

THE VISION OF PEOPLE LIVING WITH HIV ON CURRENT AND FUTURE HIV CARE IN THE NETHERLANDS

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BACKGROUND

There is a growing support for community-involvement and shared decision making in care for people living with HIV (PLWH) in the Netherlands. Large-scale uptake of shared decision making is challenging. Recent implementation projects have shown the difficulty of getting a fair representation of the community voice.¹

The COVID-19 pandemic accelerated changes in care for PLWH. Consultations in person were replaced by phone or, to lesser extend, video consultations. Moreover, consultations previously with HIV physicians were now often done by HIV nurses/nurse specialists. What can we learn from these changes and what impact do they have? This study aimed to obtain insights in how PLWH from diverse backgrounds experience their current care and their vision for post-COVID-19 times.

¹ Van der Weijden, T. et al. Shared decision-making in the Netherlands: Progress is made, but not for all. Time to become inclusive to patients. 2022, <https://doi.org/10.1016/j.zefq.2022.04.029>.

METHODS

This is a mixed methods project executed by Volle Maan with a qualitative and quantitative phase. Interview guidelines and questions were pre-discussed in an advisory board with a panel of HIV doctors, nurse specialists, nurses, and patient representatives. The questions focused on the preferred type of consultation, the preferred HIV care provider, and the topic of conversation. In the qualitative phase, two group interviews with seven PLWH each and 10 individual interviews were conducted by Volle Maan. The results of this phase were analyzed for key themes and topics. Based on the qualitative results, a survey was made for the quantitative phase. This survey was agreed upon by the panel prior to usage. Approximately 100 respondents participated in the online survey, and another 45 people (mostly with a non-western background) have completed the survey with the help of Spiritueel hiv AIDS (ShivA) and Stichting MARA. The survey questions (n=49) could be stopped at any moment or questions could be skipped without the need to justify. The results of the survey were analyzed using SPSS. The results of both phases and the resulting implication for care were discussed with the panel and followed by two separate advisory boards with HIV nurse specialists (n=7), and PLWH (n=8).



RESULTS

1. Inclusion of a diverse population of PLWH

Participants from the post-COVID care survey included a variety of people ranging in age from 18-79 years-old, in year of diagnosis from prior to 1995 until 2021, 52% were women, 50% identified as heterosexual, and 50% had a non-Dutch background. See table 1.

2. Quality of HIV care is perceived high

Overall, the participants scored the quality of their HIV care high for both HIV doctors (8.0/10) and nurse(specialists) (7.9/10). This also reflects in the fact that 98% (91/93) and 85% (78/92) of the participants indicated that the consultation with their HIV doctor and nurse(specialist) was important to them, respectively. People from non-Dutch backgrounds valued the consultations with the nurse(specialist) more compared to people with a Dutch background (96% vs. 76%). Reasons for less valued consultations included: unpersonal or awkward approach, no real contact, lack of time/rushed, no room to ask all the questions, focus on blood results only, repetition between doctor and nurse(specialist).

3. Focus more on long-term health

PLWH would prefer more attention on the topic of blood test results, physical and mental health in the past period, and their health on the long-term with both their doctor and nurse(specialist). To lesser extend also lifestyle, mainly indicated by people from non-Dutch backgrounds. Actively discussing side-effects would be beneficial as 26% of the participants indicated to have presumed but not confirmed side effects, as was in line with remarks made during the advisory board with PLWH that taking about side effects is not always easy. Over 65% of participants indicated long-term health should be discussed intensely at the next consultation with only 37% reporting attention for the topic at their last consultation. There seems no clear difference in topics currently discussed between doctors and nurse(specialists). More details are shown in figure 1.

4. Stigma remains an issue

Make sure to let people know (self) stigma can be discussed during consultations. Over half of the participants (52%, 48/93) reported occasional shame about their HIV status and just below half of the participants indicated only a limited number of people in their social circle know about their HIV status. In people from non-Dutch backgrounds shame and selfstigma were more prevalent (68% vs 31% in people with a Dutch background). Only a minority of respondents indicated they can easily talk about stigma with their HIV doctor (45%, 21/47) and nurse(specialist) (33%, 16/48), whilst just over 10% indicated the opposite. Surprisingly, 17% and 31% of participants not willing to discuss this with their nurse or doctor respectively.

5. The ideal consultation

1. Face-to-face consultations are still the preferred type

For longer consultations, the vast majority prefers to have the interaction face-to-face at the hospital with both their doctor (93%) and their nurse(specialist) (85%). People from non-Dutch background prefer a face-to-face consultation with the nurse(specialist) more compared to people with a Dutch background (93% vs. 77%), for doctors there was no difference. Challenges with regard to face-to-face consultations include travel time, travel costs, waiting time and/or an unexpected meeting with an acquaintance that is unaware of their HIV status. Face-to-face consultations were the highest ranked with both doctor (8.6/10) and nurse(specialists) (8.3/10).

2. Phone consultations: set an appointment and call on time

For short interactions with HIV careproviders over half (53%) of the participants indicated to prefer a phone call. However, 70% indicated it is hard not to know the exact time. Over half of the participants indicated their HIV care provider could indicate an exact time of limited time frame (2h) for calling, the other half indicated wider timeframes. In 2 out of 10 cases the care provider did not call within the indicated time frame. Phone consultations are less suited for people with suboptimal language skills in the language used. Overall phone consultations were rated lower compared to face-to-face consultations, with a 7.0 for doctors and nurse(specialists) on a scale of 10.

