EXPERIENCES OF LIVING WITH HIV: DIAGNOSIS AND DISCLOSURE – FINDINGS FROM THE POSITIVE PERSPECTIVES STUDY

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Background: While treatment advances have improved the life expectancy of people living with HIV (PLHIV), important needs remain. An international survey of PLHIV was conducted to explore the impact of living with an HIV diagnosis on outlook and aspirations, rate the impact and sources of emotional support at diagnosis compared to today, and assess the extent of disclosure.

Methods: Qualitative interviews were performed with PLHIV and partners to identify key hypotheses. An online global survey was fielded from November 2016 to March 2017 in nine countries. A broad cross section of PLHIV was obtained using a mixed sampling/recruitment approach. Respondents were screened via telephone prior to accessing the online survey instrument.

Results: Beginning January 2017, 819 PLHIV were recruited. 20% were women, 32% age >50 years, 11% recently diagnosed, and >80% reporting having >1 co-morbidity. 90% believe their quality of life (QOL) will improve with advances in treatment, though 26% tend not to plan too far ahead because of their status. At time of diagnosis, 26% reported not receiving any emotional support/guidance from their healthcare provider (HCP), with 48% seeking support from a close friend. In the last 12 months, 75% continued to experience some level of stigmatisation with social (20%) and self-stigma (28%) very/quite often reported. 63% believe that improved education of the general public would help, while 25% feel that better training of HCPs would reduce stigma in the healthcare setting. 93% have disclosed their status to their primary care doctor, with main drivers being the acknowledged need to keep them fully informed and to avoid drug-drug interactions.

Conclusions: In this survey, PLHIV believe advances in treatment will improve their QOL. Support from HCPs at time of diagnosis is not always provided. Widespread stigma is still experienced, with education of public and HCPs seen as potential remedies.

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