

The role of carers in assisting OPWH with receiving HIV and non-HIV care during Covid-19 pandemic in Ukraine

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BACKGROUND

To understand how older people with HIV (OPWH, defined as ≥50 years) coped during the Covid-19 pandemic when they need support with activities of daily living and HIV and non-HIV care, we explored experiences of both OPWH and their carers living in Kyiv.

RESULTS: Participants

Among 11 pairs:

- mother-daughter (2)
- mother-son (1)
- sisters (1)
- girlfriends (1)
- heterosexual married couple (1)
- grandmother-grandson (1)
- OPWH patient (including two gay men) and social worker (4)

Care relationship:

- averaged 8 years
- ranging from 1 to 17 years

Age ranged:

- from 50 to 77 years for OPWH
- from 25 to 72 years for carers

METHODS

In April-May 2021, we conducted 22 qualitative phone interviews with 11 pairs of OPWH and their carers. HIV psychologist at Kyiv AIDS center, referred OPWH to the researcher. Our purposive sample included diverse OPWH in gender, sexuality, comorbidities (e.g., substance use disorder (SUD)), and their carers type. Recruited OPWH referred us to the person they considered their main carer (family member, friend or healthcare professional). Participants within pairs were interviewed separately, with questions for OPWH mirroring questions for their carers. Interviews were audio-recorded, transcribed verbatim, translated from Ukrainian/Russian into English and analyzed for themes using NVivo software.

CONCLUSIONS

There is a need for interventions to help OPWH accept their HIV status and make informed decisions about disclosing it to the closest people to continue living fully. Interventions should be bilateral, simultaneously focusing on both OPWH and their carers to prevent burnout. Interventions to facilitate social support for OPWH and support for their carers should be a priority

RESULTS: Four Key Themes were highlighted in both OPWH and carers interviews

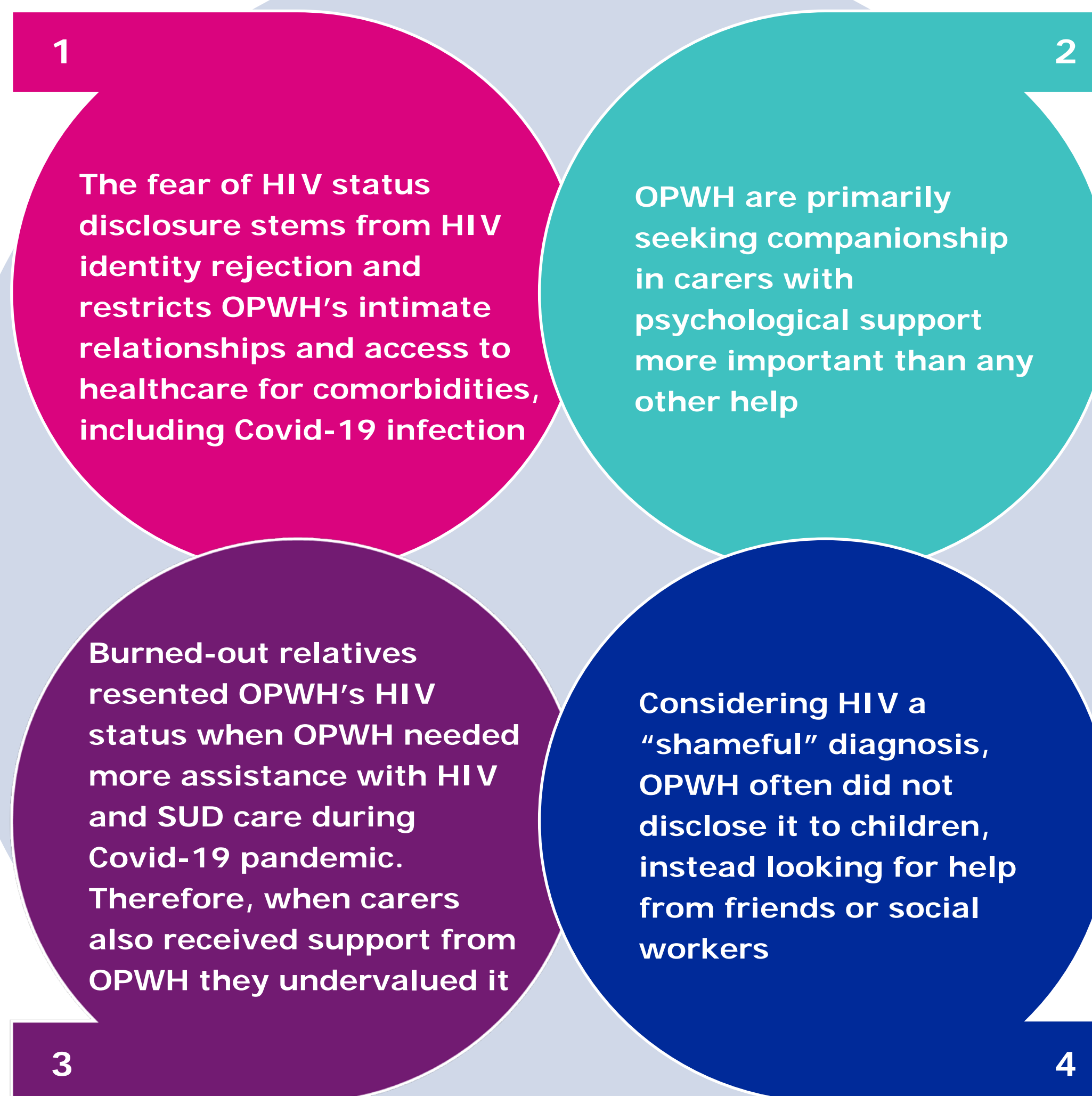
Because, God forbid, if a person goes to the hospital, it is again the medical staff should disclose the status, yes, well, as a rule, if some drugs. It's tension, it's endless tension, God forbid something happens, that somewhere someone will find out. And again, it could be found out by children. It's probably not even so much the fear that someone somewhere will find out as the children will find out if God forbid something happens there.
carer about OPWH

