

# The Patient Experience of Alcohol Use Disorder

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## BACKGROUND

- Although commonly associated with relaxation, enjoyment, and social gatherings, the consumption of alcohol carries a risk of adverse health and social effects due to its intoxicating, toxic, and dependence-producing properties. It is the leading risk factor for disease burden in the Western Pacific and the Americas and the second largest in Europe.
- Alcohol use disorder (AUD) is a problematic pattern of alcohol use leading to clinically significant impairment or distress. AUD affects an estimated 76.3 million people worldwide and is associated with 2.5 million deaths annually.<sup>1,2</sup>
- Quality of life is recognised as an important outcome in addiction research and clinical practice.<sup>3</sup>
- Health-related quality of life (HRQOL) is defined as “the patient’s subjective perception of the impact of his disease and its treatment(s) on his daily life, physical, psychological and social functioning and well-being.”<sup>4</sup>

## OBJECTIVE

- To determine the patient-perceived impact of AUD and to identify the key domains of HRQOL related to AUD from the patient perspective.

## METHODS

### Patient Sample

- The study sample included patients with current or remitted AUD in the United Kingdom (UK) and France.
- There were three patient recruitment sites:
  - Royal Liverpool and Broadgreen University Hospital Trust Alcohol Services in Liverpool, UK
  - Centre d'Addictologie of the Hôpital Paul-Brousse in Villejuif, France
  - Centre Médico-Psychologique B of the Centre Hospitalier Universitaire in Clermont-Ferrand, France
- Before initiation of the study, full approval was granted by the relevant human ethics and research review authorities in the UK and France.
- Table 1 presents the inclusion and exclusion criteria for patient recruitment.

Table 1. Inclusion and Exclusion Criteria for Patient Recruitment

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>Patient meets clinical diagnostic criteria of current or remitted (remitted for between 1 and 12 months) alcohol abuse or dependence, as defined by DSM-IV and assessed with the M.I.N.I. 6.0<sup>5</sup></li> <li>Patient is aged 18 years or older</li> <li>Patient has the cognitive ability to participate in a focus group or cognitive debriefing interview (as judged by the clinical team)</li> <li>Patient is able to provide written informed consent</li> </ul>	<ul style="list-style-type: none"> <li>Patient has learning difficulties that prevent him/her reading and responding to questionnaires</li> <li>Patient has a major physical comorbidity judged by the clinical team to be a significant influence on the patient’s day-to-day life (e.g., liver failure)</li> <li>Patient has another axis 1 disorder (with the exception of nicotine dependence), as judged by the clinical team</li> <li>Patient is judged by the clinical team to be incapable of participating in the study (e.g., if the patient is unable to give fully informed consent)</li> <li>Patient is currently taking a drug used off-label for the treatment of alcohol abuse or dependence</li> <li>Patient is undergoing acute withdrawal treatment or is experiencing acute withdrawal symptoms judged by the clinical team to be a significant influence on the patient’s day-to-day life that is likely to continue to the time of study participation</li> <li>Patient has significant cognitive impairment, as judged by the clinical team</li> </ul>

DSM-IV = Diagnostic and Statistical Manual of Mental Disorders, 4th Edition; M.I.N.I. = Mini-International Neuropsychiatric Interview.

### Data Collection and Analysis

- Focus groups were conducted in both the UK and France to determine the impact of AUD from the patient’s perspective.
  - Potential concepts of interest for exploration in the focus groups were identified from the literature.<sup>6</sup>
  - A group discussion guide was developed to explore these concepts, as well as to identify any other key areas of impact for patients.
- The groups were audio-recorded and transcribed, and thematic analysis was conducted on the data facilitated by the coding software ATLAS.ti 6.2.

## RESULTS

### Sample Characteristics

- A total of 38 patients took part in 10 focus groups: 6 in the UK and 4 in France.
- Table 2 presents patient demographic and disease characteristics.
- All patients met the diagnostic criteria for alcohol dependence. Participants in the UK groups were generally more severe, with a minimum M.I.N.I. dependence score of 4 out of a possible 7, compared with a minimum of 3 in France.

