

The impact of the pandemic on PLHIV: issues and opportunities for rethinking PLHIV care management.

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Introduction

This work comes for Coalition HIV, an initiative composed by clinicians, academics, patients' associations and pharma industries that, since 2018, works to bring the topic of HIV/AIDS back into social and political discussion.

Antiretroviral therapy has been a great innovation in the care of HIV, and has led to a considerable growth of life expectancy of People living with HIV. The new long-acting therapies will also allow to diminish the pharmacological burden, the frequency and administration modalities of the therapy. These factors, together with the pandemic experience, have made it urgent to rethink the asset of care for PLWHIV, to grant more capillarity in the access to healthcare, giving a bigger role also to the territory as opposed as the hospital being the only place for care.

Aim of the present study is to provide ideas for a new model of access to care, also considering the opinion of the relevant stakeholders.

The results here presented show what has emerged from three questionnaires, sent to associations, Infectious Diseases centers and patients. These results are a first step in finding collective ideas for a new model of care of PLWHIV.

Methodology

Different self-reported surveys were developed for three different targets – patients, Infectious Diseases centres, and patients' associations. The questionnaires were administered through an online platform using the CAWI method, with closed questions.

For Infectious Diseases Centers (IDCs) and the community, the invitation was sent through a mailing list and specific recalls, while for the patients it was disseminated via closed Facebook groups and fliers in the infectious disease centres.

The questions focused on care strategies, stigma, and the impact of Covid on the provision of the diverse services.

We received answers from 183 patients, 50 IDCs (with 63 respondents), and 32 Associations (30 National and 2 regionals).

The sample represents the entirety of the Italian territory, with all three categories represented within North, Center, Southern Italy: within patients' associations (62% North Italy, 18% Centre, 18% South); within 63 IDCs (50% North Italy, 21% Centre, 29% South).

For patients, we gathered results from three similar surveys, 2 of national implementation (111 answers), and one in a hospital in northern Italy (71 answers). The sample consist of 183 answers, 67% North, 25% Center, 8% South and islands.

