

Understanding the hepatocellular carcinoma (HCC) patient landscape: Results from the 1st global survey of people living with HCC

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Background

- Multiple support groups exist for general liver conditions & diseases
 - However, there are few organisations **focusing solely on HCC**
 - It is possible that HCC patients are **missing out** on valuable support and information
 - There is **limited information** on the global patient journey due to lack of patient surveys
- Aim:** To develop a **global survey** in order to better understand the **HCC patient experience** and to compare the **effects** of later stage treatment on **quality of life (QoL)**

Method

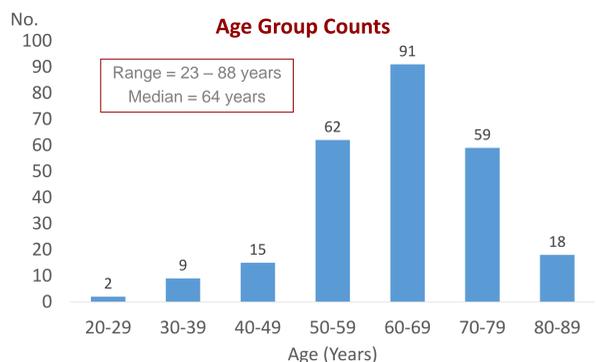
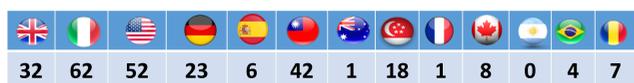
- 7 patient charities and >15 medical centres in **13 countries** developed the survey, which was approved by scientific advisory boards
- hcc-voices.com contains **32 closed- and open-ended questions** on demographics, diagnosis, and treatment (side effects, QoL, treatment access and most-recent treatment)
- Patients either completed the survey following self-identification or were asked to complete the survey by nurses at their Dr's office
- Available in **8 languages** (Chinese, English, French, German, Italian, Portuguese, Romanian & Spanish) online, and in hard-copy in some medical centres, from **1st November 2016 to April 2017**

Results

Demographics

• 256 respondents between November 2016 and April 2017

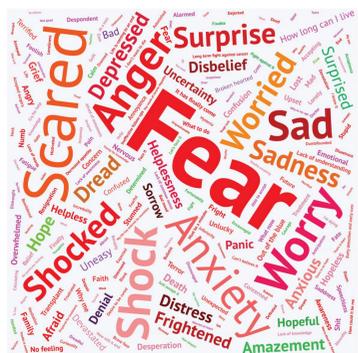
Respondents per country:



Male = 178 (70%) Female = 78 (30%)

Diagnosis

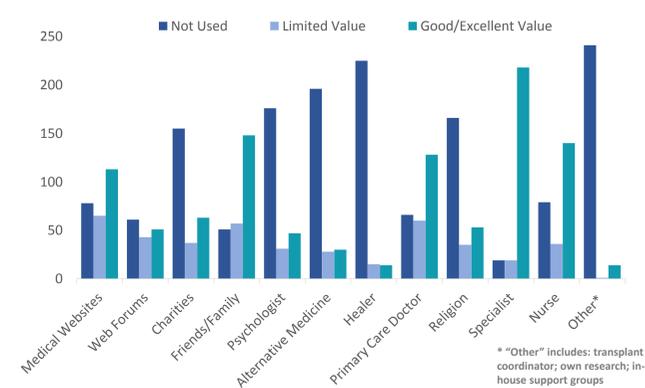
Which 3 words best describe your feelings when you learned you had HCC?



Do you feel you received enough information about HCC and its treatment at the time you were diagnosed?

Yes = 81 (32%) No = 175 (68%)

During diagnosis/treatment where did you go for advice and how useful was it?



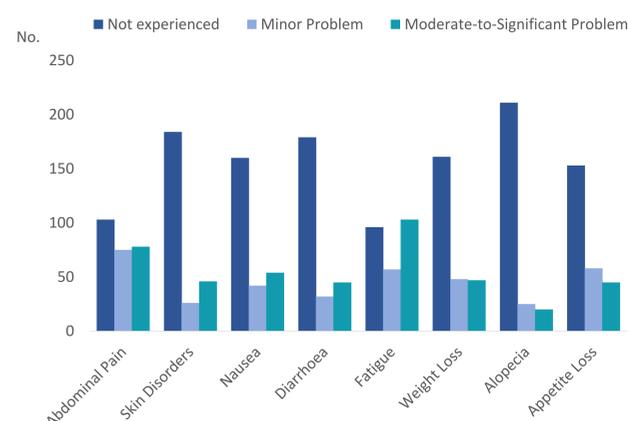
General Treatment Effects

What HCC treatments have you received at any stage since your diagnosis?

