

SHORT REPORT



Impact of a spleen registry on optimal post-splenectomy vaccination and care

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ABSTRACT

Objective: To evaluate quality of patient knowledge and rates of adherence to guidelines amongst splenectomised patients registered to the Spleen Australia registry.

Method: Registrants recruited for assessment of residual splenic function post-splenectomy also underwent an assessment of quality of knowledge and a review of their long-term management. Eligible patients were ≥ 18 years of age, registered to the Spleen Australia clinical registry and had been splenectomised at least 1 year prior to their visit. Quality of knowledge was assessed using a validated questionnaire used in similar studies. Receipt of immunisations was validated by record review. Chemoprophylaxis use was self-reported by patients. Adherence was evaluated using Australian guidelines.

Results: 77 patients were evaluated for education and adherence. 58% were female, mean age was 58 years, and median duration since splenectomy was 14 years. Most common indications for splenectomy were trauma and haematological conditions. 77% had good knowledge of key educational points to reduce chances of infection. Adherence to immunisations varied with poor adherence to vaccines introduced after 2010. Only 6 patients were adherent to all recommended immunisations. Increasing duration since registration was associated with poorer 13vPCV ($p = 0.008$) and 4vMenCV adherence ($p = 0.001$). Over 70% either currently or had previously used daily chemoprophylaxis and 66% had a supply of emergency antibiotics.

Conclusions: Although registrants are receiving initial and booster vaccinations, they do not receive newly recommended vaccines. In order to maintain long-term adherence, we recommend streamlining health information systems, improving awareness strategies and improving financial access to vaccinations in the community with additional awareness of the activities of the registry.

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Background

The spleen has a major role in immunological protection against infection, particularly against encapsulated bacteria such as *Streptococcus pneumoniae*, *Neisseria meningitidis*, and *Haemophilus influenzae* type b (HiB). After splenectomy, there is a well-established increase in infection risk characterised as overwhelming post-splenectomy infection (OPSI). Although variously defined, OPSI is often a sudden-onset illness which can be lethal within 48 hours.¹ Although OPSI is rare, it has a mortality rate of 50 to 70%.¹ It has been suggested that patient education, early recognition and presentation to medical services for treatment can reduce OPSI mortality rates to 10%.² Management recommendations are detailed in Table 1.

Spleen Australia registers patients with asplenia and hyposplenia with the primary goal of OPSI prevention through education, immunisation and antibiotics. The Spleen Australia clinical registry was first established in 2003 as the Victorian Spleen Registry. To date it has expanded and is now active in Queensland and Tasmania with scope to expand nationwide. Upon registration, patients are educated by phone or in person and receive an education kit providing information on the increased infection

risk and strategies to prevent infection. The kit contains magnet reminders, a wallet-sized medical alert card, information on commercially available bracelet/necklace medic-alerts, the most recent Spleen Australia newsletter, and a personalised immunisation record with a future plan for vaccines. Patients can access an updated immunisation record via a Spleen Australia phone application.^{3,4}

Methods

Registrants invited for assessment of residual splenic function, as part of another study, were reviewed for quality of knowledge and assessment of current management. Eligible participants were ≥ 18 years of age, registered with the Spleen Australia clinical registry and had been splenectomised at least 1 year prior to recruitment. Invitations to participate were mailed to Monash Health patients from the Spleen Australia registry, and an open invitation was published in the annual Spleen Australia newsletter.³ Additional patients were either recruited through referral or upon routine review.

Table 1. Medical recommendations for management of asplenia.

Recommended Immunisations	Schedule
Pneumococcal	13-valent pneumococcal conjugated vaccine (13vPCV)
	Initial (single dose)
	23-valent pneumococcal polysaccharide vaccine (23vPPV)
	Initial dose 8 weeks after PVC, booster at 5 years and final does at 65 (maximum 3 doses)
Meningococcal	Quadrivalent meningococcal conjugated vaccine (4vMenCV)
	Initial and 8-week booster
	5-yearly boosters
	Recombinant meningococcal B vaccine (MenBV)
HiB	<i>Haemophilus influenzae</i> type b vaccine
	Initial (single dose)
Influenza	Influenza vaccine
	Annual
Chemoprophylaxis Recommendations	
Long-term	Daily amoxicillin (or macrolide if allergic) for minimum of 3 years. Life-long chemoprophylaxis for individuals at high risk of infection
Emergency Supply	3gm amoxicillin to be taken in case of fever and sudden illness, and to seek medical attention promptly
Education Recommendations	
<ul style="list-style-type: none"> ● Patients to seek prompt medical attention if unwell ● Patients to seek prompt medical attention if bitten or scratched by an animal ● Patients are recommended to carry a "spleen specific" medical alert in the form of a wallet-sized card or bracelet to alert medical staff if presenting in a state of altered consciousness ● Patients are advised to seek medical advice prior to travel to receive additional vaccines and medications if required 	

