Implementing Nurse- and Caregiver-Supported Self-Collected HPV Screening in Adults with Intellectual and Developmental Disabilities

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BACKGROUND

Women with intellectual and developmental disabilities (IDD), including those with Down syndrome, experience significantly lower cervical cancer screening rates compared to the general population[1]. Barriers include communication challenges, sensory sensitivities, and limited tolerance of pelvic examinations. Emerging evidence suggests that self-collected HPV testing is a safe and effective alternative that may improve access and patient experience when appropriately supported[2].

METHODS

- We designed and implemented a quality improvement initiative introducing nurse- and caregiver-supported self-administered HPV screening for eligible adult patients with IDD.
- The intervention involved staff training, development of simplified educational materials, and structured caregiver guidance protocols.
- Patients are offered self-collection during routine clinic visits, with support tailored to individual communication and sensory needs.
- Outcomes include screening uptake, completion rates, and qualitative feedback from patients, caregivers, and staff using surveys. Fourteen patients (N=14) with intellectual and developmental disabilities successfully completed primary HPV self-swab screening in clinic.

RESULTS

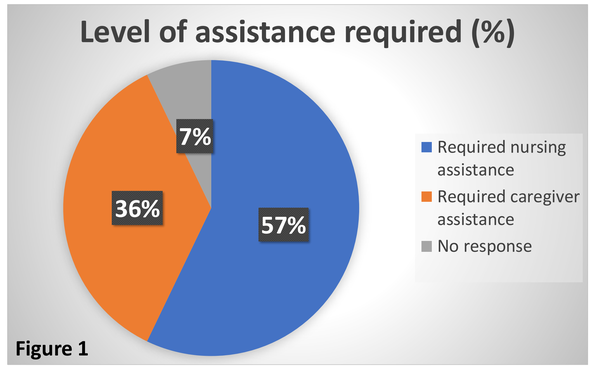

Figure 1

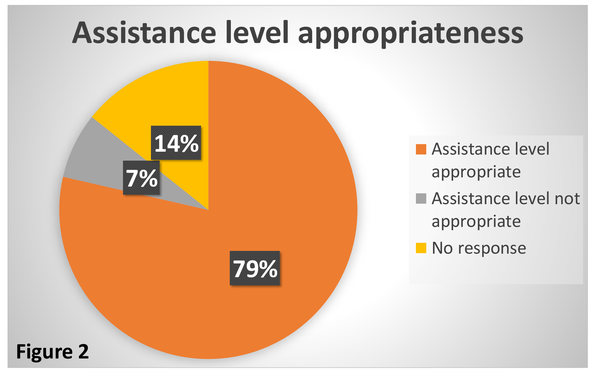

Figure 2

Figure 1. Most participants required support to complete the screening, with nursing assistance required in 8 of 14 cases (57.1%) and caregiver assistance in 5 of 14 cases (35.7%).

Figure 2. The level of assistance provided was considered appropriate by 11 of 14 respondents (78.6%).

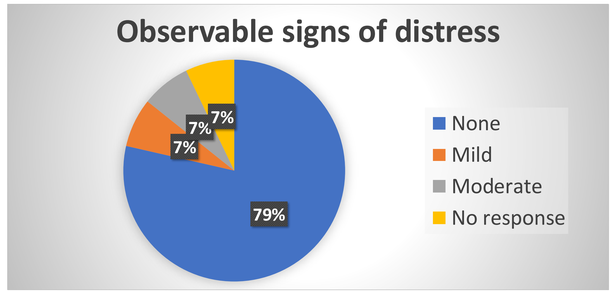

Figure 3. Signs of distress were uncommon; 11 of 14 (78.6%) respondents observed no distress, while one participant experienced moderate distress characterized by verbal refusal and anxiety/fear.

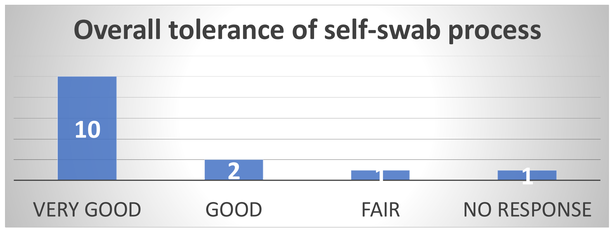

Figure 4. Most respondents reported favorable tolerance of the screening process, with 10 of 14 (71.4%) rating the experience as very good and 2 of 14 (14.3%) rating it as good.

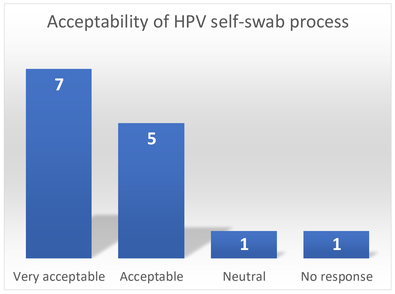

Figure 5. Overall acceptability of the self-swab process was high, with 12 of 13 respondents (92.3%) rating the screening method as acceptable or very acceptable.

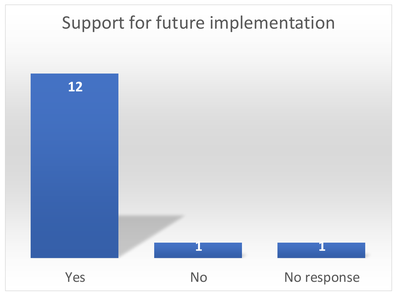

Figure 6. Of the 13 respondents, 12 (92.3%) indicated they would support offering this screening option again in the future.

DISCUSSION

- Primary HPV self-swabbing appears feasible in adults with disabilities when supported by caregivers and nursing staff.
- Most participants demonstrated high tolerance and minimal distress.
- The need for assistance highlights the importance of flexible, individualized support models.
- High caregiver acceptance suggests potential to improve cervical cancer screening access in populations that face barriers to speculum-based screening.
- Future studies should evaluate outcomes in larger cohorts and compare screening uptake with traditional clinician-collected methods.

CONCLUSIONS

- In this pilot cohort, primary HPV self-swab screening was feasible, well tolerated, and highly acceptable among patients with disabilities and their caregivers when supported by nursing staff and caregivers.
- Nurse- and caregiver-supported self-collected HPV testing is a feasible and patient-centered strategy to improve cervical cancer screening among adults with IDD.
- This model addresses key barriers and may help reduce disparities in preventive care.
- Ongoing evaluation will assess long-term adherence, scalability, and integration into routine practice.

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References

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2. Arbyn M, Verdoodt F, Snijders PJ, Verhoef VM, Suonio E, Dillner L, Minozzi S, Bellisario C, Banzi R, Zhao FH, Hillemanns P, Anttila A. Accuracy of human papillomavirus testing on self-collected versus clinician-collected samples: a meta-analysis. Lancet Oncol. 2014 Feb;15(2):172-83. doi: 10.1016/S1470-2045(13)70570-9. Epub 2014 Jan 14. PMID: 24433684.