Treatment	Number Respondents
Liver Transplant	53 (21%)
Surgery	75 (29%)
Liver Ablation	85 (33%)
External Radiotherapy	11 (4%)
SIRT	33 (13%)
TACE	111 (43%)
Sorafenib	46 (18%)
IV Chemotherapy	10 (4%)
Alternative Medicine	15 (6%)
No Treatment Offered	10 (4%)
Treatment Declined	5 (2%)

TACE followed by liver ablation, surgery and liver transplant were the most common forms of treatment

What impact have treatment side effects had on your QoL?



Fatigue had the biggest impact on QoL, followed by abdominal pain. Fatigue was longer lasting than other side effects

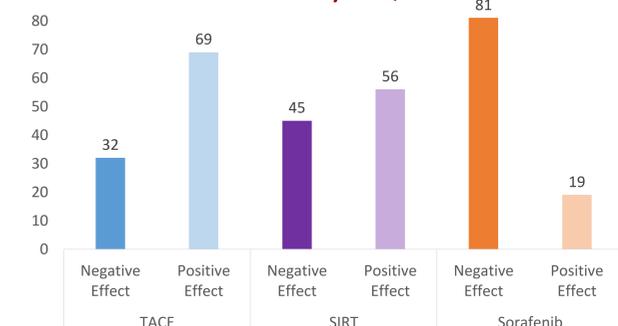
Impact of Most Recent Treatment

Excluding surgery what has been the most challenging HCC treatment?



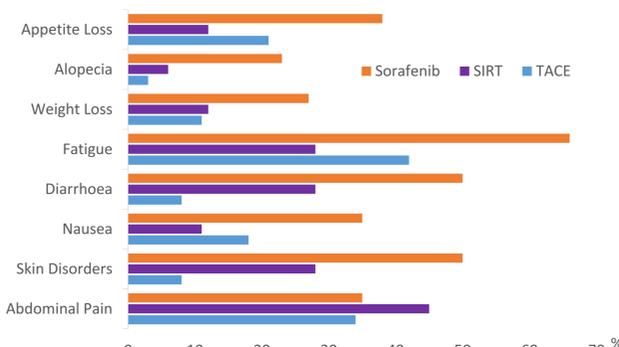
TACE was the most challenging treatment followed by Sorafenib

How has your most recent treatment affected your QoL?



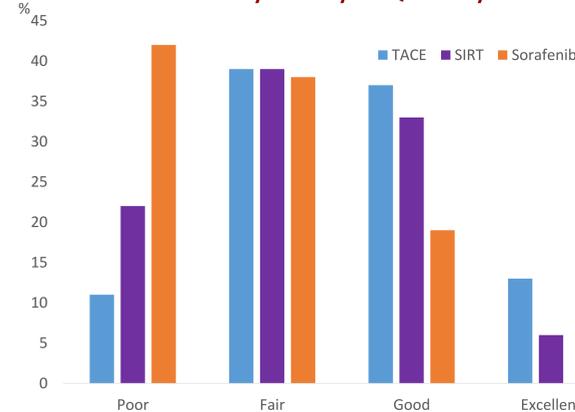
Patients requiring treatment post-surgery, transplant or ablation have TACE (used earlier in treatment), SIRT or sorafenib. Sorafenib had a larger negative, and smaller positive, impact on QoL than TACE or SIRT

Proportion of respondents whose late stage treatment side effects had a moderate-to-significant impact on QoL



Moderate-to-significant side effects impacting QoL were more frequently reported by those treated with sorafenib, compared to TACE or SIRT

How would you rate your QoL today?



Those whose most recent treatment was sorafenib were more likely to rate their current QoL as poor and less likely to rate it good or excellent than those treated most recently with either TACE or SIRT

Conclusions

- Median age was 64 (range from 23-88) and respondents tended to be male
- Feelings upon diagnosis were unsurprisingly negative
- Most patients with HCC need more information about their disease
- Side effects like fatigue and abdominal pain had the biggest negative impact on QoL
- Most patients undergoing palliative oral systemic chemotherapy report more side effects that have a significant impact than those treated with liver-directed SIRT or TACE
- Increased side effects lead to more reports of reduced QoL
- Those with incurable HCC need better treatment strategies to maintain QoL

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