Table 2. Characteristics of the Focus Group Patient Sample

Sample Characteristic	UK (n = 17)	France (n = 21)
<b>Age, years</b>		
Median (IQR)	42 (38-52)	48 (42-50)
Range	23-65	31-69
<b>Sex, n (%)</b>		
Male	12 (70.6)	14 (66.7)
Female	5 (29.4)	7 (33.3)
<b>Relationship status, n (%)</b>		
Married or living as	3 (17.6)	10 (47.6)
Not married or living as	14 (82.4)	11 (52.4)
<b>Employment status, n (%)</b>		
Working	5 (29.4)	11 (52.4)
Not working	12 (70.6)	10 (47.6)
<b>DSM-IV diagnosis, n (%)</b>		
Dependence	17 (100)	21 (100)
Abuse	0 (0)	0 (0)
<b>Current/remitted AUD, n (%)</b>		
Current	8 (47.1)	12 (57.1)
Remitted	9 (52.9)	9 (42.9)

IQR = interquartile range.

Figure 1. Thematic Map From Focus Groups in the UK

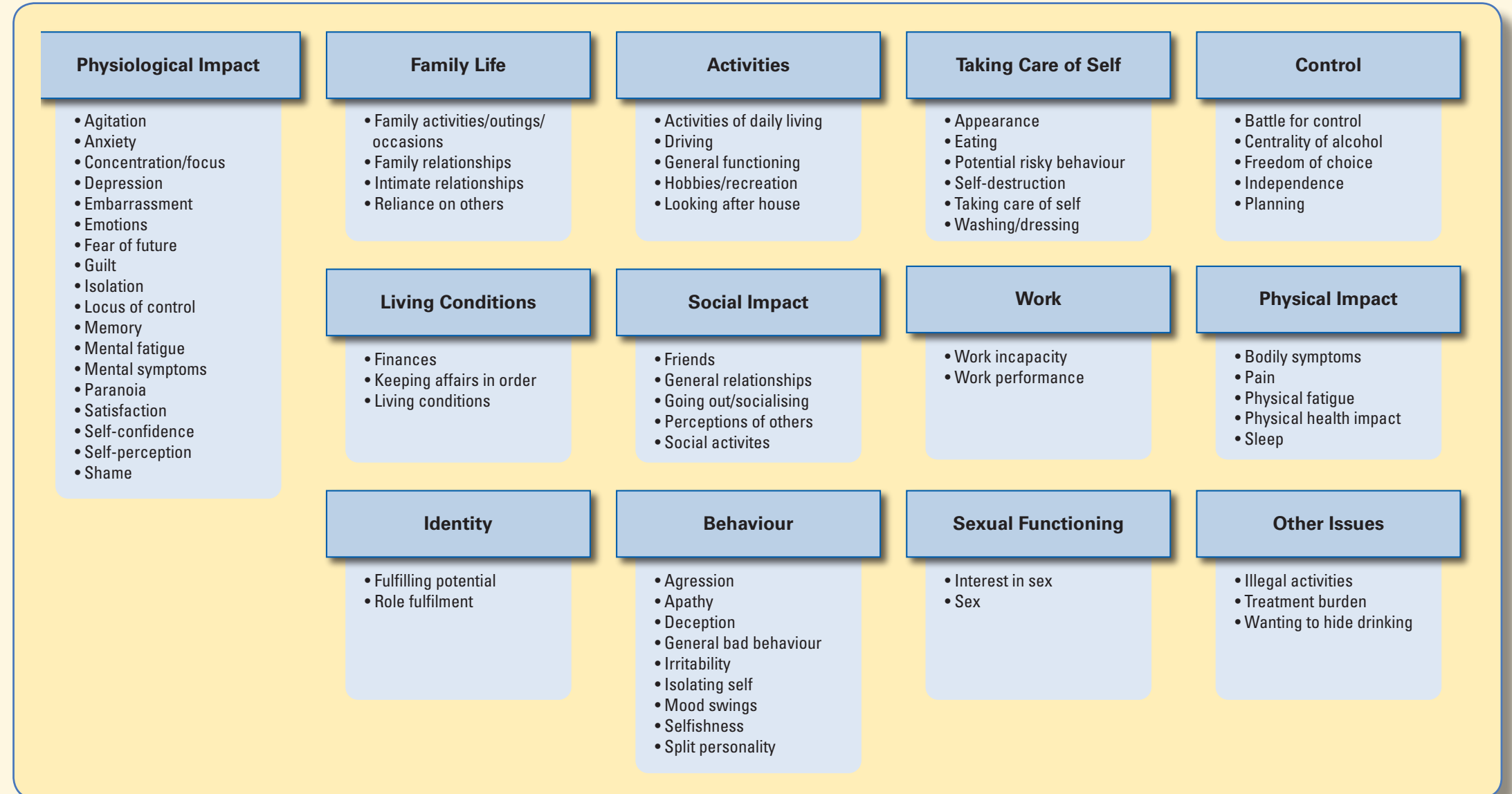


Figure 2. Thematic Map From Focus Groups in France

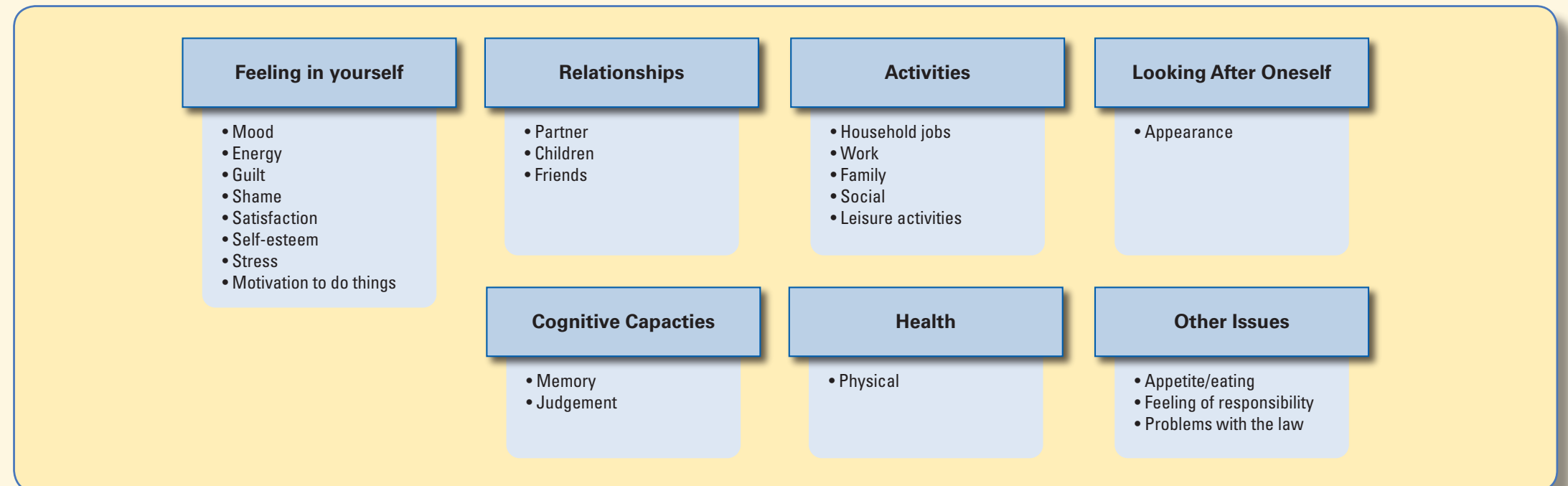
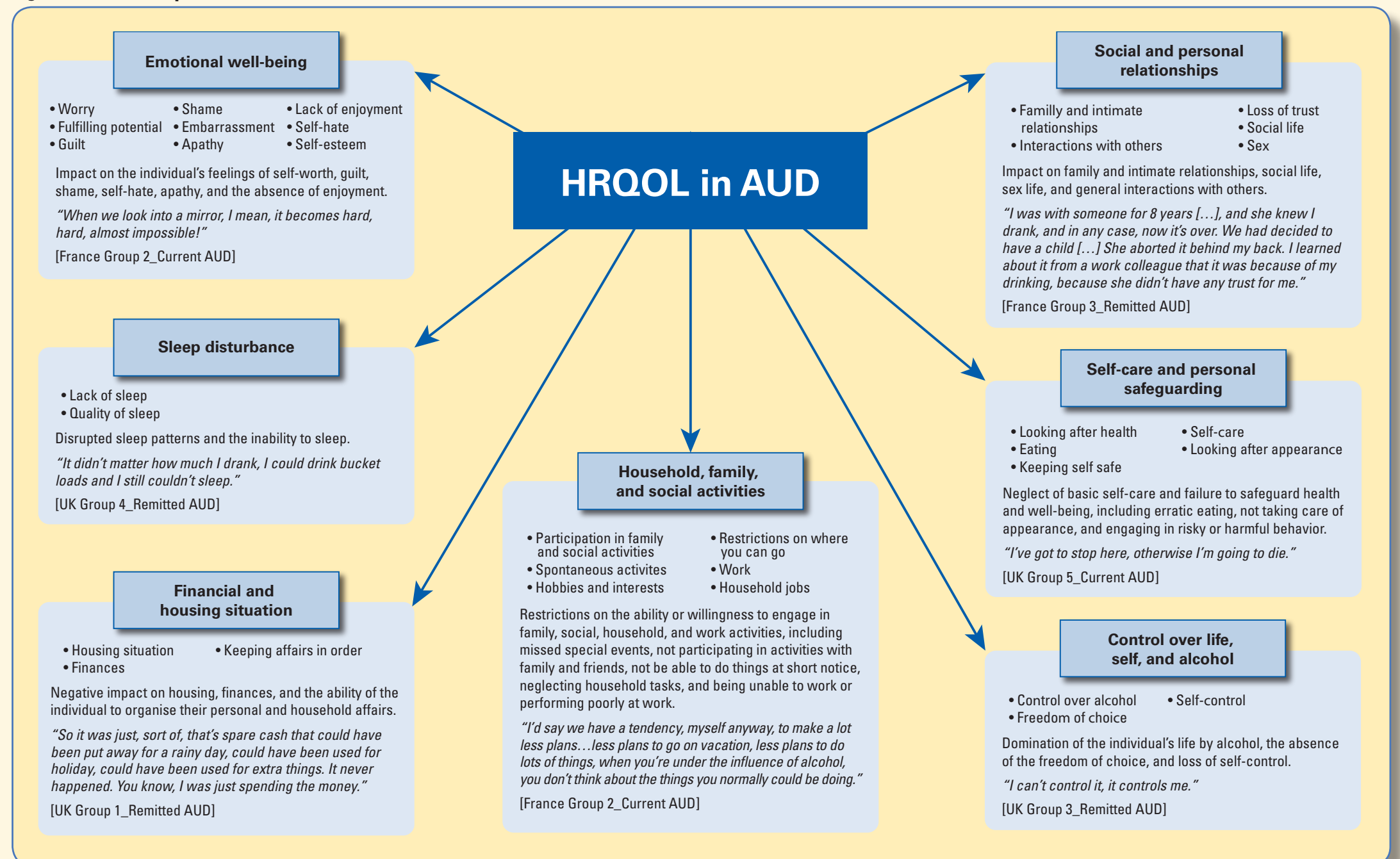


