

HOME IS A TENT AND OTHER BARRIERS-A SIX YEAR OLD ADMITTED TO HOSPITAL WITH NEW ONSET DIABETES- COULD WE, WOULD WE AND WHAT WOULD WE DO DIFFERENT

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Conflict of Interest Disclosure

I have no conflict of interest related to the
content of this presentation.

Objectives

- Identify techniques to address barriers in diabetes treatment plan.
- Discuss what constitutes a safe environment for a child with diabetes
- Explore professional judgements in working with families in a challenging home environment.

Missoula Montana

- Montana – population 1.06 million (45th in US)
- Montana – 147,000 square miles (4th in US)
- Montana - population density 6.8 per square mile (48th in US)
- Missoula – population 72,072 thousand (second largest city in state)
- Missoula sits at the convergence of 5 mountain ranges and 3 rivers
- Pediatric Endocrinologist – satellite Specialty Clinic

Day 1 (Wednesday) Hospitalist (a)

- The patient presents with chief complaint of **difficulty breathing**. A.C. is an almost 7 year old with asthma who has been noted to be fatigued with polyuria for 3 days, also noted today to have more labored breathing. His breathing improved so he was **sent to school**. **Due to concerns about a constellation of above symptoms by school nurse he was taken to ED**. Here workup demonstrated acidosis and likely diagnosis of **T1DM with DKA**.
- **Social History**: A.C. *lives with mom and dad in a tent since 5/2014*. Mom states that they were evicted from home, rather than management company removing mold, and since then, they have been living in a tent though slept in a motel last night so they could shower. Tent location was not able to be well described. A.C. is in 1st grade and **received Comprehensive School and Community Treatment (CSCT) as well as counseling due to home stressors per mom**. They have plans to move to another town soon to **“get a fresh start”**. Parents have other children who do not live with them.

Day 2: (Thursday) Hospitalist (b)

- Per parents, pt. seems a lot better. They are excited that he is able to eat this morning and that he has improved. **Mom states that the patient has been living with them only X 4 days or so, but prior to that was with grandmother**. When she is asked whether grandmother should receive DM teaching, A.C.'s mom states that he will no longer live with her. **This was a temporary guardianship they needed to do to get custody back**. They all live in a tent throughout the summer, with occasional hotel stays so they can shower.
- Family homeless, will consult SW and see if any temp housing available. **Need to review barriers to med administration with family tent camping, no running water or refrigeration**. Mom says they can borrow a car.

Day 2- (Thursday) Social Worker(a)

- **Housing:** Parents reside in tent and have since 2014. *They sent pt. to live with his maternal great grandmother for the winter and the reunification with parents was 6 days ago.* They have coolers and a lock for tent. They will be moving the tent to East Missoula near hotel where friend resides. They do not have concerns about tent safety, or their ability to keep medication and testing supplies safe. *They are bared to public housing, Family Promise and other housing resources due to past situations.* They are not interested in shelter or housing opportunities. They have their needs met with their 8 person tent. They may move to Great Falls, there is a family shelter they are considering for next winter and dad has employment opportunities.
- **Transportation:** Parents have motorcycle, access to 3 cars they can borrow and use free city bus.
- **Communication:** They have a cell phone which is always connected. Aware of being in available for regular communication with provider. Receive mail through MGGM house.

Day 2 – (Thursday) Social Worker (a)

- **Insurance/RX:** Pt. insured by Medicaid. They have access to refrigerator.
- **Family support:** Pt's. MGGM is involved but is 83. Parents do not want to burden her with any diabetes education at this time. They do identify some friends who help them. CPS is not currently involved. Pts. **3 older siblings all reside elsewhere.** Parents identify one person at CPS they trust.
- **Food:** The family eats meals at Poverello Center as well as food stamps and using the food bank. They do not anticipate having major problems to obtaining food and will contact SW if needs arise.
- **Parental Status:** *Parents appear to be loving and supportive. Mom identifies herself as having bipolar, anxiety, depression and chronic pain.* Mom has a case manager at mental health. She is prescribed valium, Adderall and Depakote, which she doesn't take. *Discussed at length the need for her to manage her mental health and encouraged her to have regular contact with case manager.* Now with A.C. diabetes it is understood they have a lot of changes and stressors

Day 3 (Friday) Hospitalist (b)

- Learned DM skills from CDE and feel they did well.
- Met with SW for assessment
- Correction, I:C ratio and Lantus increased due to escalating glucoses yesterday
- Parents are glad A.C. are feeling better but report feeling overwhelmed with information. RD met this morning and parents each had difficulty with some carb counting.
- Parents administering insulin but A.C. is having difficulty with shots, especially when his mother give them he tends to cry.

