Knowledge of Autism Spectrum Disorder care needs among health care professionals in the intensive care units

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AND PARENT OF CHILD WITH AUTISM SPECTRUM DISORDER.
Background

- In 2006, one in every 110 children was classified as having an autism spectrum disorder (ASD).
- The CDC claims that the incidence of ASD is rising.
- People with developmental disabilities, including ASD, are living longer.
- More adults with developmental disabilities, including ASD, are being seen in the hospital.
The hospital environment can be an overwhelming place for those with sensory issues.

In the Intensive Care Unit(s) (ICU), these issues are magnified.

ICUs are not prepared to meet the unique needs of people with ASD.

Research is needed to determine what the current knowledge about ASD care needs is among health care professionals.
The challenges of the hospital environment
Special care needs for persons with ASD in the Hospital

- Sensory issues
From the literature it is evident that people with ASD have unique needs and require individualized treatment plans to address those needs.

It is also evident that parental or caregiver involvement in those treatment plans is essential.

The involvement of parents in the care of people with ASD is in keeping with the current movement in health care toward family-centered care.
Importance of family-centered care

- Among other things, family-centered care has been shown in literature to improve family outcomes, increase satisfaction among patients and families, increase professional satisfaction, and lead to more effective use of health care resources.

- One of the principles of family-centered care is “ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family” (CHC, 2003).
Objective

The goal is to conduct a need assessment of the gaps in knowledge about ASD care needs among professionals in one hospital’s ICUs in Connecticut.

“Gap analysis directly informs the development of learning objectives for educational activities” (Greene, L. & Prostko, C., 2008).
Method

- Invite all health professionals working in the ICUs, including physicians, physician assistants, nurse practitioners, respiratory therapists, social workers, speech, physical and occupational therapists, to participate in a survey about their knowledge of ASD care needs, including family-centered care.
The first section of the survey was meant to elicit the professionals’:

- frequency of contact with people with an Autism Spectrum Disorder (ASD),
- type of relationship with a person with an ASD,
- frequency that they cared for someone in the ICU with an ASD, and
- their feelings on whether there were necessary policies and procedures in place to care for people with an ASD.
The second section was meant to ascertain whether the professionals:

- felt their training had prepared them to care for people with an ASD,
- felt it was important in their profession to know how to care for a person with an ASD,
- felt comfortable caring for a person with an ASD, and finally,
- felt parents and caregivers should always be welcome in the ICU and/or during change of shifts and during treatments.
A comments section allowed the respondents to provide additional information about caring for people with an ASD in the ICU.

Each person was also asked to report their age, sex, race, specific profession, and number of years in that profession.
## Survey distribution and responses by discipline

<table>
<thead>
<tr>
<th>Discipline</th>
<th>ICU staff</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending resident physicians</td>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>PAs NPs</td>
<td>13 25</td>
<td>2 5</td>
</tr>
<tr>
<td>Nurses</td>
<td>227</td>
<td>35</td>
</tr>
<tr>
<td>Social workers</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Respiratory therapists</td>
<td>71</td>
<td>11</td>
</tr>
<tr>
<td>PT OT speech therapist</td>
<td>23</td>
<td>5 2 4</td>
</tr>
<tr>
<td>NP=nurse practitioner</td>
<td>PA= physician’s assistant</td>
<td>1 respondent skipped the demographics section</td>
</tr>
</tbody>
</table>

Number of surveys sent out = 391; number of responses = 73
Response rate = 18.7%
Demographics

At least:

- 80% of respondents were female (2 people skipped this question).
- 48.6% of the respondents were nurses (1 person skipped this question).
- 50% of respondents had worked in their current profession for over 10 years (1 person skipped this question).
Results

How often do you care for someone with an Autism Spectrum Disorder in the intensive care unit?

