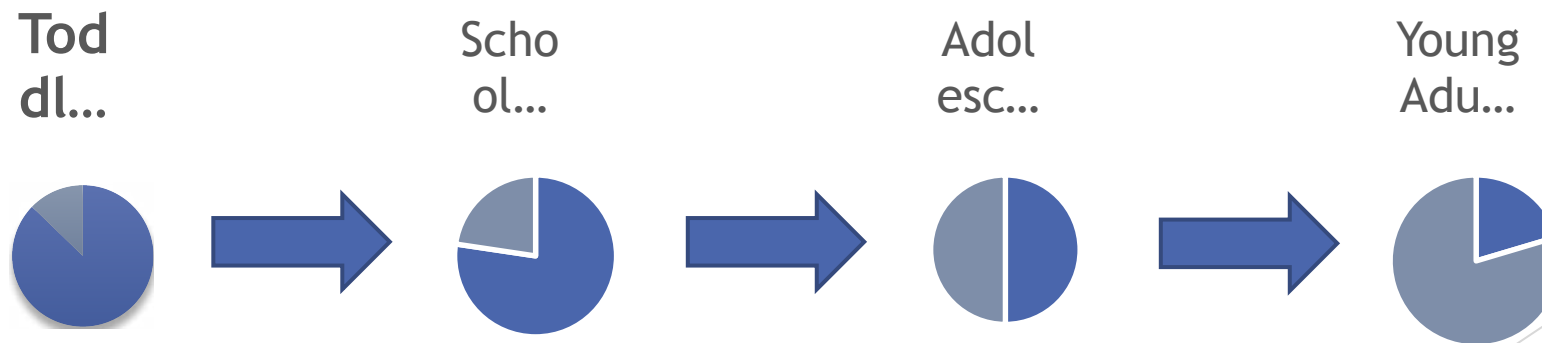
No More Diabetes Police: Allowing for Independence in T1D Youth

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What do we know about Youth with T1D + our Families

- *Social support from parents + other family members is critical for managing T1D in youth (1)*
- *Levels of diabetes specific family support are inversely related to age + developmental stage (2):*



1. ISPAD Clinical Practice consensus Guidelines 2018: Psychological Care of Children and Adolescents with Type 1 Diabetes.
2. Markowitz, J. et al (2015): Developmental Changes in the Roles of Patients + Families with T1D.

What do we know about Youth with T1D + our Families

- *Shared responsibilities for diabetes tasks is associated with (1):*
 - *Better metabolic outcomes*
 - *Improved adolescent psychological health*
 - *Improved self care*

- *Adolescents with good adherence describe interactions = open + empathetic (2)*

- *Adolescents with poor adherence described interactions = emotionally charged + confrontational (2)*

1. Markowitz, J. et al (2015): Developmental Changes in the Roles of Patients + Families with T1D.

2. La Greca AM. et (1995): I get by with a little help from my family and friends: adolescent support for diabetes care.

“The Diabetes Police”