3. Offer to have video calls

For short interactions with both doctor and nurse(specialist) and also for longer interactions with the nurse(specialist) 11-15% indicates a preference for a video call. Among the respondents, only 2% of the last consultations with doctors and none with nurse(specialists) was via video call.

4. Provide PLWH the choice for their preferred care provider (doctor or nurse(specialist)) and frequency of interaction.

The current standard of care in most hospitals (alternating doctor and nurse visit, twice a year) was preferred by 43% (41/95) of participants. About 31% (29/95) would like to see both at each consultation. A minority prefers their consultation always and only with the doctor (16%) or nurse(specialist) (3%). Most people (58/96) are happy with 2 visits per year, 39% would prefer a different frequency of visits, either less or more.

5. Stimulate consultation preparation

About half of the participants prepare their consultation with their doctor and nurse (specialist) (see figure 2a). Most people think about the topic they want to discuss, only 11% (6/54) indicated they were provided with a preparation questionnaire (see figure 2b). Interestingly, 89% (48/54) indicates they got more out of the consultation after preparation, but that did not reflect in a difference in consultation quality rating.



Table 1: Demographics

Demographic	Category	n/total (%)
Age	18-29	6/94 (6)
	30-39	16/94 (17)
	40-49	22/94 (23)
	50-59	25/94 (27)
	60-69	20/94 (21)
Year of diagnosis	<1995	22/140 (16)
	1996 - 2000	20/140 (14)
	2001 - 2005	24/140 (17)
	2006 - 2010	36/140 (26)
	2011 - 2015	25/140 (18)
	2016 - 2021	13/140 (9)
Sex	Male	44/96 (46)
	Female	50/96 (52)
	Other	2/96 (2)
Sexual preference	Heterosexual	47/94 (50)
	Homosexual	42/94 (45)
	Bisexual	2/94 (2)
	Other	3/94 (3)
Level of education	Primary school	9/93 (10)
	High school	20/93 (22)
	Secondary vocational (VMBO)	17/93 (18)
	Higher professional (HBO)	33/93 (35)
	University	14/93 (15)
Background	Dutch	48/96 (50)
	Non-Dutch	48/96 (50)

Figure 2a: Consultation preparation

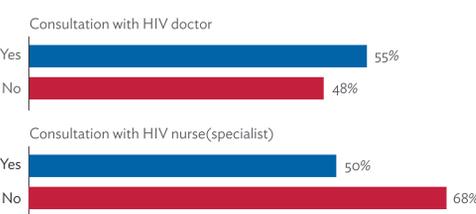
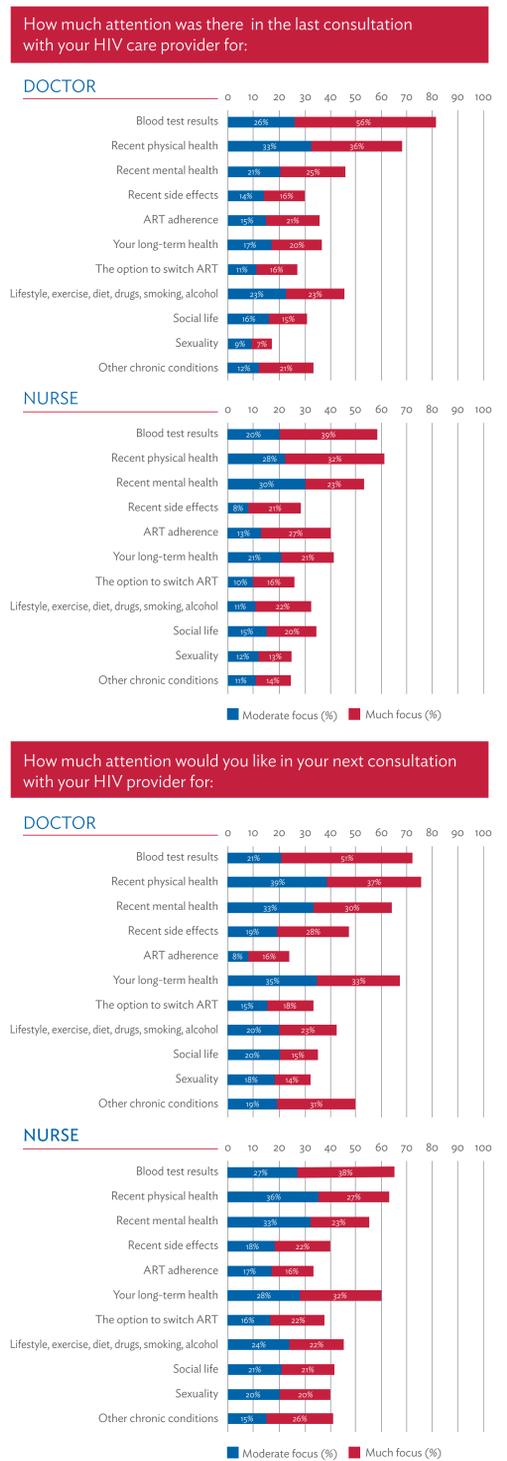


Figure 2b: Topics of consultation preparation

How did you prepare your consultation	n/total	Percentage
I have looked at my blood results	22/54	41
I have thought about the topics I want to discuss	40/54	74
I have noted down the topics I want to discuss	28/54	52
I have prepared using a questionnaire or checklist	6/54	11

Figure 1: Current and preferred balance of topic discussed during HIV consultations with doctors and nurses (specialist)



CONCLUSIONS

This project aimed to capture the visions of PLWH of diverse backgrounds on HIV care. In general, the quality of care was perceived very satisfactory. The focus of the consultation should be personalized with more focus on their long-term health. The type of consultation and organization of this should also be tailored to the specific needs of the person.

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