

# Long-Term Education, Employment and Family Outcomes in Biliary Atresia Patients, Post-Kasai



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## Background

Biliary atresia (BA) is an **idiopathic neonatal cholangiopathy**, requiring Kasai portoenterostomy during infancy. If unsuccessful, liver transplantation (LT) is required. Between **23-44% survive with native liver (SNL) into adulthood**, most with chronic liver disease (CLD).<sup>1</sup> **Unemployment rates for adults post LT is estimated up to 55%.**<sup>2</sup> This study aimed to synthesise information on **education, employment and family outcomes** for patients with BA who had SNL up to 16 years and had not received a transplant.

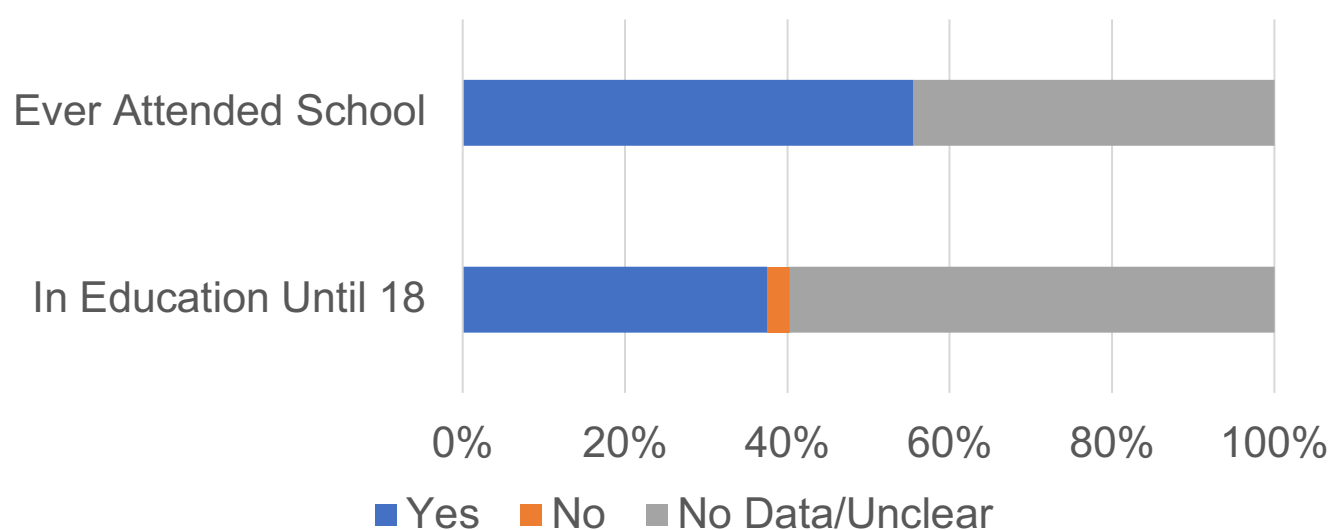
## Methods

- We reviewed electronic patient records (EPR) for patients diagnosed with BA between 1980-96, who SNL > 16 years, until last follow-up.
- **Inpatient notes and outpatient clinic letters** were scanned and searched for key phrases relevant to Family Status, Employment Status and Education Status.
- Information on schooling was achieved by searching for 'school' 'education' 'college' in inpatient notes; for employment, 'work', 'employ', 'job'; for family, 'husband', 'wife', 'partner', 'child', 'pregnancy', 'boy/girlfriend'. Liver clinic letters stored on our EPR system were read in full. International Standard Classification of Jobs (ISCO) were used.

## Education Status

- For those with data (n=40) **100% attended school**.
- 27 students for whom there was data stayed in full time education until the age of 18, studying A Levels or BTEC exams. For 2 students finishing age was unclear. 2 further students left school at the age of 16. For the remainder there was no data.
- **Sixty-five percent (n=26) attended university**, 35% (n=14) did not.

BA SNL Patients and Education Status



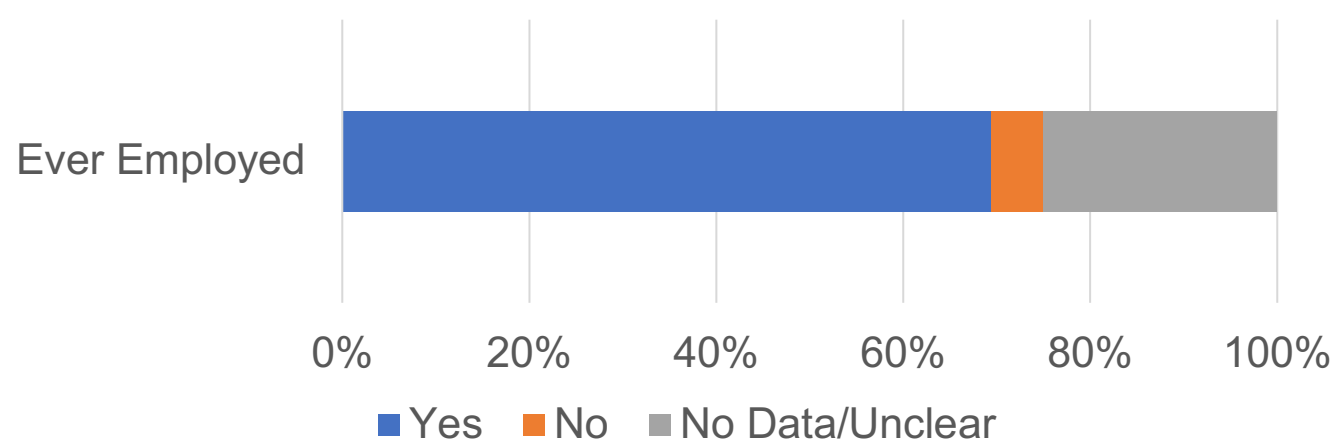
## Patient Characteristics

- The cohort included **72 patients** (49% female), **median age 25 years** at last follow-up (range 16-36).
- Twenty-nine percent had portal hypertension (platelets<150x10<sup>9</sup>/L) and jaundice (bilirubin>20umol/l).

