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Education of Healthcare Professionals on an Integrated Care Pathway in order to Standardize Practice and Improve Outcomes for Individuals with Intellectual and Developmental Disability (IDD) who engage in Self-Injurious Behavior (SIB)

Dr. Regina Gentlesk Green

Stockton University Asst. Professor

Assurance Behavioral Health- Training & Community Outreach

ABSTRACT

This paper addresses the lack of knowledge and lack of standardization for treating individuals who engage in self-injurious behavior (SIB) to the head. An evidence-based integrated clinical care pathway is described that was created for health care professionals treating individuals with intellectual and developmental disability (IDD) who engage in frequent and/or significant SIB. It is anticipated that this pathway will increase treatment team knowledge of best practices, decrease clinical variation, standardize care, and improve clinical outcomes with this vulnerable population.

Keywords: SIB; IDD, Intellectual and Developmental Disability, Self-Injurious Behavior

*Correspondence to Author:

Dr. Regina Gentlesk Green
Stockton University Asst. Professor
Assurance Behavioral Health-
Training & Community Outreach
rgentleskgreen@gmail.com

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The Centers for Disease Control (CDC, 2020) describes intellectual and developmental disability (IDD) as a group of conditions that occur due to impairment in physical, learning, language, or behavior areas. CDC reports that over the last decade or so, the prevalence of IDD has increased 7.1%. IDD is associated with a variety of problematic behaviors including self-injurious behavior (SIB). Based on these statistics, it is critical that all health care providers increase their knowledge in how best to manage and support individuals with IDD. A major concern regarding those with IDD is the presence of SIB. According to Murphy (1999), "SIB is any behavior initiated by the individual that directly results in physical harm to that individual" (p.5). Moreover, Symons (2011) states "self-injurious behavior (SIB) among individuals with intellectual and developmental disabilities (IDD) is a clinically daunting and scientifically challenging behavior problem with profound implications for a person's general health and overall quality of life" (p. 1266).

Boyle, Boulet, Schieve, Cohen, Blumberg, Yeargin-Allsopp, Visser, and Kogan (2011) state nearly one in six children in the United States copes with some type of developmental disability. One reason this group is growing is the survival of extremely low birth weight, premature infants whose gestational status places them at risk for overt and subtle neurologic and other physical disorders. Additionally, there has been increased vigilance in screening for autism and developmental risks in general (Gardner, 2012). Perhaps the most important impact of this increase may be found in the fact that the growing population of children diagnosed with IDD will become a population of adults and older adults (Gardner, 2012). These realities will increasingly require specialized, high-quality health services. A primary focus in the literature regarding SIB is

the incidence of head banging, and head hitting. Symons and Thompson (1997) report that over 50% of self-injurious behavior with IDD individuals are directed toward the head. The tendency for head-focused SIB makes it not only a "highly problematic and damaging behavior, but (one that) has profound implications for quality of life" (Symons et al., p. 456). While SIBs are not a new problem with this population, it is believed to be one of the most dangerous and complicated behaviors for staff to manage. At present, there is no standardized approach within the field for treating individuals with IDD for SIB.

Because there is no standardized approach to individuals with SIB, responses to the problem are likely many and varied depending on the context with most approaches having little validation. In short, most organizations do not follow a clinical pathway. This variation in addressing the problem is likely to lead to less effective clinical interventions as well as the potential for delayed treatment which, in turn, gives rise to a lack of appropriate and timely follow-up care. Moreover, the impact of repeated SIB is unknown. Lastly, there is a knowledge deficit that exists for treatment team members (e.g.; nurses and direct care staff) related to caring for individuals with IDD who frequently engage in SIB.

In Taylor et al.'s (2011) longitudinal study of quality of life and behavior changes in 49 people with IDD who engage in SIB, the authors found that SIB are relatively stable throughout the lifespan. More specifically, 84% of the group studied by Taylor, et al. continued to engage in SIBs for over 20 years, with the no significant changes in frequency or severity across the group. Because of the chronicity of these behaviors once they've been established, the authors stress the importance of early intervention.

Gardner's (2012) review also examined trends in the field specifically addressing nursing practice with individuals with IDD. According to Gardner,

going forward nurses in all settings will encounter increasing numbers of patients with IDD. Gardner also identifies important differences between these individuals and the general population. For example, Gardner highlights what can be characterized as inadequate training for nurses in treating this population, citing for example the fact that few training programs require experience and/or require clinical experiences with this population.

In a review article on evidence-based practice (EBP) in nursing, Hahn (2009) provides a historical overview of evidence-based practice in nursing and offers practical steps toward achieving it. Hahn identified current deficiencies in knowledge and support that limit nurses' present ability to fully engage in evidence-based nursing practice (EBN). She argues that, just as in other disciplines, there is an increased need and focus on utilization of EBP and that such an emphasis is especially needed for nurses working with individuals with IDD. She outlines general steps for nurses who support individuals with IDD in order to bring EBN to practice. Hahn also identified a limitation in the current literature: that there are very few randomized control trials conducted with this population which in turn may depress new research and evidence to support evidence-based practice.