Maybe get her to "let it go" a little bit in that respect, because, I mean, I get nervous, and she knows very well that I can't get nervous. So, perhaps this is what I would wish for. That she would let it go a little bit, even if she's living this hour, as they say, and knows what's coming next, so that she wouldn't teach me, but maybe clarify, because she's always teaching me, "That's not how you do it! Do this!"
OPWH about carer

She can go to work, to her family, but-oh, her life, her life passes by. Her life passes by, and as if with this, as if for me, yes, with the diagnosis, she doesn't see her life continuing, you know, to the fullest extent.
carer about OPWH

All the more, we knew nothing about this disease. If I had to go to some kind of doctor - my daughter was with me. Drove and get drugs - my daughter is with me. I'm watching my nutrition. Well, we live together, of course, she supports me morally. We read a lot of sorts of ...literature, articles, well, what kind of literature is it now? On the Internet. About it. If there is something interesting, she tells me ... and obliges me to read. Well, in short, thank God that I'm not alone.
OPWH about carer

...but, I haven't told anyone, I keep it all a secret. I struggle with myself. For nine years I have been in a state of depression. Well, all the time I think only about it, well thank God that at least my health is more or less normal.
OPWH



Oh, well, I, to be honest, I'm already exhausted from this, from this whole story... Well, how I see it, well, I guess so far I see it going the same way, there's no way out. She won't quit the OST. Neither will she quit ART. And I understand that, so, for now, it will be like that.
carer about OPWH

She's learned to live with it, she's learned to live yes, that's purely physical, but she doesn't accept herself in that status. She doesn't accept it. She, for her, she doesn't classify herself as a risk group, and she's not a risk group, yes, and thinks, here's this stereotype that it's only a risk group. She believes that if someone finds out, they will definitely compare her to a risk group.
carer about OPWH

You know, when a person gets used to having someone around to control, that's how the roles have changed, you see? Instead of a sister, I became like a mother, in a teen age, that kind of thing.
carer

And it is convenient for them to live this way. And they will not solve any problems. And for today, here, well, at least for my sister, she is so comfortable, she lives a comfortable life. She gets lost in time. She knows that I, if she has to go somewhere, I wake her up. I bark twenty times, I bark twenty times, well, anyway. You see? Still, and, well, people get used to it. At first it's kind of, like, a good thing, and then it becomes a habit. And at the end, it becomes a duty, you know. Here, and they wean themselves off taking responsibility for their lives.
carer about OPWH

I have three daughters. All married, well-established, as they say, an educator in their own right. I have a very, you know, I think, like, decent family, and my children, my daughters, they're very, like, negative about it. Well for them it's all kind of, you know, what kind of people are at risk, so I keep it all to myself, and no one knows about it.
OPWH

I serve her completely, completely, because I understand what she does for me and I'm very much the host at home. I mean, she doesn't have to stand by the stove after work. I have time to do all that, and to do laundry, washing, and well, she just likes to clean, and that is how I am a host. All the holidays I cook, so it would be nice for her. I know what she likes.
OPWH about carer

You know, it's not even that I'm in need, I'm an addict. I'm telling you seriously. She's, she's my drug, really.
OPWH about carer

On the physical level, people take pills, something happens in life, but the word HIV, they're afraid to say it, they're afraid to pronounce it, they say it as such, just a disease, or an infection, or something, but they don't say HIV. It's something like that, something I can't relate to myself, yeah, that's how.
social worker about OPWH