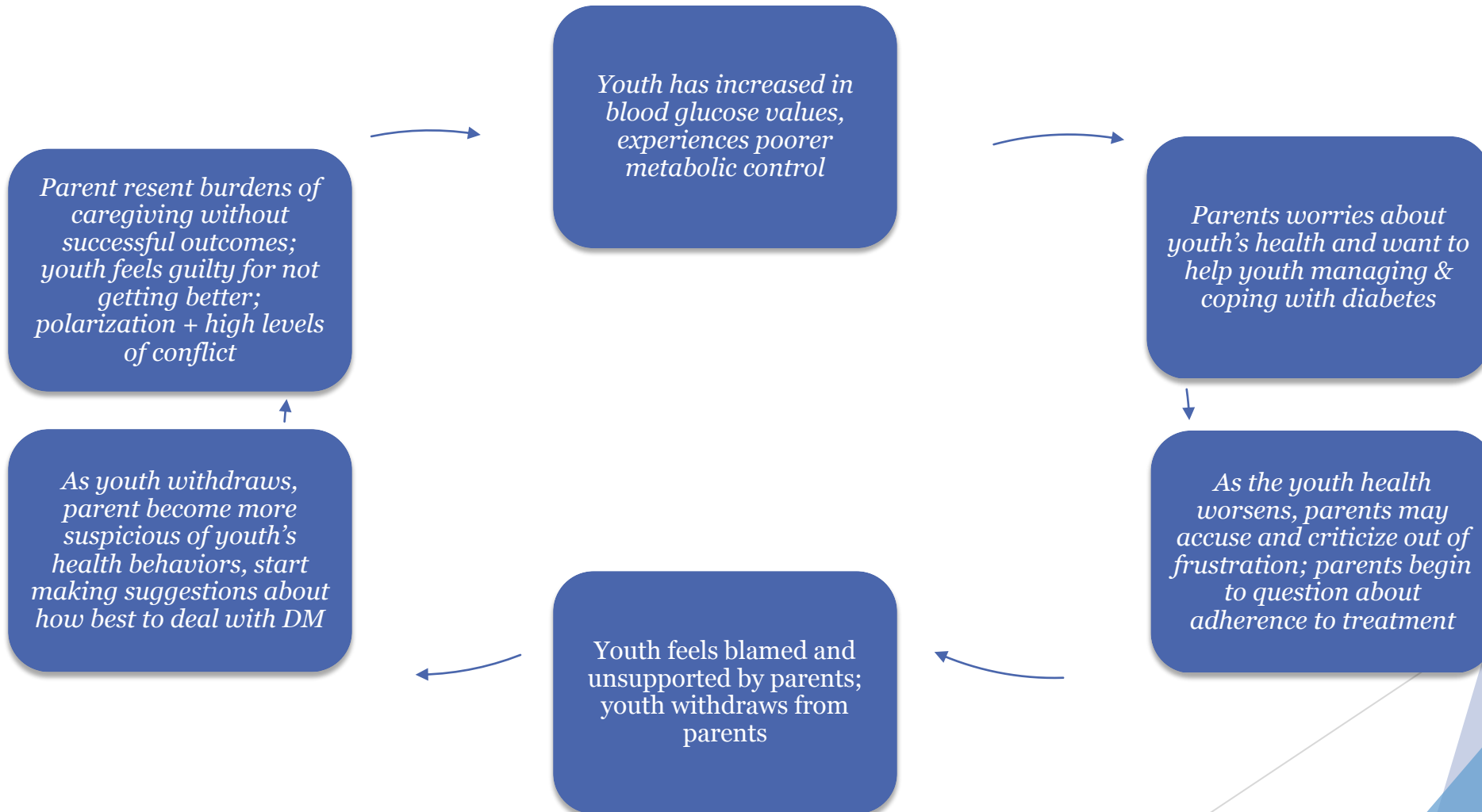


“The Diabetes Police” / Miscarried Helping: What is it?

- *Well intentioned attempts by parents or caregivers to support youth with T1D may result in family conflict, poorer health behaviours and poorer health outcomes (1, 2)*
- *Often associated with over-involvement where the parent is focused on authority vs. autonomy (2)*
- *Can result in both parent + child being stressed out and overwhelmed (3)*

1. Anderson, B. J., & Coyne, J. C. (1991). "Miscarried helping" in the families of children and adolescents with chronic diseases.
2. Cameron, FJ et al. (2008). Are family factors universally related to metabolic outcomes in adolescents with T1D.
3. Harris, M.A; Hood, K.K.; & Benchell, J.W. (2014) Teen with Diabetes: A Clinician's Guide

“The Diabetes Police” / Miscarried Helping: How Does It Happen?



“The Diabetes Police” / Miscarried Helping: What I want you to know

- *It comes from a place of love + concern // wanting the best for your child + Health Care Professionals do this too!*
- *The T1D exchange found that 2/3 adolescents age (13-18) had elevated HbA1Cs, meaning that a lot of teenagers have a hard time managing their diabetes*
- *Adolescents*

1. Anderson, B. J., & Coyne, J. C. (1991). "Miscarried helping" in the families of children and adolescents with chronic diseases.
2. Cameron, FJ et al. (2008). Are family factors universally related to metabolic outcomes in adolescents with T1D.
3. Harris, M.A; Hood, K.K.; & Benchell, J.W. (2014) Teen with Diabetes: A Clinician's Guide

“The Diabetes Police” / Miscarried Helping: What is a parent to do?



How Do T1D Youth Deal With “The Diabetes Police”?

- *Stop doing diabetes related things*
 - *Stop checking blood sugars*
 - *Stop giving insulin boluses*

- *Pretend they haven't stopped*
 - *Make up blood sugars readings*
 - *Lose meters*
 - *Say they have given a bolus when they haven't*

Clues that your child is facing the “The Diabetes Police”

- *T1D Youth’s Blood sugars:*
 - *Are all in range and taken at the exact same time*
 - *Don’t match the HbA1C*

- *T1D Youth’s Diabetes Related Behaviours*
 - *Not willing to check sugars or give insulin in front of parent*
 - *Does not want to talk about diabetes*

Autonomy in T1D

- *Responsible Independence (1)*
 - *Independent Decision Making vs. Independent functioning*
 - *Recognize that autonomy for normative developmental tasks are different than T1D tasks*
 - *Establish clear roles and boundaries.*
 - *Example: Negotiate a family meeting time once or twice a week to review diabetes related tasks. Then and only then talk about T1D.*



Autonomy in T1D

- *Responsible Independence (1)*
 - *Negotiate a family meeting time once or twice a week to review diabetes related tasks.*
 - *Then and only then talk about T1D.*
 - *How are you vs What was your number?*



Strategies to Encourage “Responsible Independence” During the Family Meeting

- *Diabetes CPR (1):*
 - *C for Communicate*
 - *P for Problem Solve*
 - *R for Realistic Diabetes Goals*

Strategies to Encourage Responsible Independence During the Family Meeting

□ Diabetes CPR (1):

□ *C for Communicate*

- *What is going well?*
- *What is going right?*
- *Focus on strengths*

□ Practical Strategies:

- *Listen to your tween or teen*
- *Compliment: face to face or “overheard” or text*
- *Turn statements into questions – get curious*
- *Balance your worry thoughts with actionable items*
- *3 to 1 Rule*

Strategies to Encourage Responsible Independence During the Family Meeting

- Diabetes CPR (1):
 - *P for Problem Solving*
 - *What are your family's challenges with T1D?*
 - *What can you change? //*
 - *what is in your control / vs not in your control*
 - *Negotiate to create a solution together*
 - Practical Strategies:
 - *Focus on one issue at a time*
 - *Use "I" statements + avoid accusations*
 - *Establish clear roles + boundaries*

Strategies to Encourage Responsible Independence During the Family Meeting

□ Diabetes CPR (1):

□ *R for Realistic Diabetes Goals*

□ *Recognize not all BGs are explained or controlled*

□ *Parents are not 100% responsible for things*

□ *Perfect is not achievable*

□ *Reward the behaviour, not the number*

□ *Remember sustained effort in management is the goal*

□ Practical Strategies:

□ *Change definition of “success” together*

“The Diabetes Police”: How can parents prevent family conflict?

- *Recognize that most T1D’s know have the same concerns as you. If you are feelings angry/frustrated/worried, how must your T1D youth feel?*
- *Have different expectations of normative developmental tasks vs. diabetes related-tasks*
- *Seek support. Have an outlet for your own worries + concerns*

Comments & Questions?