

When healthcare professionals express themselves: results overview of the qualitative phase of the HERO initiative

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L Palareti;¹ S Potì;¹ A Iorio;² F Cassis³

¹University of Bologna, Bologna, Italy; ²McMaster University, Hamilton, ON, Canada; ³University of São Paulo Faculty of Medicine Clinics Hospital, São Paulo, Brazil

Objective

- To evaluate the main issues that characterize the experiences of healthcare professionals (HCPs) while treating patients with hemophilia.

Conclusions

- Five main themes were identified that affected engagement, well-being, and perception of self-efficacy that each HCP may face when treating patients with hemophilia, regardless of geographic location.
- Increased awareness of these themes can improve the quality of care, focus more attention on the meaning of comprehensive care and of multidisciplinary approach, and reduce burnout and psycho-emotional difficulties.
- These results can be used to develop a 'core curriculum', focused on cross-professional competencies and 'soft skills', to improve the comprehensive care for patients with hemophilia. Giving the timing of the interviews, perceptions may have changed since 2010.

Introduction

- Assessing the subjective experiences of healthcare professionals (HCPs) who treat patients with hemophilia is relatively new, with little information in the literature.
- Effective relationships between HCPs and patients are highly relevant to achieving good treatment outcomes.¹
- Using qualitative data from the Haemophilia Experience, Results and Opportunities (HERO) initiative, we evaluated the main issues that HCPs experience while treating patients with hemophilia.

Methods

- HCPs were invited to participate in a semi-structured interview process.
- Thematic analyses of the interviews (which were all in English) were performed using the software T-LAB (<http://tlab.it/en/book.php>, Milan, Italy) to identify the dominant themes.
- The interviews were conducted in 2010 and the process is summarized in Figure 1.

Results

- A total of 62 HCPs from seven countries completed the interview (Figure 1).
 - Most of the respondents were physicians (n=31), while other respondents included nurses (n=16), physiotherapists (n=9), social workers (n=3), and psychologists (n=3).
- Five dominant themes emerged, identifying factors that could stimulate growth and motivation, and reduce work-related burnout:
 - 1. Policy, Resources, and Network**
 - This theme described the general vision of care.
 - Central to the theme were ideas of multidisciplinary care and the influence of (for example) local policies, and organizational structure.
 - All possible stakeholders were mentioned, except the patients and their families (critical to comprehensive care).
 - The main concerns were financial (both as a resource for care and salary) and the HCPs' allocated time for each patient.
 - 2. Working with Adult Patients**
 - HCPs tended to mostly view adult patients from an impersonal, biological perspective.
 - Both patients and HCPs viewed the development of the most ideal treatment option as a difficult challenge to achieve, and often dependent on serendipity.
 - Chronicity and hemophilia-related complications conveyed frustration and feelings of helplessness to both HCPs and patients.
 - Factor replacement therapy was seen as the main reason for improvement.

3. Coping with Adolescents

- Although this theme contained many emotions and challenges in communication, the HCPs seemed motivated, hopeful, and focused on a psychosocial perspective rather than a biological perspective.

4. Counselling and Communication During Diagnosis and Reproductive Choices

- Giving medical information to patients and their family members while coping with emotional reactions (panic, fear, denial, etc.), and adjusting the language to be appropriate for different social/cultural contexts, was challenging for HCPs.
- The 'mother/woman' was viewed as the main communicator.
 - There was a lack of knowledge regarding the feelings and worries of the 'husband/man' with respect to the diagnosis of a son, or the wife's carrier status.

- There was also a lack of optimal strategies about how best to manage communication with the entire family.

5. Considering Family Dynamics

- For HCPs, the family plays an important role during childhood, but this importance diminishes over time as patients become less dependent on their parents.
 - Considering each patient within the context of their relationships to understand their motivations and to find conditions for successful treatments, regardless of their apparent autonomy, is a competence that still requires improvement.

