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Feasibility of Screening for Mental Health in Young Adults With Childhood Onset Disabilities

Andrea B. Lauzon, NP¹

Mark T. Bayley, MD²

Sarah E. P. Munce, PhD²

Laura Langer, BSc²

(1)LIFEspan Service, UHN-Toronto Rehab, Toronto, ON, Canada

(2)UHN-Toronto Rehab, Toronto, ON, Canada

Purpose:

Living Independently Fully Engaged (LIFEspan), a Nurse Practitioner (NP)-led clinic, is a unique service facilitating transition of young adults with Cerebral Palsy (CP) or Brain Injury (BI) from paediatric to adult rehabilitation. Anecdotally, clinicians reported an increase in the number of young adults with mental health concerns, specifically, anxiety and depression symptomatology.

A systematic literature review to find the prevalence of anxiety and depression in young adults with CP or BI revealed conflicting results. Many articles endorsed an increased risk for depression, anxiety and other mental health issues (i.e., psychological distress, suicidal ideation, psychosis) in children and young adults with CP or BI.^{1,2,3,4,5,6,8} Yet, one study did not find an increased prevalence of mental health issues in youth with CP.⁷

In 2016, a pilot study using Patient Health Questionnaire-4 (PHQ-4) in LIFEspan Service was completed. The results showed 73/133 had positive screens for anxiety or depression. In September 2017, Research Ethics Board approval was received for a study to identify the prevalence of mental health concerns in young adults with CP and BI.

Objectives:

- Describe the levels of depression, anxiety and community integration among a sample of LIFEspan patients with CP or BI
- Provide an overview of the feasibility considerations for administering PHQ-4 and Community Integration Questionnaire (CIQ) among young adults with CP or BI
- Provide an overview of the facilitators and barriers in administering PHQ-4 and CIQ among young adults with CP or BI

Methods:

Study participants were recruited from 460 current patients in LIFEspan Service between 18-55 years old, with a childhood onset disability of CP or BI.

To date, October 31, 2018, a total of 430 charts were reviewed; with 206 unique participants and 7 participants in follow up consented in the study; 30 young adults did not give consent and completed the PHQ-4 and CIQ; and 187 were ineligible due to having a moderate to severe intellectual disability. Reasons given by young adults who did not consent included: not feeling comfortable with mental health data being used for analysis and publication; or did not feel confident the study was anonymous.

The study was a cross sectional quantitative study. Data collection involved a chart review, clinic assessment; and self-assessments using PHQ-4 and CIQ.

Data collected related to the feasibility of administering the tools included completion rate, and time required to complete PHQ-4.

Comments were collected from participants to identify facilitators and barriers of using the CIQ and PHQ-4, such as, physical ability to complete the forms; or clarification questions for completing the tools.

Demographic statistics were performed including group means and frequencies counts; student t-tests and Chi squares analyses were used to examine group differences and associations between variables.

Results:

Preliminary analysis in July 2018 from 167 recruited participants showed a mean PHQ-4 of 3.188-3.258, indicating a positive screen for anxious or depressive symptomatology in young adults with CP or BI. CIQ results showed that females were more integrated in the community than males.

There was a significant difference in young adults with CP who had “little interest or pleasure in doing things everyday” at 11% in comparison to patients with BI at 3%.

40% of males versus 55 % of females experienced pain; there were no significant differences in males versus females in terms of depression scores, as measured by the PHQ-4.

CIQ and PHQ-4 were completed within the clinic appointment.

PHQ-4 and CIQ questionnaires presented some challenges, such as, young adults with quadriplegia or fine motor challenges required support to physically complete the tools; there was a desire for clients to use 0.5 rather than whole number ratings, and both the CIQ and PHQ-4 required clarification of some statements and rating scales.

Conclusion:

Mental health is a global chronic health concern.⁹

The PHQ-4 offered a validated, quick screening tool for anxiety and depression. Healthcare providers are able to review, interpret and provide recommendations for early intervention and treatment, when needed.

The CIQ identified the level of community integration; and led to conversations with young adults to establish goals to increase their level of community integration and independent living skills.

The preliminary study results supported the feasibility of screening for mental health and community integration.

Mental health screening is integral in chronic disease management. Patient care and quality of life may be enhanced with increased disability awareness, increased conversations about mental health and awareness of and participation in intervention and treatment.

Our intent is to publish a manuscript after the conclusion of the study in September 2019 and consider a proposal to revise the CIQ, with permission, to increase the usability of the CIQ with young adults with CP or BI.

