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**Armstrong, A., Duracinsky, M., Lalanne, C., de Silva, M., Jamal, L., Herrmann, S., Carrieri, P., Davril, J. and Chassany, O. (2011)**  
***A new framework for understanding the impact of hepatitis C and its treatment on quality of life.*** In: **ISPOR 14th Annual European Congress, 5 - 8 November, Madrid, Spain.**

Poster presentation

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# A NEW FRAMEWORK FOR UNDERSTANDING THE IMPACT OF HEPATITIS C AND ITS TREATMENT ON QUALITY OF LIFE

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## DEVELOPMENT OF CONCEPTUAL FRAMEWORK

### Objective

To develop a conceptual framework demonstrating the impact of Hepatitis C (HCV) and treatment on health-related quality of life (HRQL).

### Methods

(1) PUBMED literature were reviewed. HRQL issues raised by patients in qualitative studies were compared with those emphasized in quantitative studies. Numerous issues important to patients were not adequately covered by commonly used HRQL instruments.

(2) An in-depth interview guide was developed to investigate the issues raised in both study types. HCV patients (M age=51; 18 men, 21 women) from Australia (n=8), Brazil (n=20) and France (n=11) have been interviewed, the goal being to interview 20 patients from each country. Interview data were translated into English and examined for recurring issues, which were grouped by code, category, concept and theme as shown in Figure 1. Commonalities and variation within emerging codes, categories, concepts and themes were explored, iteratively re-examined and refined.

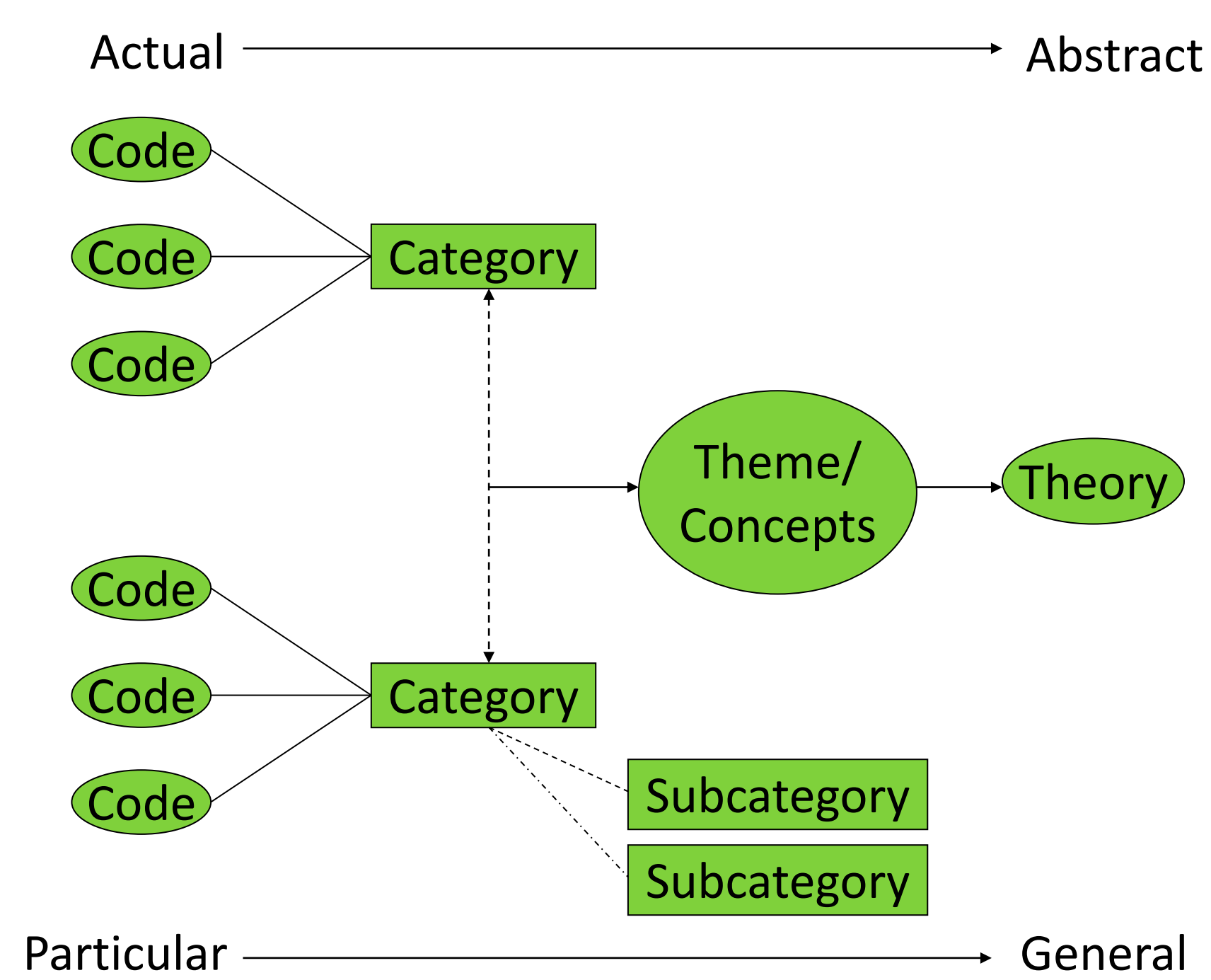


Figure 1. Interview coding scheme

### Results

The process of analysis facilitated construction of an HCV-specific HRQL Conceptual Framework (displayed Right) within which salient and frequently-raised issues were organized into Physical, Mental, Social, Adaptation and Treatment domains. This framework was compared against HRQL instruments commonly used in HCV research, including the SF-36<sup>1</sup> and Hepatitis Quality of Life Questionnaire (HQLQ)<sup>2</sup>. HCV-related issues absent or not adequately represented by these instruments include: (Physical) bodily changes, sexual dysfunction, and fatigue variability; (Mental) illness uncertainty and unpredictability, identity change, emotional volatility, minor cognitive impairment, concerns for the future; (Social) social identity change, transmission-related issues, multidimensional nature of stigma, social isolation and withdrawal, loss of independence and reduced participation modes; (Adaptation) positive disease impact, adjusting current activity levels and future perspective; (Treatment) treatment fears, side effects, management and adherence.

### Conclusions

Numerous important issues raised by HCV patients were absent or inadequately represented by commonly used HRQL instruments. The proposed HCV HRQL conceptual framework encompasses these issues. This framework forms the foundation for the development of a new HCV-specific HRQL instrument.

### References

- Ware JE, Sherbourne CD. The MOS 36-Item Short Form Health Survey (SF-36). Med Care 1992; 30: 473-83.
- Bayliss MS, Gandek B, Bungay KM, Sugano D, Hsu MA, Ware JE Jr. A questionnaire to assess the generic and disease-specific health outcomes of patients with chronic hepatitis C. Qual Life Res. 1998 Jan; 7 (1) :39-55.

## CONCEPTUAL FRAMEWORK: HEPATITIS C-SPECIFIC HEALTH-RELATED QUALITY OF LIFE