Assessment of adherence were based on 2017 Australian guidelines.⁴ Adherence constituted receipt of vaccines in accordance with schedule recommendations. Immunisation history was validated from patient records (hospital records, general practice records and Spleen Australia records). Patients who were ineligible for vaccines due to contraindications were considered adherent to recommendations. Unclear or no documentation of vaccines were considered not administered. Current and previous antibiotic use was self-reported. Quality of knowledge was assessed using a standardised patient knowledge questionnaire⁵ with additional questions assessing engagement with the registry (Table 2). Using the same scoring system and quality of knowledge groups as Hegarty et al,⁵ responses to the first 10 questions were scored from 0 to 2, and quality of knowledge was determined by the total score. Scores of 0 to 5 represented poor knowledge, 6 to 14 represented fair knowledge and 15 to 20 represented good knowledge.⁵

Statistical analysis was performed using SPSS Statistics v25 (IBM). One-sample Kolmogorov-Smirnov test was performed to determine distribution of datasets. Chi-squared tests were performed to assess associations between categorical variables, and Pearson's correlation between continuous variables. Mann-Whitney U tests were used to compare non-parametric datasets. A p value of ≤ 0.05 was considered statistically significant. P values were not adjusted for multiple analysis.

Ethics approval was granted by the Monash Health and Monash University Human Research Ethics Committee. Written consent was obtained from participants.

Table 2. Quality of knowledge and registry engagement questionnaire.

Quality of Knowledge Questionnaire, adapted from Hegarty et al. ⁵	
(1) Do you know what operation you had in (year)? <i>Are you aware if you had your spleen removed?</i>	
(2) Are you aware of any effects this surgery has on your general health? <i>Do you think it increases your chances of certain infections?</i>	
(3) Is there any way of preventing this? <i>Do you know if you had any vaccinations?</i>	
(4) Is there anything else you can do to prevent infection? <i>Are you taking antibiotics?</i>	
(5) How long will you take antibiotics? <i>Will you take them for life?</i>	
(6) What if you are travelling far abroad? <i>Is there a greater risk of malaria?</i>	
(7) What would you do if you got sick, for example catching a cold or flu? <i>Would you take a full dose of antibiotics?</i>	
(8) Do you know the name of your antibiotics?	
(9) Do you have up-to-date full dose antibiotics at home?	
(10) What would you do if you got a scratch or small dog-bite? <i>Would you visit your family doctor?</i>	
(11) How did you get your information about this? Other sources of information?	
(12) Have you discussed this with your family doctor?	
Registry Engagement	
(1) Is your family aware of these risks, if so how?	
(2) Do you remember when you first registered to the Spleen Registry and who referred you to the service?	
(3) Do you carry a medic-alert bracelet or card with you at all times?	
(4) Did you receive a Spleen Australia Education Kit when you were first registered, and did you read through the material?	
(5) What reminders from Spleen Australia do you use (Newsletter or Phone App)?	

Table Legend: If patient did not respond adequately to initial question, prompt question (italicised) was asked. Responses to first 10 questions scored from 0 to 2: 0 = does not know; 1 = moderate passive knowledge; 2 = good active knowledge. Quality of knowledge determined by score on questionnaire: 0 – 5 = poor knowledge, 6 – 14 = fair knowledge, 15 – 20 = good knowledge.

Results

77 of 78 patients recruited participants were reviewed for adherence to guidelines and quality of knowledge. One patient was excluded from this assessment due to time limitations during the appointment. All participants spoke English, 45 (58%) were female, with an average age of 58 years. Our cohort represented long-term splenectomised patients, most commonly splenectomised due to trauma (30%) or haematological conditions (28%), see Table 3.

