

Quality of Life and experience of patients with HIV and of other chronic diseases with Spanish health care system. Insights from the IEXPAC project.

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BACKGROUND

- Improvements over the time in quality-of-care lead to a more positive experience for patients with chronic diseases. Careful measurement of patients' experience can provide meaningful data for further enhancements in quality-of-care, clinical effectiveness and patients' safety.
- This study describes the experience with the health-care system and health-related quality of life (HRQoL) in Spanish patients with HIV (PHIV) infection and other chronic diseases.

METHODS

- 1,618 patients participated in an observational cross-sectional study. Surveys were handed to patients with 4 different chronic diseases with at least one comorbidity: PHIV, rheumatic diseases (RD), inflammatory bowel disease (IBD) or diabetes mellitus (DM).
- The experience with the health-care system was measured through the validated IEXPAC scale (<http://www.iemac.es/iexpac/>). This scale contains 12 items with 5 possible answers from “always” to “never”, it yields a score from 0 (worst) to 10 (best experience), and measures three dimensions: productive interactions, new relational model and patient self-management. HRQoL and beliefs about medication were measured by EQ-5D-5L and BMQ questionnaires respectively. Also the survey incorporated another variables related to the management of the disease and to health care process.
- Patients filled the questionnaire anonymously at home and sent it by pre-paid mail.

RESULTS

- 2,474 patients received the survey and 1,618 were returned (65.4%):467 corresponded to PHIV [mean-age 51.5±10.8 years, 27% women]. Mean IEXPAC score for PHIV was 6.6 ± 1.7. Responses to IEXPAC are displayed in table 1.
- Patients declared a median of 8 visits to primary care or specialty clinics in the last year and 29% had visited an emergency room. In the last 3 years, 48% had been hospitalized. PHIV attended least frequently to primary care (76.20% vs all 83.40%), declared a median of 3.89 visits to specialty clinics and reported higher % of once-daily dosage medication (50.20% vs all 31.80%).
- PHIV differ significantly in terms of: considering themselves well informed about their disease (82% versus all 75%); their perception of need of medication, which is significantly the highest (22.20±3.87); and being the least concerned about medication (13.32±4.82) (Figures 1 & 2).
- PHIV described most often no limitations in any of the 5 dimensions included in EQ-5D-5L; their scores on the visual analogue scale "Your health today" were the highest (73.3±19.1) (all multiple comparison tests HIV infection versus other, p<0.001) (Figure 3).

