PATIENTS WITH DEVELOPMENTAL DISABILITY AND THE HEALTHCARE ENCOUNTER

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WHAT IS A COMMUNITY?

- A social group of any size whose members reside in a specific locality, share government, and often have a common cultural and historical heritage.

or

- A social, religious, occupational, or other group sharing common characteristics or interests and perceived or perceiving itself as distinct in some respect from the larger society within which it exists.

PATIENTS WITH DEVELOPMENTAL DISABILITY: A NON-GEOGRAPHIC COMMUNITY

People with developmental disabilities may share common experiences or a sense of isolation from the rest of society.

We are interested in learning more about the challenges unique to this community in the healthcare setting.

DEVELOPMENTAL DISABILITY

Developmental disabilities are lifelong disabilities attributable to mental or physical impairments manifested prior to age 18.

Patients with developmental disabilities may have functional limitations including:

1) Self-care
2) Receptive and expressive language
3) Learning
4) Mobility
5) Self-direction
6) Capacity for independent living
7) Economic self-sufficiency

Some examples of developmental disabilities: ADHD, autism spectrum disorders, cerebral palsy, epilepsy/seizure disorders, hearing impairment, intellectual disability/mental retardation, or vision impairment.

BACKGROUND: DEVELOPMENTAL DISABILITY SURVEY AT LAKESHORE FROM BLOCK 2

54 patients with at least one developmental disability.

74% were >18 years old.

7/22 physicians at Lakeshore routinely participated in these patients' care.

One provider was the PCP for 26/54 of the patients.

Some physicians admitted feeling uncomfortable seeing patients with DD because they lacked expertise.

OUR FOCUS: PATIENT PERSPECTIVES

The purpose of the Block 2 project was to assess physician comfort with patients with developmental disability.

The aim of our project is to explore the challenges of healthcare encounters from the perspective of patients with developmental disabilities and their caregivers.

SOURCES AND METHODS

We conducted open ended interviews because we could not assume that we knew what the issues would be within this community.

Using a database of patients with developmental disabilities at Lakeshore, we identified 16 patients with appointments in the past 2 months or upcoming appointments during our rotation.

We contacted their PCPs to ask permission to observe their appointment or interview them and their caregiver on the phone regarding their recent clinic visit.

We succeeded in observing 4 clinic visits and making 5 phone calls to patients and their families and caregivers.

OUR 8 CASE STUDIES

Patient A: 32 year old woman with juvenile rheumatoid arthritis. Lives alone, dependent on motorized wheelchair. Limitation 4.

Patient B: 28 year old man with autism and seizure disorder. Lives with parents and attends adult day program. Limitations 1, 2, 3, 5, 6, 7.

Patient C: 54 year old man with achondroplasia. Lives alone, unable to work due chronic pain. Limitations 4, 7.

Patient D: 56 year old man with cerebral palsy including spasticity and cognitive deficits. Lives with brother and sister in law. Limitations 1, 2, 3, 4, 5, 6, 7.

LIMITATIONS

1. Self-care
2. Receptive and expressive language
3. Learning
4. Mobility
5. Self-direction
6. Capacity for independent living
7. Economic self-sufficiency

OUR 8 CASE STUDIES

Patient E: 32 year old man with autism, cerebral palsy, and visual impairment. Lives in group home and attends vocational adult day programs. Limitations 1, 2, 3, 4, 5, 6, 7.

Patient F: 67 year old woman with a non-specified cognitive disorder. Lives alone, has part-time caregiver, sister is health advocate. Limitations: 1, 2, 3, 5, 6, 7.

Patient G: 51 year old woman with autism and possible schizophrenia. Lives with mother. Limitations 1, 2, 3, 5, 6, 7.

Patient H: 61 year old man with autism. Lives with mother. Limitations 1, 2, 3, 5, 6, 7.

LIMITATIONS

1. Self-care
2. Receptive and expressive language
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ISSUES WE IDENTIFIED

- Clinic Logistics
- Physician-Caregiver Relationship
- Physician Conscientiousness
- Continuity of Care

CLINIC LOGISTICS

- Patients with mobility limitations may not be able to use a standard-height exam table. At Lakeshore, patients who need the lower exam table are not automatically assigned to that room.

- This may result in…
  - an **inefficient** use of time, if patients change rooms mid-visit.

  or

  - physicians performing an **incomplete** physical exam due to inability to position the patient appropriately on the exam table.

- The clinic could develop a protocol for flagging charts of patients who require the lower exam table.

PHYSICIAN-CAREGIVER RELATIONSHIP

- Many patients with developmental disability have a caregiver who is highly involved in their medical decision-making.

- Physicians occasionally **ask caregivers to leave the room** in order to speak to patients alone, or, at the same time, may **ask caregivers personal questions** about their own habits, lifestyles, or emotional health seemingly unrelated to the patient.

- This may result in…
  - caregivers feeling **hurt or mistrusted.**

  or
  - caregivers feeling an **invasion of their personal space.**

- Physicians could preface these requests and questions by explaining to caregivers how this information offers a more complete picture of the patients' home environment and ultimately contributes to medical management.

PHYSICIAN CONSCIENTIOUSNESS

- Patients with communication challenges may be **unable to describe their symptoms**, making it difficult for physicians to arrive at a diagnosis.
- Patients with cognitive limitations may be **unable to follow-up with their physician** to ensure that all the "plan" items are completed.

- This may result in…
  - medical decision making in the face of **limited information.**

  or
  - **delay** or **incompletion** of planned tasks.

- Objective diagnostic tools may be even more crucial in providing care to patients with developmental disability.

- Patients and their caregivers have expressed appreciation for doctors who "follow through" and "go the extra mile," especially when the patient is unable to advocate for themselves.

CONTINUITY OF CARE

- Continuity of care is important in all physician-patient relationships, but especially for patients with developmental disability, because they may **communicate in a unique way**, or they may have **special needs** which a new provider may be unaware of.

- Acute care visits with a different provider may result in…
  - **misunderstanding** of the patient's level of pain or distress.

  or
  - **failure to consider** acute illness in the context of chronic disability.

- Patients with developmental disabilities may have atypical life circumstances. A longstanding relationship with a PCP familiar with their disability and home environment allows their unique situations to be taken into consideration when treating their acute illnesses.

TIPS FOR SUCCESS!

- Clinic Logistics: Clinic administrators could develop protocols for flagging charts of patients who require unique exam room set-ups.
- Physician-Caregiver Relationship: Smooth communication with caregivers is essential to providing optimal patient care.
- Physician Conscientiousness: Physicians should be especially thorough with their diagnostic processes and must follow through with their treatment plans.
- Continuity of Care: Physicians should emphasize the importance of establishing longstanding relationships through routine visits.

TYPICAL M^2 COMMITTEE MEETING