Day 3 (Friday) Hospitalist (b)

- Social
 - *Family homeless, SW involved, it seems temp housing not available*
 - *Family seems to have secure place for medications, reliable food source, cell phones*
 - *Mom says they can borrow a car to get to follow up*
 - *SW feels no indications for CPS referral currently but would need to keep all medical follow up and manage DM care reasonable well otherwise may need to involve CPS*
- Disposition
 - *Home once education and follow up plan complete, likely Sunday depending on skill learned, parents must be completely independent with insulin administration and carb counting.*

Day 3 (Friday) CDE (b)

- Parents asking appropriate questions. They do not have access to Wifi so cannot use internet applications.
- Reviewed dosing using typical meal for both carbohydrate ratio and correction. School Diabetes Plan Completed. Prescriptions should be written today so family can obtain before discharge. Discussed strategies for storage of insulin. Follow up and contact information discussed.
- ***Parents need reinforcement of calculating doses of insulin. Insulin supplies should be "on" patient before discharge.***
- ***Parents should look at food tray and use resources in Pediatric Education Notebook to estimate carbs and then determine dose.***
- Close follow up after discharge.

Day 4 (Saturday) Hospitalist (a)

- ***Parents able to do basic carb count***, but parents feel that they struggle at times. A.C. cried with his injection, but otherwise doing well. ***Mom is tearful at bedside because "nobody knows how hard it is to do this all in a tent"***. They have not found a place to put their tent in the East Missoula area yet. They also have yet to pick up prescriptions at Wal-Mart.
- Disposition
 - *Home once education and follow up plan complete, likely Sunday or Monday depending on skills learned, parents completely independent with insulin administration.*

Day 4- (Saturday) Social Worker (b)

- SW has provided parents with **3 meal vouchers on a one time basis. RN to arrange for parent tray for special circumstances.**
- SW requested by Hospitalist to meet with family d/t concerns for dc plan. Family stated they have no need/worries for dc. Pt.'s mom seemed very shut off and questioned SW as to why SW was in room. **At the beginning of the conversation A.C.'s mom quickly became very escalated in behaviors and language stating that "no one cares if my kid dies".** SW offered packet with list of resources but refused, reporting that they had **'tried them all', and none of them cared or worked.** Pt. 's dad stated that they were already aware of all available resources. **Packet of resources was left in the room.**

Day 4 (Saturday-6 AM) Nursing

- **Education need reviewed Mother very frustrated with test strips and testing of blood, frustrated she has to do everything.**
- Came back later and A.C. eating Goldfish and yogurt brought in by grandmother. Explained could have this but need to count carbs and give an injection to cover insulin. Mother frustrated and took food away. Mom does not want another shot for child, but appeared to understand reasoning.
- Father restated no food in between meals, yelling at Grandmother for giving child Goldfish.

Day 4 (Saturday-7 PM) Nursing

- **Mother emotions continue to escalate at interval very tearful and appears upset. Stating we can't help her and her kid may die.**
Explained again the forms to be filled out to try for housing. Father stated they have filled them out 5 times and no one will help them or give them a chance due to their past history.
- Social worker up to visit with parents, parents upset and yelling at SW stating they have filled out forms before and have sat with people. Stating everyone listens to their story with judgment. **Security called, parents yelling at each other.** Mother of child wanting father to make some decision, questioning rationale conversation between parents. Both parents calming down.

Day 5 (Sunday- 6 AM) Nursing

- **Parents in room with voices raised. Attempted to have parents figure out carb count on tray. Mom had no idea where to go to do that,** they can't download any apps on phone, when asked by this nurse how to look on box of cereal for carb count and **became frustrated and stated this is too hard. They want to stay another night,** housing and trying to learn this is all to much.
- **Loud language between parents.**
- Mom was able to choose proper insulin syringe and inject insulin with some coaching. Child crying and increased mom's frustrations and anger towards father.
- Approved parent trays for breakfast for parents per SW note.

Day 5 Sunday (Hospitalist) (a)

- Parental abilities to care for A.C. given behavior interacting with staff and behaviors when outside hospital during A.C. hospitalization (possible impairment on return) as well as challenges with them demonstrating return education.
- ***Spoke with SW who agreed with placing CPS referral based on above concerns.***
- Family agrees with inability to DC given their incomplete education and housing difficulty.
- Anticipate discharge when determination that home cares would be safely provided.

Day 5 (Sunday) Social Worker (b)

- Spoke with hospitalist today and d/t continued ***concerns for safety***, including parent behaviors/lack of coping skills throughout admission and very slow progress in diabetic education/administration by parents and tenuous home situation ***CPS was contacted for informational report.*** CPS stated that they would investigate their records for prior family involvement.