An overall assessment of quality of education revealed over 75% with good knowledge. No patients had poor knowledge. Over 90% of patients reported engagement with their general practitioner (GP) regarding their spleen care, and 77% of patients carried at least one medical alert at all times (Table 4). 80% of patients recalled receiving the education kit and reading through all the material provided. Only five participants reported not receiving or utilising any reminders from the registry.

Review of immunisation history revealed good adherence rates to 23-valent pneumococcal polysaccharide vaccine, *Haemophilus influenzae* type b vaccine and the annual influenza vaccine (Table 4). However, poorer adherence was observed with 13vPCV (57.1%) and 4vMenCV (39%), which were both not recommended for high risk patients until after 2011.^{6,7} Poorest adherence was observed with the newest vaccine, MenBV (20.8%), which was introduced locally in 2013 and recommended by

Table 3. Patient demographics.

Demographics	
Mean age (range)	57.5 (29 to 88)
Median years since splenectomy (range)	14 (1 to 71)
Median years since registered (range)	5.0 (0 to 14)
Sex	n (%)
Male	32 (42)
Female	45 (58)
Indication for Splenectomy	n (%)
Trauma	23 (29.9)
Haematological	22 (28.6)
Haematological Malignancy	5 (6.5)
Malignancy	8 (10.4)
Iatrogenic Non-malignant	6 (7.8)
Other	13 (16.9)
Recruitment Mode	n (%)
Letter of Invitation	34 (44.2)
Annual Registry Newsletter	37 (48.1)
Routine Review	3 (3.9)
Referral	3 (3.9)
Who completed registration?	n (%)
Self	14 (18.2)
Hospital Staff (Surgeons, Physicians)	36 (46.8)
GP or Practice Nurse	11 (14.3)
Spleen Australia Registry	5 (6.5)
Family	2 (2.6)
Unknown	9 (11.7)

Spleen Australia from 2014. All patients received at least one vaccine. Many patients had previously received at least one dose of 23vPPV (98.7%) or 4vMenCV (62.4%), but had not received booster doses when due, represented by the lower adherence rates (81.8% and 39% respectively). Only six patients were adherent to all recommended immunisation schedules. Meanwhile, 23 were adherent to five of the six recommended schedules, 16 of which had not received MenBV. Poorer 13vPCV and 4vMenCV adherence was observed with increasing duration since registration ($p = 0.008$ and $p = 0.001$, respectively). Whereas poorer uptake of the influenza vaccine was seen in individuals with shorter duration since registration, and among younger patients, consistent with previous epidemiological studies.⁸ Increasing duration since splenectomy was associated with poorer HiB adherence ($p = 0.032$). However this was likely to be confounded by absence of patient records. Education scores were better among those

adherent to 4vMenCV ($p = 0.038$) and MenBV ($p = 0.014$). Recruitment type, utilisation or registry reminders and receipt and use of the education kit were not associated with vaccination uptake (data not shown).

Review of antibiotic use revealed that 35 patients take daily antibiotics and 51 have a valid emergency antibiotic supply, see Table 4. Of the remaining 42 not currently taking daily chemoprophylaxis, 21 had previously been on therapy, 9 ceased after an appropriate length of time (after 3 years), and 7 were unable to recall why they ceased. Of the 26 who did not have an emergency supply of antibiotics, 7 (27%) had never been given a supply, 4 (15%) had a prescription but not dispensed, and 11 (42%) did not renew their prescription. Better knowledge was observed among those with current daily prophylaxis ($p = 0.001$) and current emergency chemoprophylaxis use ($p \leq 0.0001$).

Discussion

The key finding of our study was of poor adherence to newly introduced vaccines amongst registrants despite good quality knowledge. Patient education is a key factor in OPSI prevention along with immunisation and chemoprophylaxis to reduce infection rates post-splenectomy.⁹ In addition to guidelines, use of a registry has been shown to be associated with good quality of knowledge and uptake of vaccines amongst patients¹⁰ and reduction in risk of infections.¹¹

Previous studies have investigated quality of knowledge in other patient cohorts, where Hegarty et al. showed 32.5% asplenic patients had good knowledge⁵ and El Alfy et al. showed 44.8% had good knowledge using the same assessment and scoring system.⁹ In addition, Corbett et al. showed 47% had adequate knowledge using a modified assessment.¹² Premawardena et al. indicated among both registered and non-registered patients 30.6% had good knowledge.¹³ We were unable to recruit non-registered participants through our recruitment model. Although we are unable to directly assess the effect of registration to adherence, our registry cohort had high rates of good quality knowledge, similar to another registry

Table 4. Adherence to guideline recommendations.