In a descriptive study regarding the implementation of a program to educate staff on preventing and managing challenging behaviors, Johnson, et al. (2012) suggest that nurses (and other direct care staff) lack the knowledge and skills to prevent and manage difficult behaviors in individuals with IDD. These authors discuss the significance of this reality in terms of prevention and current patient care. Similarly, in a review and case study examining educational trends in nursing Cervasio (2013) identified several factors driving curriculum development in IDD nursing such as the lack of education and various

other social, political and legal forces. Cervasio also identified trends in population demographics and their impact on nursing practice, highlighting gaps in the way nurses are trained. In an article by Oliver et al. (2012), the independent association between certain behaviors and risk for self-injury and other destructive behavior was examined. These authors found that certain behaviors (e.g. repetitive or ritualistic behaviors) were associated with a risk for self-injury 16 times greater than for those without these behaviors. Utilizing their data, the authors identify certain behavioral targets for early intervention. The authors concluded that despite their widespread use, pharmacological interventions are far less effective than behavioral ones (e.g., Applied Behavior Analysis).

In an interesting study focusing on body site preference among those who engage in SIB, Symons, et al. (1997) highlighted the often slow process of addressing SIBs and offered a potential explanation. Symons and his colleagues argue that a cyclical pattern involving not only social cues but also neuropathic pain may be at work. Further, these authors discussed the impact SIB-site preference has on factors including severity of injury and treatment.

Ahmad, et al. (2007) reported that the utilization of care pathways for individuals with IDD led to improved outcomes. Specifically, they identified three explicit targets for intervention and tailored pathways to address each area, including: epilepsy, challenging behavior and hearing impairment. They concluded that the introduction of care pathways led to increased communication within services, greater satisfaction and improved outcomes for patients. In fact, an independent auditor of the process by which the pathways were utilized found that 94% of those involved in the pathway-directed treatment (e.g. patients and families) reported that they were pleased with the care they received and 100%

responded that the care pathway clarified their care journey. The notion that integrated care pathways improve care is found elsewhere in health care as well. Powell and Kwiatek (2006), in their chapter on integrated care pathways, opined that such pathways are not only consistent with EBP, but that they also standardize care, decrease clinical variation, improve quality of care, and improve patient outcomes. The idea that such pathways are useful is further supported by Lock (1999), in a review of a clinical pathway for anorexia

nervosa in adolescents, found that integrated care pathways demonstrated effectiveness, identified problem areas and supported arguments for changes in referral and treatment models. Finally, with regard to nursing support Currie and Harvey (1998), recommended that nurses be identified as facilitators of integrated care pathways. They went on to suggest that because nurses are the largest group of providers in the healthcare system and because they are familiar with other providers that they can play a pivotal role in achieving EBN.

Figure 4: Biological / Environmental causes that may have caused and or exacerbated behavior	Figure 5. Rule-outs (Post- SIB injury)
Ear Injury Gastrointestinal / Genitourinary Speech Difficulties Dental Problems Eye Injury Epilepsy Sleep Disturbances Head Injury Medicine Changes Medical and / or Psychiatric Diagnosis Environmental social positive (e.g., attention) Environmental social negative (e.g., escape)	Head Injury Eye Injury Mouth Injury Nose Injury Ear Injury Other: (e.g., Jaw, Nose, etc.)

Common themes apparent in using EBN in the care and treatment of IDD patients include: (1) nurses and staff working with IDD individuals lack knowledge to properly manage SIBs (2) SIB is common, difficult to treat, and can lead to serious consequences if not addressed early and consistently and (3) evidence supports the use of integrated care pathways to improve consistency and quality of care.

Purpose of an Integrated Care Pathway (ICP)

An evidence-based integrated care pathway for individuals who engage in frequent and significant SIB to the head was developed by this writer as part of a doctoral project, with support

from both a doctoral committee and multidisciplinary team members (Figure A).

By addressing the lack of response, unstandardized or in some cases ineffective response to SIB, a SIB pathway provides a clear, stepwise guide for treatment team members to assess and manage individuals who exhibit SIB to the head and are in danger of acute head injury. Moreover, such a pathway assists in the identification and evaluation of signs and symptoms to rule out potential injuries caused by SIB to the head (Figure 5). Additionally, the pathway identifies factors that are common problems associated with IDD and may have contributed to SIB

to the head (Figure 4). Moreover, when these areas go untreated and/or are poorly managed, can lead to behavioral problems or an escalation of current behaviors and SIB to the head.