Title:

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Keywords:

community integration, mental health and young adults with cerebral palsy or brain injury

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Abstract Summary:

Results from a quantitative study on mental health and community integration screening are shared. Participants are recruited from LIFEspan Service, a NP-led program, facilitating transition of youth with cerebral palsy or brain injury from paediatric to adult rehabilitation. Facilitators and barriers to using the screening tools are discussed.

Content Outline:

I. Introduction: The incidence of mental health disorders and level of community integration in young adults with Cerebral Palsy (CP) and Brain Injury (BI) are discussed.

II. Body

A. Main Point #1: Young adults with CP or BI may have higher rates of mental health issues and lower rates of community integration in comparison to the general population.

Supporting Point 1 a) In 2016, a pilot project was completed using the Patient Health Questionnaire-4 (PHQ-4) with patients in LIFEspan Service resulting in 73/133 positive screens.

Supporting 1 b) A preliminary analysis in July 2018 with a sample size of 167 participants of young adults with CP or BI showed a PHQ-4 of 3.188-3.258 (a positive screen) and there were no significant differences in males versus females in terms of depression scores.

Supporting 1 c) In July 2018, a preliminary analysis of Community Integration Questionnaire (CIQ) data showed a trend towards significance in that young adults with BI were more integrated than young adults with CP; and females were more integrated than males.

Main Point #2: There are validated tools available to screen for mental health and level of community integration in a clinical setting.

Supporting 2 a) PHQ-4 is a validated screening tool for anxiety and depression easily administered to the general population.

Supporting 2 b) CIQ is a validated tool used to provide a measure of community integration in adults following a traumatic brain injury.

Main Point #3: Facilitators and barriers using the PHQ-4 and CIQ in a clinical setting were observed during the research study.

Supporting 3 a) Facilitators: CIQ and PHQ-4 are self-report tools which were completed and interpreted in clinical appointments. PHQ-4 was completed in less than 3 minutes.

Supporting 3 b) Barriers identified with using PHQ-4 and CIQ:

-Participants completed the PHQ-4 with a 0.5 rating rather than the whole number on the scale given.

-CIQ statements required clarification, such as, do you have a best friend; who usually cares for children in your home; an option to answer was 'not applicable, retired due to age'.

-Some participants with significant physical disabilities were unable to complete the tools without assistance to record their answers.

-CIQ and PHQ-4 have limited use in young adults with moderate to severe intellectual disabilities.

III. Conclusion

The pilot project in 2016 showed more than half of the young adults with CP or BI screened positive for mental health symptomatology. This was further endorsed with the preliminary analysis and a PHQ-4 mean over 3, a positive screen in July 2018.

Mental health screening is encouraged with each interaction nurses and health care providers have with young adults with CP or BI. Early identification of a mood disorder, such as, anxiety or depression leads to early intervention, and treatment.

PHQ-4 is an easily administered, validated screening tool for anxiety and depression.

Young adults with CP or BI may benefit from opportunities to increase their independent living skills and increase the levels of community integration.

First Primary Presenting Author
Primary Presenting Author

Andrea B. Lauzon, NP
UHN-Toronto Rehab
LIFEspan Service
Nurse Practitioner
Toronto ON
Canada

Author Summary: Andrea received a bursary in 2016 for 'Chronic Disease and Innovation' from Nurse Practitioners Association of Ontario, which led to this research and knowledge translation opportunities for 'Is there an increased prevalence of anxiety and depression in young adults with cerebral palsy or brain injury. The study received Research Ethics Board approval in September 2017; and a renewal in September 2018.

Second Author
Mark T. Bayley, MD
UHN-Toronto Rehab
Doctor
Toronto ON
Canada

Author Summary: Mark Bayley is a non-presenting author for this poster presentation for Congress 2019. He is a Principal co-investigator for this brain health study at UHN-Toronto Rehab.

Third Author
Sarah E. P. Munce, PhD
UHN-Toronto Rehab
Research Scientist
Toronto ON
Canada

Author Summary: Sarah is a non-presenting author for this poster presentation and an integral team member in this research study. Sarah has been working with the LIFEspan Service since 2017.

Fourth Author
Laura Langer, BSc
UHN-Toronto Rehab
Research analyst
Toronto ON
Canada

Author Summary: Laura is a non-presenting author for this poster presentation at Congress 2019. She is an integral team member in this brain health study with her expertise as a research analyst and assistant.