DGM and knowledge: HIV as a chronic disease

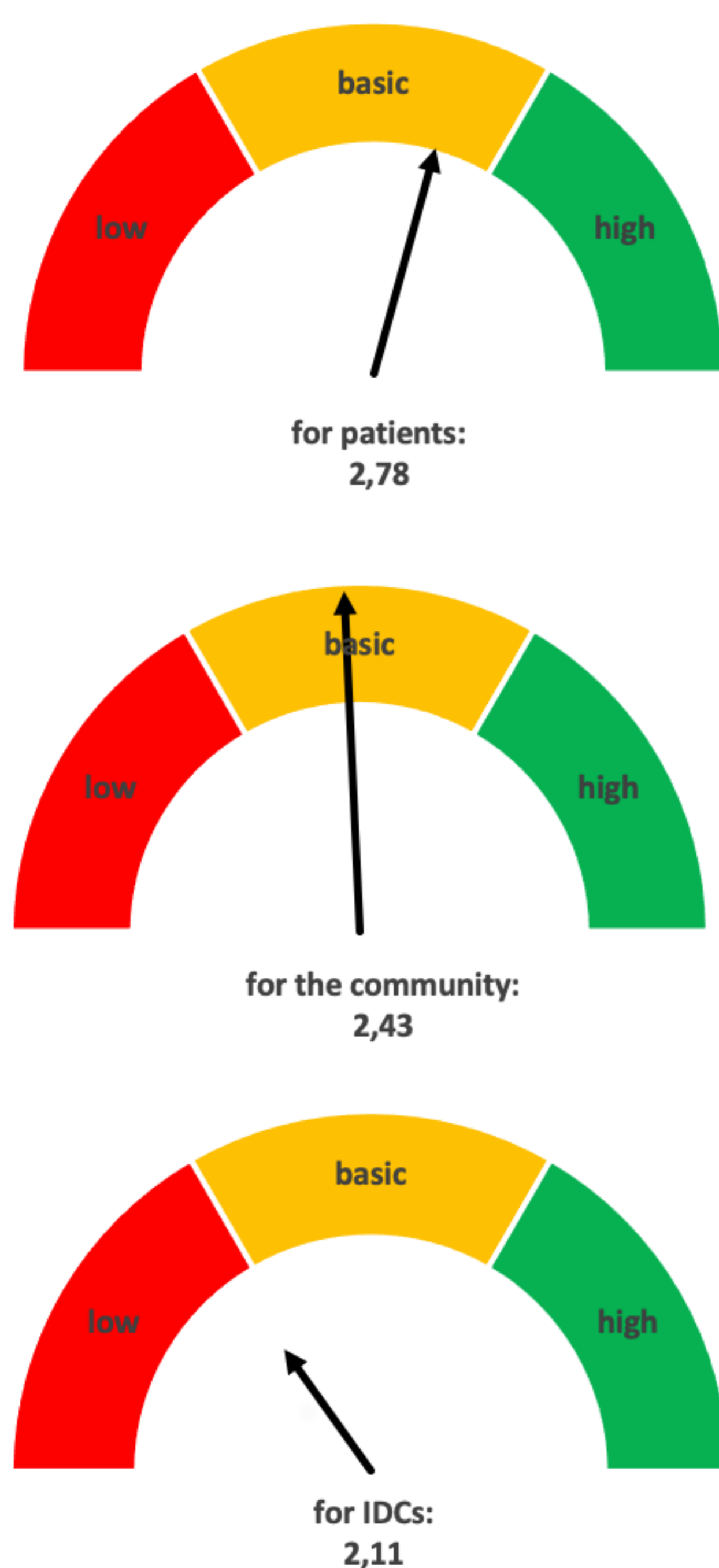


Fig. 1 Opinion on the knowledge of HIV by DGMs.

Since, with a correct adherence to antiretroviral therapy, PLWHIV have a controlled viral load and a life expectancy comparable to the one of the general population, HIV could be considered a chronic disease: the entirety of the respondents from IDCs say it is indeed a chronic disease, and the same for 81% of the community. But, due to the toxicity of the pharmacological burden and the effect of the virus on the immune system of PLWHIV, they often develop a number of comorbidities, for example diabetes, osteoporosis, and cardiovascular diseases. In light of a model that focuses on the territory, and therefore aims to extend the care of PLWHIV also outside the boundaries of the IDCs, the sample was asked their opinion of the knowledge of HIV of Doctors of General Medicine (DGM) and other specialists other than virologist.

The results (Fig. 1) show that the prevalent opinion among the community and virologist is that DMGs and other specialist have a basic or somewhat lacking knowledge of HIV, with a very low percentage of respondents that believes they are very well versed on the virus. For patients there seems to be more trust of the expertise of DGMs and other specialist.

Despite these results, the community and IDCs remain favorable to a model in which DGMs are more involved in the care of HIV (62% of the community and 54% of IDCs).

Covid and cancelled appointments

The recent pandemic has put in light the limits of the current Italian healthcare, but it has also accelerated the switch towards a territorial model of healthcare, able to reach the patients with the capillarization of services. To better understand the impact that Covid-19 has had on the provision of services for PLWHIV, the survey asked if there were instances of cancelled appointments, and by whom were these cancelled.

The results (Fig.2) show a different view among clinical centers and patients, with IDCs addressing patients as main source of cancellation, and the community and patients the opposite. Both IDCs and patients' associations recognize the "guilty" party as being both the clinics and the patients. It is interesting that IDCs and the community find a higher number of appointments canceled overall, with instead 44% patients claiming to have not suffered any; this could be explained by considering that, as opposed to patients, they experience a more thorough involvement on the matter.