- About once a week
- A few times a year
- Very infrequently
- Other (please specify)
Results

Who do you know with an Autism Spectrum Disorder? *(select all that apply)*

- **I have an Autism Spectrum Disorder:**
  - Close Relative: 15
  - Distant Relative: 10
  - Close Friend: 5
  - Co-Worker: 0
  - Patient/Client: 35

- **No Contact:** 20
How often do you care for someone with an Autism Spectrum Disorder in the intensive care unit?

- About once a week
- About once a month
- Very infrequently
- Other (please specify)

The diagram shows the number of respondents for each category, with 'Very infrequently' having the highest number of responses.
Do you feel the ICU has the necessary policies and procedures in place to care for people with Autism Spectrum Disorder?

- Yes: 76.7%
- I don't know: 16.4%
- No (please explain): 6.8%
My training has prepared me to care for a person with an ASD.

In my profession, it is important for me to know how to care for a person with ASD.

Number of respondents

- Strongly disagree
- Moderately disagree
- Somewhat disagree
- Somewhat agree
- Moderately agree
- Strongly agree
I know enough about ASDs to feel comfortable taking care of a patient with it.

I think that caregivers of people with ASDs who are in the ICU should always be welcome to be with the patient and not be seen as visitors.

- Strongly disagree
- Moderately disagree
- Somewhat disagree
- Somewhat agree
- Moderately agree
- Strongly agree

number of respondents
I think parents or caregivers of people with an ASDs should be allowed to remain with the patient during nurse change of shft, in accordance with patient preference.

I think parents and caregivers of people with ASD should be present during treatments in accordance with patient preference.
Comments by nurses regarding need for staff training

- "help staff familiarize with patient population and provide evidence based practice."
- "the noise level and lack of education about this population is paramount..."
- "an in service on autism would be helpful."
- "other than in school never had any info on patient with autism."
- "tips on communication..."
Comments by other professionals regarding need for staff training

- “...more education for staff about the disorder and associated special needs would be most helpful.”

- “Like any diagnosis that one is unfamiliar with should necessitate information on how to best care for patient with”...

- “There are Healthstream presentations on several other types of patients with unique needs. We should have one on ASD as a minimum...”
Comments regarding family-centered care

- “each case should be looked at individually…”

- “…changes in visitation policies.”

- “…information about specialized strategies to provide care in the best manner to maintain independence and pt-centered care.”

- “Policies that allow continuity of pre-hospital care.”
More comments

- “early psychiatry consult more to assist the staff in education for appropriate and expected interactions.”

- “dedicated speech/PT/OT specialists”

- “…Psych consults are an important part of our team and will utilize their skills if certain behaviors are a challenge for the staff.”
“New policies not necessary” comments

- “this comes up infrequently...a large population of our patients are sedated, unconscious or confused.”

- “NONE!! DO NOT confuse policy and procedures with PROPER TRAINING!! Autism spectrum disorder is the psych. flavor-of-the-decade. There is not a large older population because the diagnosis was not in vogue decades ago!...”
Limitations

- The small number of people who responded
- The fact that all the participants were from one hospital
- The possible deficiencies of the survey to elicit desired information about health professionals’ current knowledge about ASD and family-centered care
- Giving the participants so much information in the “background” piece of the informed assent section probably steered some people’s thinking as it gave them ideas on some of the issues people with ASD might have in the ICUs.
Implications

The results are an important addition to literature as they provide some information about the knowledge of ASD care needs (or lack of) among professionals in the ICU.

- From this need assessment it is unclear whether or not training among ICU professionals about the care needs of people with ASD is important at this time. Although people want to be prepared to care for people with ASD, they are probably not seeing enough people with ASD in the ICUs to justify the cost of providing training for all the staff in the ICUs. However, it would be most reasonable to create some sort of informational pamphlet that staff could access at their will.
Conclusion

- This need assessment may show very different results in years to come. Hospitals that wish to be leaders in the future should begin to plan how they will prepare their staff to best care for people with an ASD and their families. Family-centered care is key and will not only benefit people with ASD and their families, but all people.
Bibliography


Prevalence of ASDs. Retrieved December 20, 2010, from [http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm)


Bibliography