Overall Immunisation Schedules Adherence	n (%)	Overall Quality of Education	n (%)
Adherent to all (six) vaccines	6 (7.8)	Poor Knowledge (0 to 5)	0 (0)
Mode of vaccine adherence	5 vaccines	Fair Knowledge (5 to 14)	18 (23.4)
Adherent to five vaccines	23 (29.8)	Good Knowledge (15 to 20)	58 (76.6)
Immunisation Recommendations (On-schedule)	n (%)	Quality of Knowledge	n (%)
13-valent pneumococcal conjugated vaccine (13vPCV)	44 (57.1)	Increased risk of infection after splenectomy	65 (84.4)
23-valent pneumococcal polysaccharide vaccine (23vPPV)	63 (81.8)	Prevention through use of:	
Quadrivalent meningococcal conjugated vaccine (4vMenCV)	30 (39)	• Vaccination	56 (72.7)
Recombinant meningococcal B vaccine (MenBV)	16 (20.8)	• Antibiotics	54 (70.1)
<i>Haemophilus influenzae</i> type b vaccine (HiBV)	69 (89.6)	Understanding of antibiotic use	51 (66.2)
Annual influenza vaccine (2017)	66 (85.7)	Travel recommendations	53 (68.8)
		Take emergency antibiotics and seek prompt medical attention when unwell	57 (74.0)
		Animal scratches or bites	57 (74.0)
Chemoprophylaxis Recommendations	n (%)	Registry Engagement	n (%)
Current Use of Daily Chemoprophylaxis	35 (45.5)	Education kit – Received and utilised	62 (80.5)
Median years of current use	5	Registry Reminders (Newsletter, App)	72 (93.5)
Range	2 to 31	Spleen Medical Alert (Card/Bracelet)	59 (76.6)
Previous Use of Daily Chemoprophylaxis	21 (27.3)	Patient reported GP engagement	73 (94.8)
Median years of previous use	2.0		
Range	0.25 to 14		
Current Emergency Antibiotic Supply	51 (66.2)		

study.¹⁴ Good quality knowledge may have been influenced by recruiting a pro-active cohort and patient initiative to review their management and refresh education principles prior to medical review. A study with both registrants and non-registrants would better assess the effects of registration.

We observed higher uptake of emergency antibiotic supply compared to previous other studies.¹⁵⁻¹⁸ However, some patients did not receive a prescription or a supply of emergency antibiotics, and some did not renew their prescription, suggesting poor initial engagement post-splenectomy or eventual disengagement from their health management. Variable durations of long-term chemoprophylaxis use were noted, despite clear recommendations for its use. The evidence supporting long-term chemoprophylaxis use remains limited,^{19,20} which may explain reluctance of practitioners and physicians to both prescribe long-term chemoprophylaxis as well as cease its use after the recommended 3-year period.

It appeared that registration status alone is inadequate in ensuring immunisation adherence. Consistent with observations by Wang et al,¹⁰ most registrants received some booster vaccinations. However, not all registrants adhered to all recommendations. Particularly poor adherence was seen with vaccines introduced after 2010. *S. pneumoniae* is frequently implicated in severe infection in asplenic.^{21,22} Yet uptake of the conjugated pneumococcal vaccine (13vPCV) was poor, despite evidence of better efficacy than polysaccharide vaccines.²³

We believe that baseline rates of vaccination in registry patients exceed those who have not been registered based on a preliminary study of 218 individuals registered between May 2017 – April 2018, who live in Victoria and were splenectomised before 2003 [1944 – 2002] (prior to establishment of the study). For example, if we look at older vaccines: only 29% had received HiBV and 44% were adherent with 23vPPV at time of registration. Lower rates were seen with newer vaccines: only 9% were adherent with MenBV and 18% with 4vMenCV. In comparison to adherence rates prior to engagement with the registry, adherence rates are higher following registration.