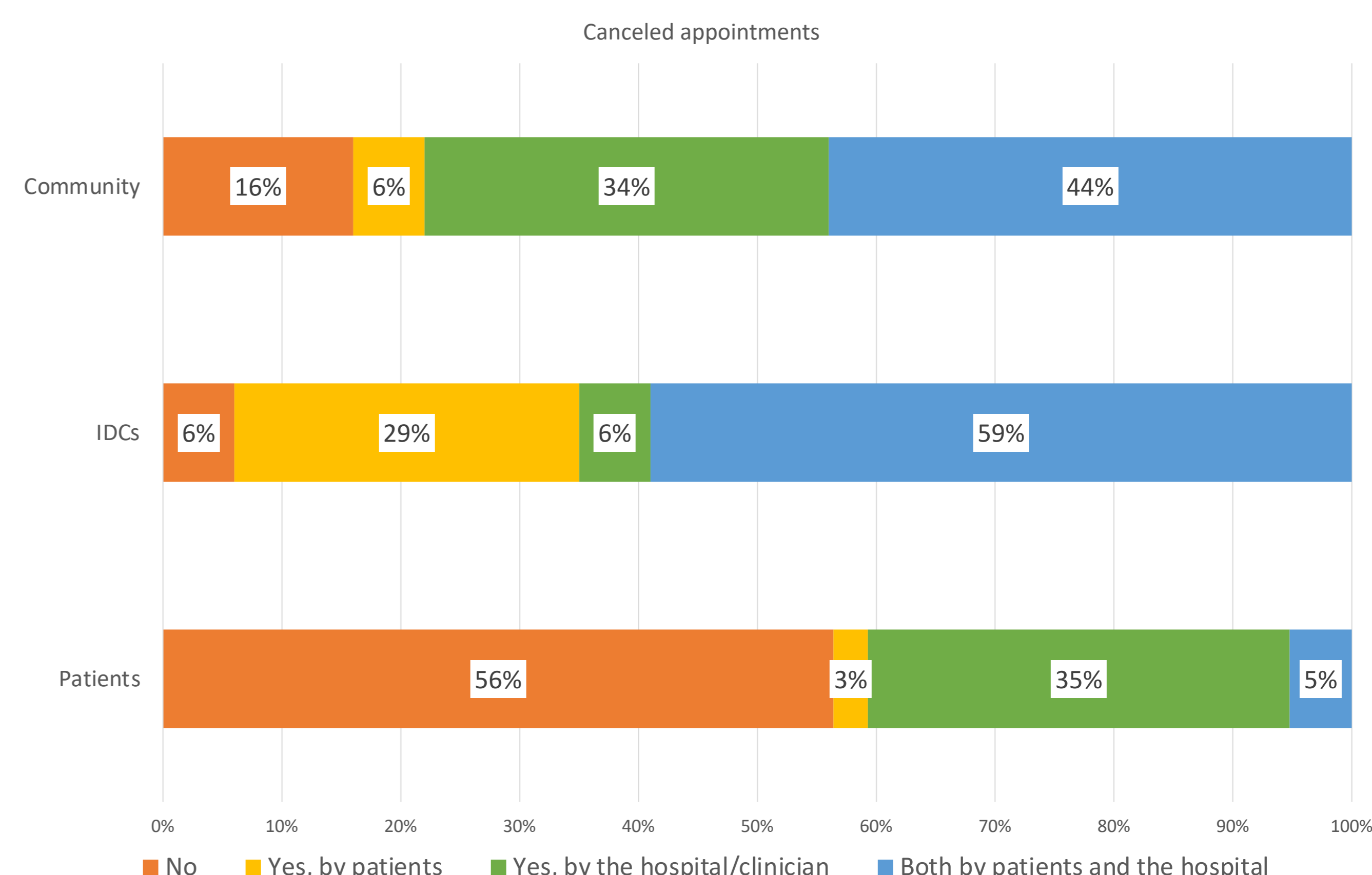


Fig. 2 Canceled appointments because of Covid-19.