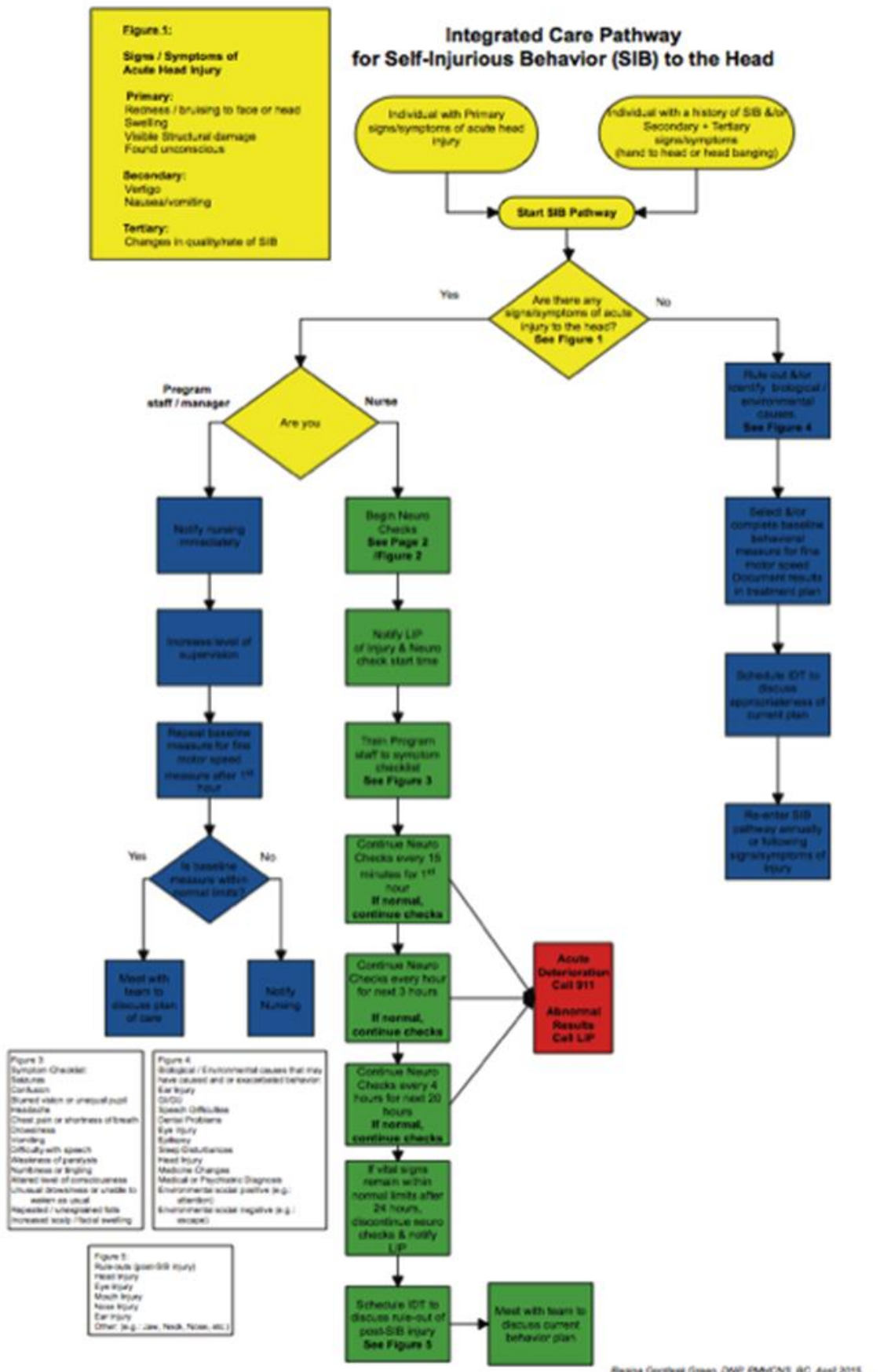


Figure A. Integrated Care Pathway for Self-Injurious Behavior (SIB) to the Head

It is important that individuals not go through the pathway unnecessarily. An individual enters the SIB pathway following primary symptoms signs/symptoms (Figure 1) and / or a history of SIB to the head with secondary and tertiary symptoms, and will re-enter SIB pathway annually. Once the SIB pathway has been initiated, and the individual has been identified as either a program staff or manager, will go ahead and follow steps of the decision tree in pathway.

There is growing evidence to support the development and use of an integrated care pathway for standardizing care provided to individuals with IDD (Ahmad, et al., 2007). Such pathways will help to reduce variation that currently exists in the behavioral treatment of SIB. Finally, such a pathway provides nurses and other personnel with the knowledge and skill to meet the needs of individuals with IDD.

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