Day 5 (Sunday 6 AM) Nursing

- Parents returned to bedside. ***Strong smell of marijuana noted by staff. Parents appeared red-eyed and giggling.***
- BG tested, mom did finger poke mostly independently. Parents with supplies, binder of education and 2 insulin pens. Able to determine type and amount of insulin required with some coaching from RN. ***Both parents somewhat confused with education binder,*** not sure which page to go to at bedside to give to pt. then suddenly indicated he had to go to the bathroom right away. Mom took over giving shot with assist/direction from RN (i.e. hold pt. arm, rolling up sleeve).
- Reviewed HS snack. Provided suggestions for a snack <15 g carbs. Mom chose appropriate snack from menu.

Day 5 (Sunday 7 PM) Nursing

- Education again attempted to help family count carbs. They live in a tent and mother does not know how she is going to do this ***"I'm over the wall, just leave me alone"***. During injection of Lantus and carb counting mom very tired and hasn't slept and didn't want to deal with it, very upset with staff always talking to mom and not asking father to do things.
- ***Could not count carbs*** and knowing what he eat and the timing of meals and snacks. Unsure who is eating from tray at this time.
- Explained the importance of child eating and knowing what he eats and the timing of meals and adding snacks. Encouraged snacks less than 15 g carbs.
- ***Parents are having a very difficult time with the education and timing of event.***

Day 6 (Monday 6 AM) Nursing

- Parents of A.C. *left several times throughout the night to smoke and came back smelling of cigarettes and sometimes smelling of marijuana.* The parents also took food from the patient's refrigerator when this RN had informed them that the food in the refrigerator is for patients only.
- The father of the patient performed the evening insulin injection and he did fair with a lot of reinforcement from this RN and appeared to be overwhelmed with the task. Safety with needles had to be taught several times after injection. Parents appear to still be having difficulties with performing insulin injections.

Day 6 (Monday) Nutritionist

- *Today when entering room, mom first words were "I need a cigarette, I can't handle this."*
- Parents having difficult time grasping concepts of carb counting. *They were NOT able to identify 3 main food groups that contain carbohydrate.* RD tried *numerous times to refocus mom* and to simplify teaching more however education session did not appear to be productive.
- Attempted to assist with further understanding by asking about meals at home and at the Food Kitchen only lead to expletive's from mom stating *"do you realize we live in a fucking tent. I don't know what the hell he eats, sometimes he doesn't get to eat a fucking thing. You people don't have a fucking clue."* Dad attempted to call mom numerous times, however this only lead to more crying and lashing out stating her own mental health is to blame for her actions.
- Provided family with a week's worth of BKE 1.5 as supplement to diet and for use when food is not available. Reviewed how to count carbs for this product.

Day 6- Monday-Social Worker (c)

- CPS referral informational only, *not planning to investigate*
- Spoke to outpatient SW and will follow after discharge
- Met with mom and dad. Encouraged mom to contact mom's mental health for support. Mom reports she is meeting with caseworker tomorrow.
- Pt's family has inquired about meal passes . Parents have adamantly declined any other resources for housing. SW has discussed that meal passes are not available in addition to meal passes provided on Friday. Does not qualify for Medicaid meal pass because do not live out of town.
- SW discussed referral to PHN and mother agreeable.
- *SW has heard parents yelling, swearing and throwing clothing.*

Day 6 (Monday) Hospitalist (c)

- *Parents were growing increasingly frustrated with difficulty carb counting and administering insulin regimen. The father became angry and threw a stool in the room.* BGs trending in 200s. Lantus 10 units and I:C 1:12.
- **Plan to switch to straight sliding scale** and carb count for simplification purposes. Family was counseled about this method and seemed to appreciate and are willing to give it a try.
- Pt. current living situation is questionable and concerns have been raised about refrigeration of insulin supplies. There has been discussion with the entire team about the safety of child in respect to hypoglycemia and shock. There is also concerns that the coping mechanism of both parents are maladaptive. *Referral to CPS.*

Day 6 (Monday)- Treatment Plan

Humalog Dosing

- 4 units BG <150
- 5 units BG 151-200
- 6 units BG 201-250
- 7 units BG 251-300
- 8 units BG 301-350
- 9 units BG 351-400
- 10 units 400+++

Day 6 (Monday 4 PM) Nursing

- *Parents in room fighting foul language noted, screaming at each other. Father stating “they haven’t slept or eaten and nobody give a fuck about them.” “We haven’t ate any food and no tickets for meals, everything is taking too long.*
- CDE here and explained new sliding scale coverage.
- Explained again to parents we are trying to make this care for them to do with child where ever they are, but this type of behavior is not acceptable.

