

Time for a change: People with Haemophilia and Hepatitis C in New Zealand

Topic: Medical – Infectious Complications

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OBJECTIVES

Of the 189 people with bleeding disorders (PWBD) who contracted hepatitis C (HCV) in New Zealand, nearly a third continue to live with a chronic infection.

For the past 4 years an annual survey has been conducted to better understand the demographics affected and the impact of HCV in this community.^{1,2} A review of the results was undertaken to identify any trends or changes among this community in terms of their health and well-being.

METHODS

A self-completed survey was circulated to PWBD and chronic HCV in New Zealand each year from 2010 to 2013.

Respondents were asked about demographic information, employment, treatment for hepatitis C, symptoms, liver health, HCV education, their general health, activities and psycho-social functioning. Annual data was also collected on treatment and deaths.

For the review, the results of the surveys were collated and compared. Statistical differences were calculated with Fisher's exact tests.

RESULTS

An average of 31 surveys (58%) were completed and returned each year. In that time the total number of PWBD affected by HCV alive had reduced from 157 to 139, with the number of PWBD and chronic hepatitis C reducing from 66 to 47 people; 12 having died and seven having achieved a sustained viral response (SVR) to treatment. Another four were awaiting confirmation of an SVR following recent treatment.

There has been a meaningful shift in the make-up of the survey cohort since 2010 [Figure 1]. At the end of 2013, the number of PWBD who had cleared HCV through treatment surpassed the number of PWBD with chronic hepatitis C for the first time. Another change has been the number PWBD and HCV who had not yet tried treatment has halved from 42 to 21.

Until recently, approximately half of the respondents each year reported ever having attempted treatment, with an average of two respondents having attempted treatment in the 12 months prior to the survey, however, in 2013 68% of respondents reported ever attempting treatment, including 14 who had been treated in the last 12 months. The reason for the large uptake of treatment was due to the participation of several members in a clinical trial for HCV therapy, all of whom successfully attained an SVR.³

The majority of survey respondents were consistently aged over 61 years (39 - 53%), with only two people aged under 30 years. A little over half (52-63%) of those aged under 61 years were in full-time employment.

The liver health of PWBD affected by HCV is being better monitored over time. The percentage of respondents having undergone a FibroScan[®] has increased each year from 53% in 2010 to 79% in 2013. The percentage of respondents who indicated they had been diagnosed with fibrosis has increased from 34% in 2010 to 53% in 2013, perhaps due to the increased access to a FibroScan. The percentage indicating they had cirrhosis has, however, remained consistent around 20%. An average of two respondents per year reported having liver cancer.

Trends in well-being are shown in Table 1. Fatigue was reported to affect the most respondents and was the symptom that most impacted on their lives. Also of note, reported feelings of depression have significantly risen over the monitoring period from 3% to 46% (p<0.001).

The majority of respondents reported making beneficial lifestyle choices that support liver health. On average, half of respondents (51%) do not drink alcohol, 77% do not smoke, and 80% felt they had a healthy or very healthy diet. Over time, there has been a significant increase in the percentage of respondents reporting exercising at least once a week from 75% to 86% (p=0.013). This may be partially due to the increased availability of specialised physiotherapy services for haemophilia in New Zealand.