Figure 3. HRQOL Impact of AUD



### Emergent Themes

- Twelve themes were identified from the analysis of the focus group data in the UK (Figure 1), and eight themes were identified in France (Figure 2).
- Many of the issues expressed by patients were similar across the two countries, even if categorised in the analysis under different themes.
- Patients in the UK described a greater impact of drinking on their behavior (e.g., aggressive behavior) and were more likely to engage in solitary drinking than patients in France. Patients in France described greater negative social consequences of abstinence.

### Patient Experience of AUD

#### Cycle of Consumption and Dependence

- A number of patients used alcohol as a coping mechanism to deal with other problems. It provided an escape from reality, acting as a relaxant, inducing a sense of euphoria, and boosting self-confidence.
- However, for many, the negative consequences of drinking began to overshadow any short-term benefits.
- As consumption increased, several patients described needing a drink to feel “normal” or, for some, to take away withdrawal symptoms.

*“I have an ideal of quality of life, and when I can't have it, I feel insufficient, incapable. That's when I need a boost from alcohol. I say to myself 'I'm going to have a little bit of wine, and things will go better.' But then I have another and another and so on so that finally it goes beyond the limit, and my quality of life is made less.”*  
[France Group 1\_Current AUD]

#### Key Areas of Impact

- Patients described the considerable and far-reaching consequences of AUD, related to consumption, intoxication, and dependence on alcohol.
- Patients who had stopped drinking described the continual battle to remain abstinent, the lasting legacy of damaged relationships, and the ongoing feelings of guilt and low self-worth resulting from past behaviors.
- Across the two countries, seven key areas of impact of AUD were identified (Figure 3).

## CONCLUSIONS

- AUD has a profound impact on the way individuals feel and function, and the consequences of intoxication and dependence permeate all aspects of life.
- Loss of control is a significant area of impact for many patients, but this concept is not assessed in existing measures used in AUD studies.<sup>6</sup>
- The negative consequences of alcohol persist beyond periods of drinking, suggesting that drinking cessation or reduced consumption may not be the most relevant outcome to determine treatment benefit from the patient perspective.
- There is a clear need for a new instrument that assesses the impact of AUD, focusing on issues of importance to patients.
- The findings from this qualitative study were used to develop the Alcohol Quality of Life Scale (AQoLS), a new instrument designed to assess the impact of AUD from the patient’s perspective.<sup>7</sup>

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