Figure 1: Level of information about disease

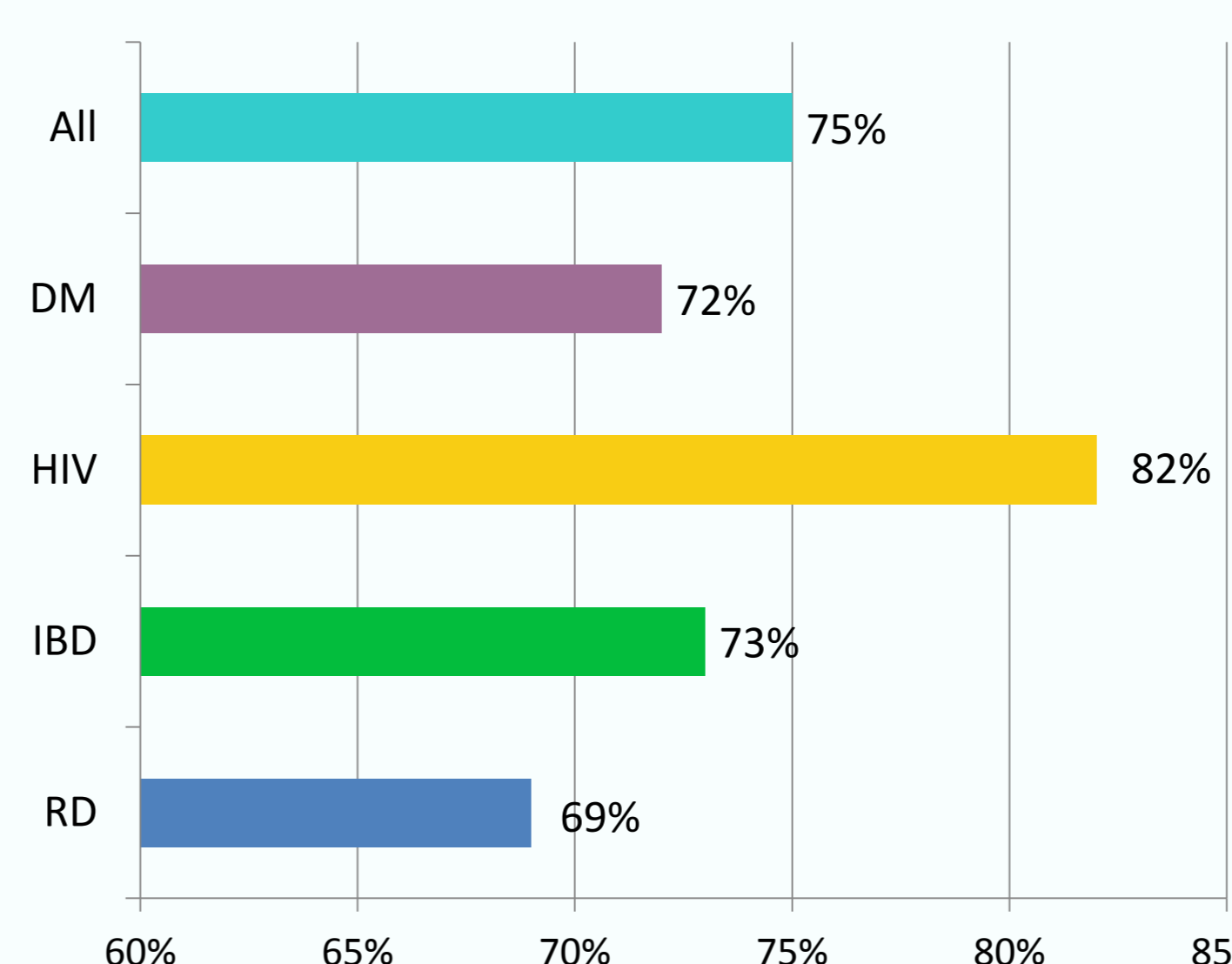


Figure 2: Perception of need of medication

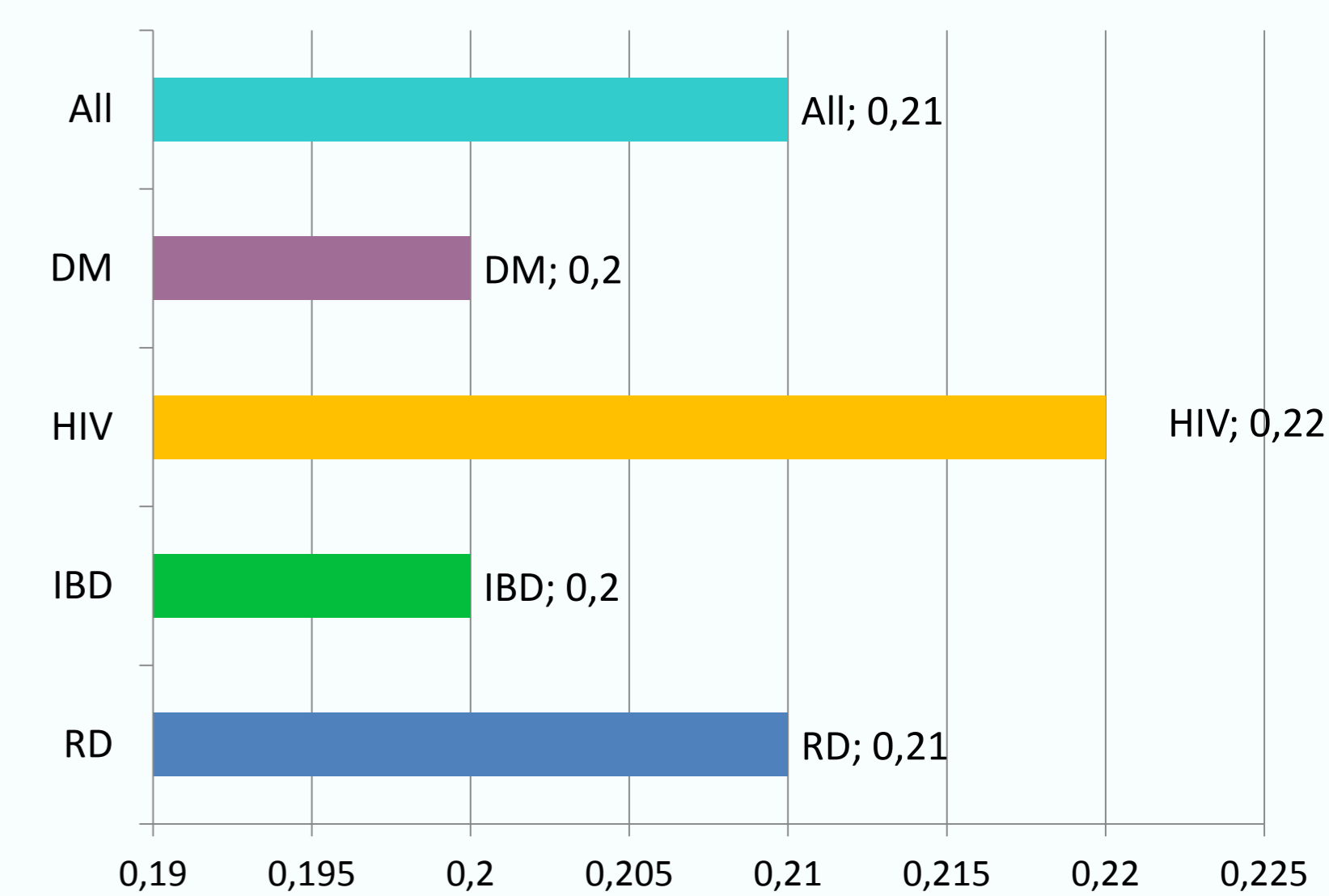


Figure 3: Answers to Visual Analog Scale EQ-5D-5L

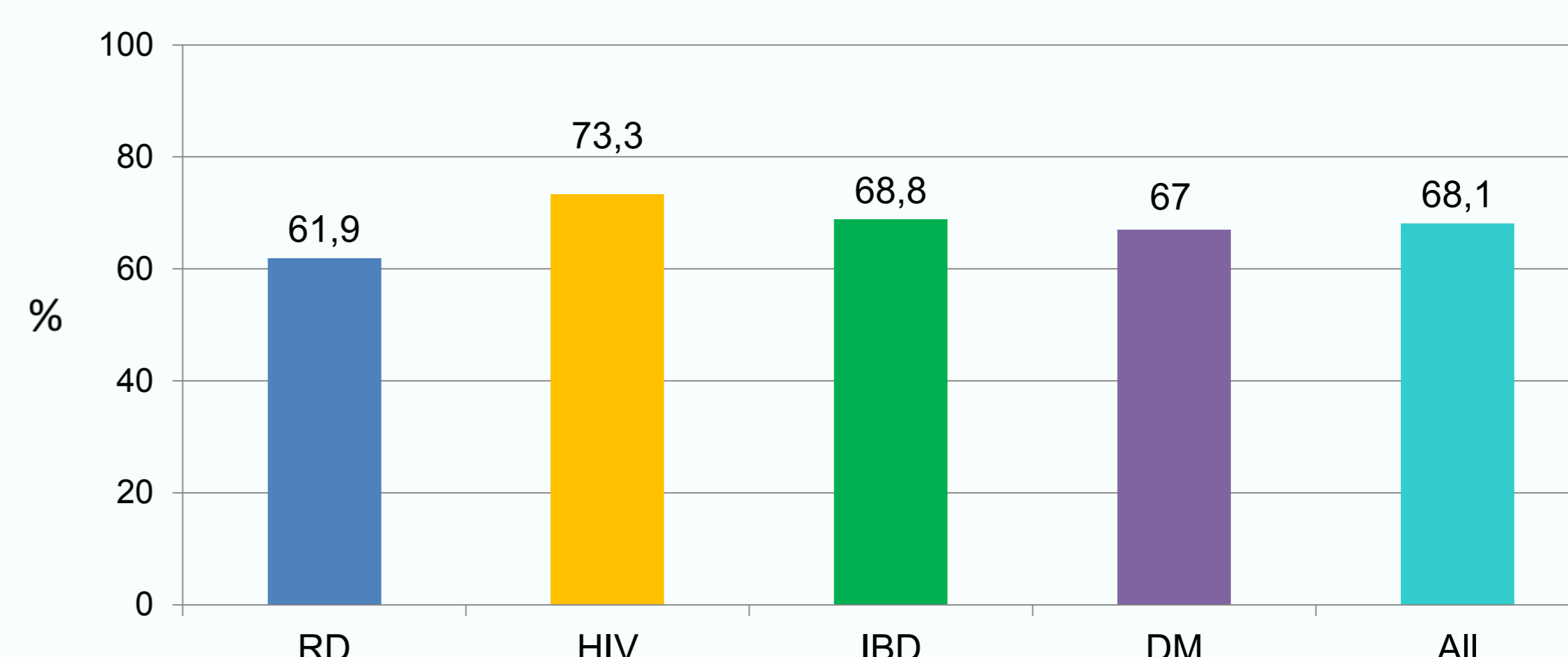


Table 1 Percentages of patients who responded “always” or “mostly” to the 12 IEXPAC items.

IEXPAC item	All patients (n=1,618)	RD (n=359)	IBD (n=341)	HIV (n=467)	DM (n=451)	p
1. They respect my lifestyle.	81.5%	76.5%	75.1%	89.6%	81.9%	<0.001
2. They are coordinated to offer good health care to me.	69.3%	60.6%	69.1%	76.8%	73.3%	<0.001
3. They help me to get information from the Internet.	15.0%	12.8%	19.0%	19.8%	8.3%	<0.001
4. Now I can take care of myself better.	81.0%	74.3%	79.3%	89.7%	78.3%	<0.001
5. They ask me and help me to follow my treatment plan.	79.8%	73.5%	77.8%	87.6%	78.2%	<0.001