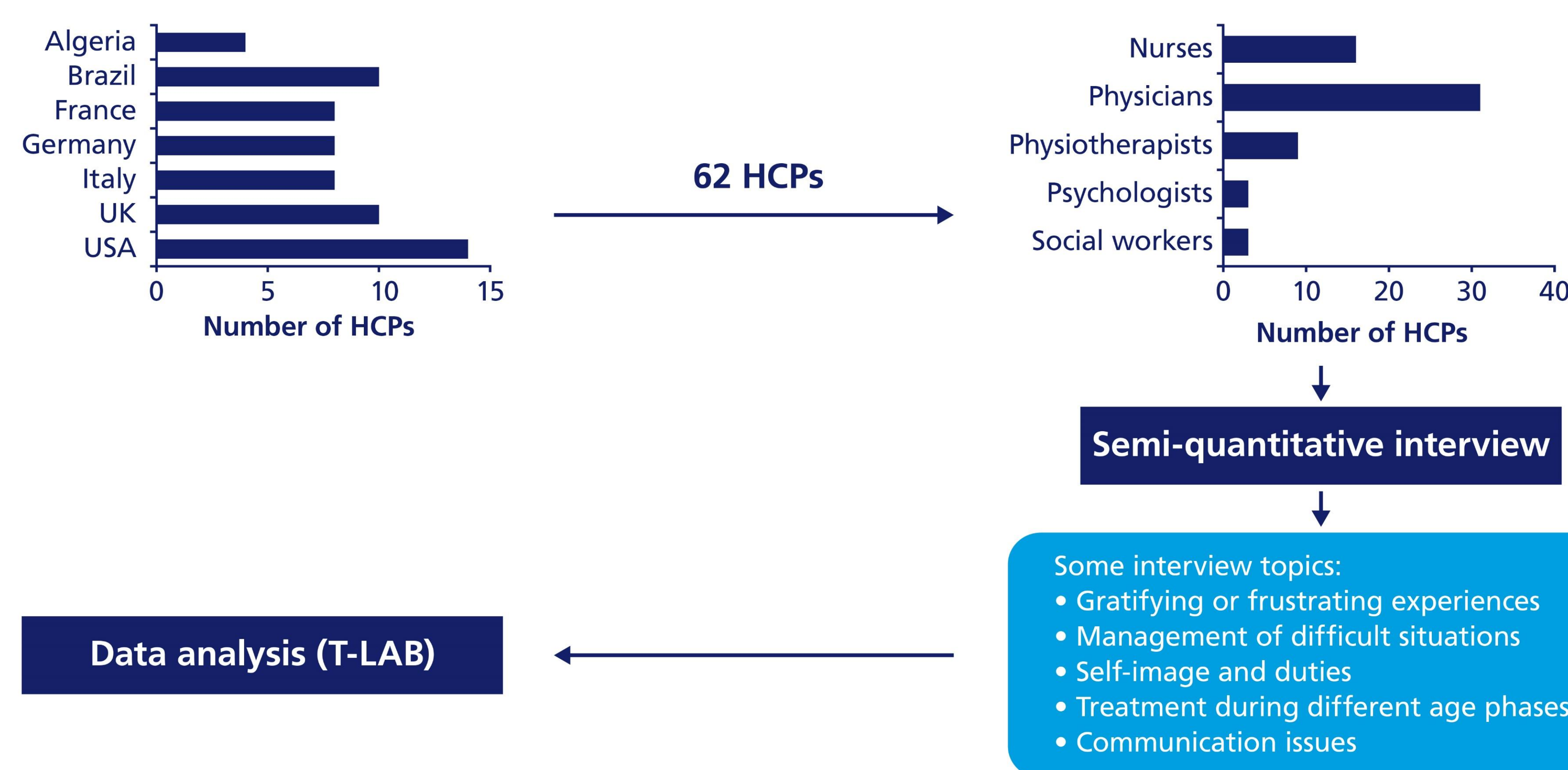
Reference

1. Palareti L, et al. *Int J Qual Health Well-Being* 2015;10:28915–28925.

Conflict of interest disclosure

LP, SP, and FC have nothing to declare. AI's institution has received project-based funding via research or service agreements with Baxalta, Bayer, Biogen Idec, Grifols, Novo Nordisk, Octapharma, and Pfizer.

Figure 1 Semi-structured interview process.



HCPs, healthcare professionals.

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Care Delivery
Laura Palareti

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