Day 7 (Tuesday) Hospitalist (d)

- Family has had challenges learning new diabetic home-care, but ***seems to be functioning at an acceptable level.*** The ***biggest challenge is their homeless state.*** SW is hoping to find them appropriate short-term housing, or d/c will be held.
- Appts Friday at Pediatric Specialty Clinic. School nurse will be following.
- SW is very involved and CPS referral has been made, but it is a “information gathering mode” at present.
- Some minimally acceptable d/c housing has to be arranged if d/c is to occur today.

Day 7: (Tuesday 6 AM) Nursing

- Parents were encouraged to perform all care involving diabetes care. ***Parents were unable to perform tasks without reinforcement from RN.***
- ***Parents were arguing with each other during the process*** of who was going to give the shot and how to actually give the HS doses.
- Parents had to be prompted several times on the actual amount of insulin to be given using the sliding scale table.
- ***Parents were heard at the nursing station yelling and objects being thrown.***
- Dad stated: ***“this is all a lot and I would be curious to know how many people have to deal with diabetes when they are homeless”***
- This RN is concerned of the welfare of the patient and whether or not the parents are able to perform the task need the keep the pt.’s BG WNL as well as having the proper coping skills to handle this life change of their child now having a chronic disease.

Day 7 (Tuesday 6 PM) Nursing

- *Today the parents have demonstrated blood sugar testing and administering insulin without prompting or guidance.* Further teaching to complete diabetes education checklist done with mother.
- Later this afternoon *our chaplain and SW were in the room trying to assist the family in housing* and I overheard mom yelling and being belligerent, cursing, and to de-escalate the situation. Mom has cried many times today stating she doesn't "*know how much more she can take*".

Day 7 Tuesday (Pastoral Care)

- I had a brief visit with A.C. upon RN suggestion.
- I suggested that pt. parents might look into Missoula Family Promise program to help with temporary housing. Parents went into an immediate fury when SW woke her up to talk about placement options. She became more and more agitated, verbally aggressive and mocking as we asked her how and if we might help them secure a place to stay. I was concerned about her son's exposure to her verbal aggression and volatility. Mom finally yelled that I was "pissing her off and to get away" from her son.
- I am concerned about Arthur's lack of response/affect around his mother's intense anger and verbal aggression.
- I made a report with CPS (next day).

Day 7 (Tuesday) Social Worker (c)

- Mom met with mental health caseworker.
- Contact Christian Life Center for housing. Not available on short notice.
- PHN has met with family.
- ***SW has offered information for YWCA Gateway program and Union Gospel Mission. Family has declined both resources as they have had bad experiences with them.***
- Contact with pharmacy and confirmed that family has picked up diabetes supplies.
- Pt.'s mom reported numerous times that no one would help family but when attempts were made to identify challenges or offer resources they refused by Pt's mom. Pt.'s mom asked SW and chaplain to leave the room.

Day 8 (Wednesday 2 PM) Nursing

- ***Referral made today regarding serious concerns for patient's safety.*** The family is homeless and has no possibilities for shelter at this point. The family states they have access to someone's fridge to keep insulin temperature stable. This is a woman who runs a hotel in East Missoula and honestly, I feel this is unreliable and I can't imagine this woman would want to have the family enter her home 3-4 times a day for medication. ***Today, our SW was talking to the family about possibilities for places for the patient to stay and the patient's mom became angry and aggressive.*** Security was called to de-escalate the situation and advise parents to remain calm or they would be asked to leave.
- ***In my last 3 days with this family, my concerns have only increased. It is alarming to me that the pt. might go home with these unstable, unpredictable, volatile family with no money, no home, and no certain way to keep the medications stable.***

Day 8 (Wednesday 3 PM) Hospitalist (d)

- Pt has been medically cleared for d/c for several days now, but family has had on-going challenges learning new diabetic home-care. The biggest challenge is their homeless state. ***They have refused to have the pt d/c'd to a maternal GM, who by report, could house and care for him.*** There was also a shelter bed available in Kalispell, but mom refused to go there alone with the patient. ***Her partner cannot be housed there since he has a felony record.***
- SW is very involved and CPS referral has been made, but is only in a “information gathering mode” at present. I feel strongly that the patient needs to be placed in foster care to meet his IDDM management needs, given that the mom & her partner cannot secure appropriate housing and are not taking the resources offered. I made an ***additional referral to CPS today.***
- Anticipate discharge when determination that home cares would be safely provided.