Previous adherence studies have investigated initial vaccination rates and/or generalised uptake of booster vaccines.^{10,17,24-27} Our study was able to not only quantify uptake, but also assessed adherence to guidelines as we collected administration dates and verified administration using patient records. Recent guidelines published in 2017 recommend the two pneumococcal vaccines, two meningococcal vaccines, HiB and influenza vaccines.^{4,28} Most previous studies have investigated 23vPPV, 4vMenCV and HiB vaccine adherence^{24,25,29} and only one included 13vPCV adherence.²⁵ A strength of our study is that it evaluates adherence to 13vPCV and MenBV.

We may have under-reported adherence if vaccine administration was inappropriately recorded or recorded with a different health provider. We may have recruited proactive registrants leading to higher rates of adherence and education. If this were true, this would imply the overall registry population have poorer adherence and education rates. Despite our small sample size, our cohort is a good representation of the registry population as our method of recruitment was largely unbiased and random. In addition, our demographic data follows similar distribution to epidemiological data previously published.³⁰ To establish the true registry adherence rates, a larger cohort study

could be performed. More importantly, we still have yet to define the role and efficacy of antibiotic use in this population and establish infection risk reduction with varying adherence. Registration appears to be associated with infection risk reduction.¹¹ However, we did not investigate infection rates and therefore are unable to comment on the direct protective effect associated with adherence. Further studies correlating infection risk and uptake of recommendations would help guide future management and shape prevention guidelines.

Ongoing health care engagement is essential in maintaining education and adherence.²⁵ The registry primarily provides education at initial registration over the phone where patients can interact with the nurse. We noted that poorer adherence to newer vaccines was associated with increased duration since registration. Although limited by funding, there remains scope for the registry to continually engage and re-educate patients. A workshop or seminar available in-person and online, utilising podcasts and web-based seminars, could be facilitated on a yearly or 3-yearly basis for this purpose, as 3 years has been previously suggested to be the best time for re-education.¹² On a larger scale, a national spleen health day could remind and provide an opportunity for review of patients who are not routinely seen. However, although we did not record location of vaccine administration, most of our patients appeared to engage with a health care worker at least once throughout the calendar year, noted by receipt of their influenza vaccination. Thus, this encounter could be opportunistically facilitated, not only by GPs but also pharmacists and nurses, to review immunisations and have antibiotic supplies renewed.

It appeared that patients and GPs did not recognise when immunisations were due and when vaccine recommendations were updated, as only six patients were adherent to all immunisations. Although the annual newsletter attempts to alert readers of new vaccines or changes to recommendations, including the need for booster doses, evidently it has not been as effective as desired with this area of medical advice. In order to improve adherence, delivery of reminders and alerts must be improved. This could be executed by ensuring important information is the headlining front-page article in the newsletter, as well as utilising push notifications via the phone application. Furthermore, we noted that retrieval of vaccination histories was difficult as they were often duplicated, missing, or with multiple records from various health providers, including the registry. A streamlined centralised patient health record, similar to databases in Denmark and Taiwan³¹ if concurrently linked with health registries, such as the Australian Immunisation Registry and the Spleen Australia registry, would reduce the unnecessary duplication of medical records. Such a platform would facilitate health care through ease of patient history retrieval and could also be utilised to alert not only patients but also their health professionals about new recommendations.

Further barriers to adherence included lack of availability and accessibility to vaccines in terms of both provision of stock and cost. Most patients who were adherent to five of the six recommendations lacked MenBV, which was unavailable due to supply shortages for over 12 months, restored mid-2017. Additionally, despite being recommended in the Australian Immunisation Handbook,³² MenBV, 13vPCV, 4vMenCV remains available

locally to consumers only on a private prescription in the community at a cost of approximately \$A90 to \$A130 per vaccine. Providing these vaccines at a subsidised cost through PBS (Pharmaceutical Benefits Scheme) funding or co-payment schemes, such as subsidies provided at some hospitals for immunocompromised patients, would allow for improved financial access for patients.

Conclusions

Although implementation of a registry appears to positively influence initial adherence and education, our small study has shown that registration alone is inadequate in maintaining long-term adherence. There remains scope for improvement through activities of the registry, engagement through health care workers, improvements in our health information systems and additional support through governmental means. With proactive health care engagement with patients, we can further improve education and adherence and, in turn, patient outcomes.

Disclosure of potential conflicts of interest

No potential conflict of interest was reported by the authors.

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