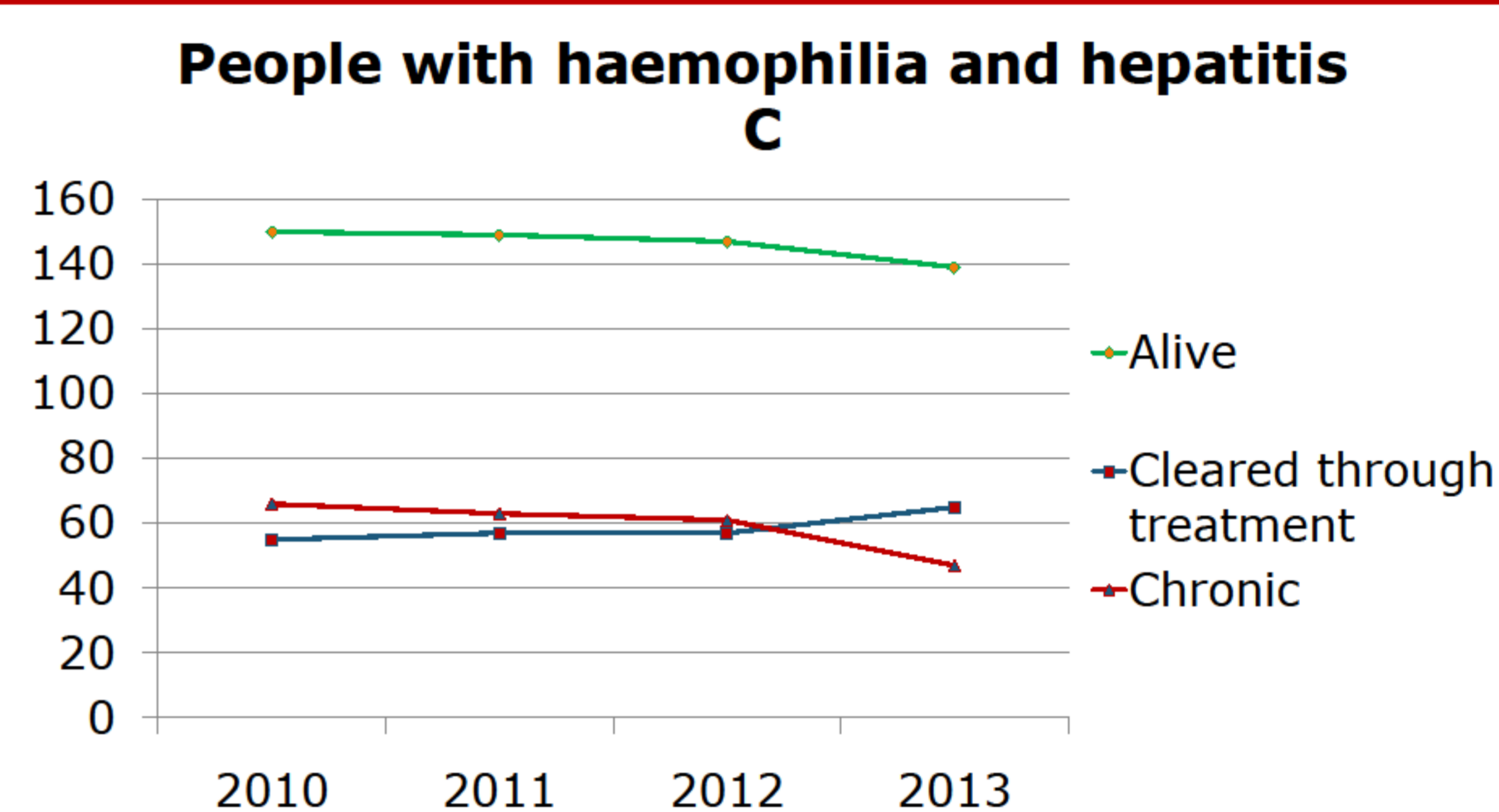


Figure 1. Trends in the numbers of people with bleeding disorders infected with hepatitis C through blood products in New Zealand, 2010-2013.

Table 1. Trends in the well-being of survey respondents with bleeding disorders infected with hepatitis C through blood products in New Zealand, 2010-2013.

Year of Survey	2010		2011		2012		2013	
	n	%	n	%	n	%	n	%
Returned surveys	32	52%	31	58%	32	52%	28	62%
Experienced Fatigue			26	84%	19	59%	16	57%
Experienced Trouble sleeping			20	65%	12	38%	9	32%
Pain - Interferes with normal some activities/all activities	14	44%	15	48%	13	41%	14	50%
Stop activity due to fatigue mostly/completely	10	31%	11	35%	13	41%	13	46%
Depression mostly/completely	1	3%	6	19%	13	41%	13	46%
Healthy diet good or very good	26	81%	26	84%	24	75%	22	79%
Do not drink alcohol	16	50%	14	45%	19	59%	14	50%
Moderate exercise at least once a week	24	75%	23	74%	24	75%	24	86%
Do not smoke	26	81%	21	68%	28	88%	20	71%

CONCLUSIONS

For the first time there has been a noticeable shift in the numbers of PWBD and chronic HCV in New Zealand. While sadly some of the reductions have been through deaths, the opportunity to trial new direct acting antiviral therapies has had a positive impact on the HCV status and overall well-being of a number of PWBD. A major reason for this shift is the additional support that HFNZ Haemophilia

Outreach Workers (HOW) have been able to provide for these people to undertake treatment since an increase in funding specifically for these services was initiated in 2009. Those that continue to live with chronic HCV do, however, continue to be negatively affected by a variety of related symptoms, especially fatigue.

- REFERENCES:**
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 - Steadman C, Hyland RH, Ding X, et al. *Once Daily Sofosbuvir/Ledipasvir Fixed-Dose Combination With Ribavirin in Patients With Inherited Bleeding Disorders and HCV Infection*. Presented at the Asian Pacific Association for the Study of the Liver (APASL), Brisbane, Australia. March 12-15, 2014.