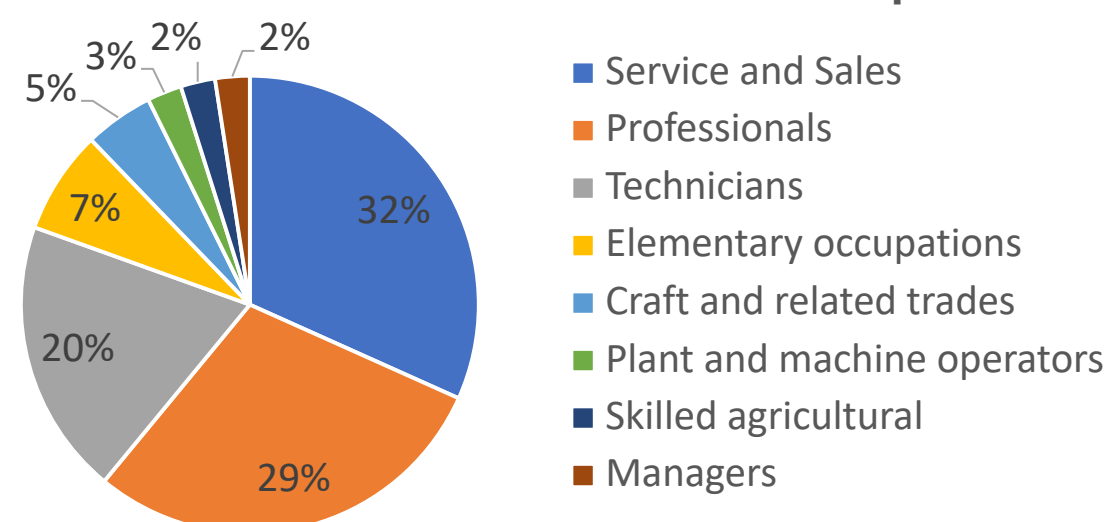
## Employment Status

- **Ninety-six percent (n=50)** of those with data **had held at least one job**.
- Seven percent (n=4) had never had a job.
- The patients were employed in a **range of professions** across various sectors.
- The most common type of employment was in service and sales. Overall 32% (n=13) worked in service and sales, 29% (n=12) as professionals, 20% (n=8) as technicians, 7% (n=3) in elementary occupations, 5% (n=2) in craft and related trades, and 2% (n=1) each in plant and machine operators, skilled agricultural, and manager groups according to ISCO classifications.
- **Sixty-eight percent (n=15)** worked **full-time**, 32% (n=7) worked part-time, with no data for the remainder.

BA SNL Patients and Employment Status



BA SNL Patients and Professional Group



## Family Status

- Overall 35% (n=25) of patients mentioned partners. For the remainder there was no information.
- Six women (of 35) had given birth at least once at last follow-up (17%).
- The six women gave birth to a total of 12 children, at a median age of 25 years (range 21-35).

## Discussion

- **Educational and employment outcomes** for young adults with BA SNL in our centre are excellent **with employment rates significantly better compared to adults** with CLD and post LT. A multidisciplinary approach during adolescence can help young people to achieve their educational and professional potential.
- Regular screening with a questionnaire such as **IMPARTS** is recommended. IMPARTS is a questionnaire initiative trialed at King's College Hospital with sub-questionnaires covering PHQ-9 (assessing depression), HADS (Hospital Anxiety and Depression Scale), AUDIT, WHODAS (quality of life), PHQ-15 (physical symptoms) and other areas assessing mental health and substance use.<sup>3</sup>
- Although research into these outcomes in this population thus far has been limited, the findings of this study were in **agreement with others reporting high employment** in patients with BA who SNL until adulthood, such as Wong et al. who found that 14 of 15 eligible adult patients were in work.<sup>4</sup>

## References

<sup>1</sup> = Ling, SC. *Management of adult survivors of biliary atresia*. Clinical Liver Disease, 2014. 4(4), 86-88.

<sup>2</sup> = Aberg, F. *From prolonging life to prolonging working life: Tackling unemployment among liver-transplant recipients*. World Journal of Gastroenterology, 2016. 22(14), 3701-3711.

<sup>3</sup> = The IMPARTS package for physical healthcare settings. Accessed 29<sup>th</sup> September 2018. Available at: <https://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Quick-links/IMPARTS-Package.pdf>

<sup>4</sup> = Wong, CWY et al. *Long term results and quality of life assessment in biliary atresia patients: A 35-year experience at a tertiary hospital*. Journal of Pediatric Gastroenterology and Nutrition, 2018. 66(4) 570-574.