Day 8- (Wednesday) Social Worker (c)

- SW has spoken with hospitalist and RN for care coordination and dc planning. Hospitalist requiring pt. have a dc location either with tent set up, shelter, MGGM, or other location for pt. to be discharge to. Family up to this point has declined and/or refused attempts from SW to assist with housing. If family not able to establish housing there has been discussion regarding initiation of additional CPS reports. RNs are to make report to CPS<
- SW has asked about setting up tent and Dave reports that they need someone to move there belongings. SW asked how family has moved belongings in past and he reports that a friend has helped them in the past but this friend is “out of town”. SW encouraged dad to reach out to their friends to see if they can assist with moving tent. SW discussed idea of pt. staying with his MGGM until family can get on their feet. Dad said MGGM refused.
- Explored other family shelters in Kalispell and Great Falls.
- When SW suggested MGGM to Pt's mom. She faced this SW and swiftly walked towards SW with eyes widened, balled up fist yelling “GET OUT”. SW has promptly left room due to aggressive behavior and perceived threat from Pt's mom.
- Following incident in pt.'s room security was called.
- SW has called CPS worker. This SW has great concerns in regards to pt. well being with current caregivers due to safety concerning behaviors in pt.'s presence and their abilities to effectively meet pt. needs. Several housing options have been offered to family which family has declined. Due to mother's escalating behavior SW to limit face to face with family.

Day 8 (Wednesday) Social Worker (c)

- Received call from CPS worker who is assigned case and will f/u with family.
- Left message to Public Health Nurse so can follow up with family.
- 4:30 PM SW has spoken with CPS worker and will be at CMC to investigate case and for safety planning in 20 to 60 minutes. Family has reported that they have a motel for one night in East Missoula.
- 5:30 PM CPS meeting with family now for safe discharge plan.

Day 8 (Wednesday 6 PM) Hospitalist (d)

- Met with CPS workers and they have met with parents. CPS decision is to take pt. and his parents to a hotel tonight. Their regular caseworker will meet them there in AM to facilitate "next steps". Our team stressed our concerns to the CPS staff that A.C. parents are not demonstrating the emotional or financial stability to care for his new onset IDDM, but their decision remains to discharge tonight. Parents have obtained the insulin and other supplies for home.

Day 8 (Wednesday 7 PM) Nursing

- Despite voicing grave concerns regarding pt. going home with parents to a hotel for a night and then subsequent homeless, ***the child was decided by CPS to discharge to parents.***
- SW decided to send him anyway with the ***CPS worker driving them personally to their hotel in East Missoula.*** Discharge education complete and the glucagon kit discussed and demonstrated.
- Two Humalog pens and one Lantus pen relabeled for home use and sent with parents. All other supplies and prescriptions have been picked up by parents and are in their possession. Pt. left in satisfactory and stable condition with parents and the CPS worker.

Barriers In Hospital-Family

- *Unable to grasp carb counting*
- *Volatile parents-behaviors seemed to escalate as hospitalization progressed and during the night possibly due to mind altering substance use*
- *Inconsistent ability to perform self care diabetes management skills*
- *Homelessness (parents had no place to sleep while child hospitalized)*
- *Food insecurity?*

Barriers In Home Situation

- Lack of refrigeration
- Food insecurity
- *Lives in a tent, but tent not up because of "rain".*
- *Unknown mental status of parents*
- Parents use of mind altering substances.
- Lack of transportation
- No internet
- Has burned bridges with previous housing situation

Techniques to address diabetes treatment plan.

- Referral to Hospital social worker shortly after admission
- Social worker assessment
- Prescriptions in place
- PHN referral
- School Care Plan and school nurse follow-up
- Outpatient referral to Pediatric Specialty Clinic (contact information exchanged)
- CPS referral first informational and then not.
- Tools for carb counting and insulin administration

Could we do things differently

(Identify techniques to address barriers in diabetes treatment plan.)

- How to deal with parental behaviors.
- Housing issues brought up daily even when they didn't qualify.
- Food trays for all meals for parents or not?
- How to address inability to carb count.
- Referral to CPS earlier
- Referral to pastoral care not appropriate
- Expectations for discharge

What constitutes a safe environment for a child with diabetes.

- Housing
- Transportation:
- Communication:
- Insurance/RX: Pt.
- Family support:
- Food:
- Parental Status:

Explore professional judgements in working with children in challenging home environment.

- No food
- No refrigeration for insulin
- Parents volatile behavior
- Parents inconsistent behavior
- Parents “under the influence” of mind altering substances
- A tent for a home especially with child with diabetes
- Parents smoking marijuana