ART therapy between present and future

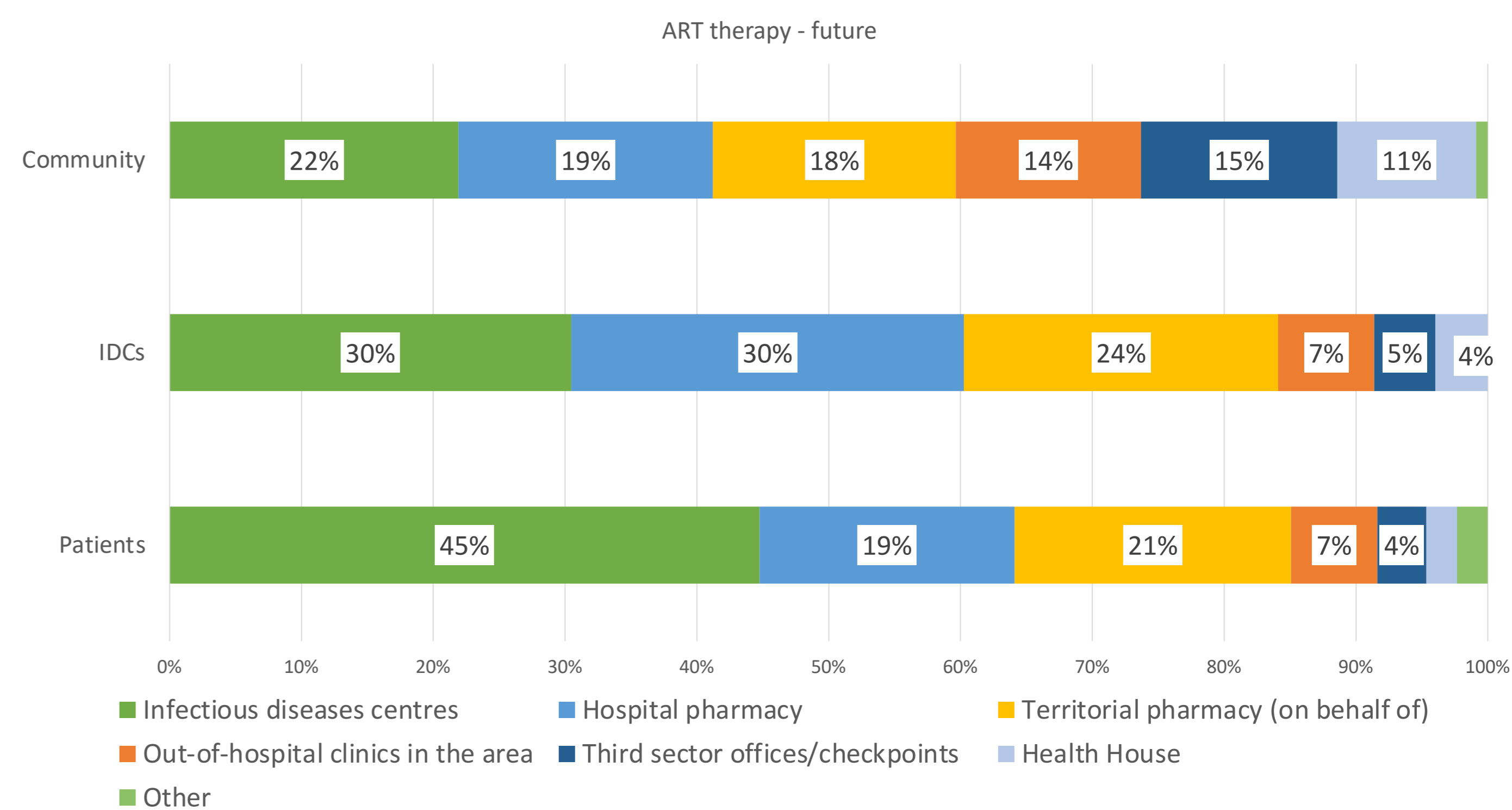


Fig. 3 Place of choosing for the dispensation of ART therapy.

With the perspective of managing the diffusion of HIV, the questionnaires inquired on the provisions of HIV tests and ART dispensation, with results showing that, as of the current moment, they are both very centralized, with percentages well over the half of the sample.

As for what regards the future, the results find both IDCs and patients' association wish for a bigger involvement of associations (59% and 100%) in the dispensation of HIV tests, even though there is also a wish for some degree of centralization (90% and 81%).

For ART, the results (Fig. 3) display a desire for keeping the dispensation of the therapy inside hospitals, with both patients and virologist choosing as preferred places the IDCs or the hospital pharmacy. The opinion of the community is more varied, with them identifying all the different option as almost equally valuable – showing a higher wish for decentralization. Moreover, it is of note the percentages across all three groups of respondents that wish for the future a bigger involvement of the third sector (15%, 5%, and 4%): this is the signal of a recent opening towards associations, also in the light of the knowledge that there are some target populations that would prefer to receive their therapy by the third sector.

Also considering the imminent application of long-acting drugs for HIV, most likely injective, and the fact that some target populations are not inclined to get their therapy from hospitals, the need is urgent for a rethinking of education, of both patients and healthcare staff.

Conclusion

- Even though the pandemic has given more credibility to the territorial model, it appears evident that both patients and IDCs are not yet ready to abandon a centralized perspective of healthcare.
- The community appears more open to the possibility of their own involvement in the implementation of HIV tests and ART therapy.
- Despite IDCs identifying HIV as a chronic disease, they seem not to qualify it in the same way of other chronic illnesses, for which the capillarization of services is viewed as a central theme.
- Associations seem more open to this kind of capillarization, for which it would be fundamental to spread awareness among patients, not yet informed.
- The capillarization of services would be central to reach all patients, the ones who find themselves geographically distant, and the ones hard to reach, for example the target populations.