6. We set goals for a healthy life and better control of my disease.	70.1%	63.4%	62.6%	74.7%	76.1%	<0.001
7. I can use Internet and my mobile phone to consult my medical records.	7.2%	7.3%	5.5%	8.6%	7.1%	0.529
8. They make sure that I take medication correctly.	76.0%	72.4%	73.7%	83.5%	72.9%	<0.001
9. They worry about my wellbeing.	84.3%	79.1%	80.4%	91.5%	83.8%	<0.001
10. I have been informed on the health care and social resources that can help me.	41.3%	33.8%	32.3%	52.6%	42.3%	<0.001
11. They encourage me to talk to other patients.	14.9%	10.3%	15.7%	20.4%	12.0%	<0.001
Answer only if you have been admitted to the hospital in the last 3 years,	30.6%	25.7%	28.9%	33.0%	32.8%	0.205
12. They care about me when I come home after being in the hospital.						
Global IEXPAC score, mean (SD)	6.0 (1.9)	5.5 (2.0)	5.9 (2.0)	6.6 (1.7)	5.9 (1.9)	<0.001

Note: items showing the lowest scores are highlighted in green color. The word “they” refers to healthcare professionals.

CONCLUSIONS

- The IEXPAC questionnaire identified areas of improvement in chronic patients’ health-care, especially those related with access to reliable information and services, interaction with other patients and continuity of health care after hospital discharge.
- PHIV scored the best, maybe consequence of a more personalized care and showed a better quality of life than patients with RD, IBD or DM.

ACKNOWLEDGMENTS



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(1) Mira JJ, Nuño-Solinís R, Guilbert-Mora M, et al. Development and Validation of an Instrument for Assessing Patient Experience of Chronic Illness Care. Int J Integr Care. 2016;16:1-13.