East African Journal of Health and Science, Volume 8, Issue 1, 2025
Article DOI: https://doi.org/10.37284/eajhs.8.1.2589

East African Journal of Health and Science
eajhs.eanso.org
Volume 8 Issue 1, 2025
Print ISSN: 2707-3912 | Online ISSN: 2707-3920
Title DOI: https://doi.org/10.37284/2707-3920

EAST AFRICAN NATURE & SCIENCE ORGANIZATION

Original Article

Exploring Community Knowledge on Hearing Loss and Attitudes Towards Persons with Hearing Loss in Southwestern Uganda

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Article DOI: https://doi.org/10.37284/eajhs.8.1.2589

Date Published:

06 January 2025

Keywords:

Hearing Loss, Attitudes, Stigma, Community, Uganda.

ABSTRACT

The World Health Organization (WHO) advocates for community accessibility of ear and hearing health services. The success of such services is influenced by a community's under-standing of hearing loss causes and attitudes towards persons with hearing loss (PWHL). A cross-sectional mixed methods study was conducted in a local community in southwestern Uganda aimed at assessing knowledge on causes of hearing loss (HL) and attitudes towards PWHL using questionnaires and Focus group discussions (FGDs). Quantitative data was ana-lyzed using STATA and reported as frequencies while qualitative data was recorded, tran-scribed and relevant themes reported. A total of 370 participants between 18-35 years were recruited for the study. Community knowledge level on HL was high for congenital anoma-lies (77.3%), drugs (77%), infections like measles (84.3%) and excessive phone use (92.7%). A few participants attributed HL to cultural factors like witchcraft (45.1%). The majority of participants had favourable attitudes towards PWHL agreeing that PWHL should seek medi-cal care (95.1%), shouldn't be isolated (95.1%) and also face unique social problems. Unfa-vourable attitudes included the belief that PWHL cannot perform as well as their hearing peers and that they are emotionally disturbed. The study revealed a community knowledgea-ble on HL causes but with limited appreciation of the capabilities and unique challenges of PWHL which negatively influences the community attitude towards PWHL.

APA CITATION

Nakku, D., Seguya, A., Nakalema, G., Nyaiteera, V., Kyobe, K. J. & Kakande, E. (2025). Exploring Community Knowledge on Hearing Loss and Attitudes Towards Persons with Hearing Loss in Southwestern Uganda. *East African Journal of Health and Science*, *8*(1), 10-21. https://doi.org/10.37284/eajhs.8.1.2589.

CHICAGO CITATION

Nakku, Doreen, Amina Seguya, Gladys Nakalema, Victoria Nyaiteera, Kiwanuka Joseph Kyobe and Elijah Kakande 2025. "Exploring Community Knowledge on Hearing Loss and Attitudes Towards Persons with Hearing Loss in Southwestern Uganda". *East African Journal of Health and Science* 8 (1), 10-21. https://doi.org/10.37284/eajhs.8.1.2589

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HARVARD CITATION

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IEEE CITATION

D., Nakku, A., Seguya, G., Nakalema, V., Nyaiteera, K. J., Kyobe & E., Kakande "Exploring Community Knowledge on Hearing Loss and Attitudes Towards Persons with Hearing Loss in Southwestern Uganda", *EAJHS*, vol. 8, no. 1, pp. 10-21, Jan. 2025.

MLA CITATION

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INTRODUCTION

Globally, an estimated 466 million people have hearing loss (HL), with over 90% of persons with hearing loss (PWHL) living in low and middle-income countries (LMICs) (World Health Organization, 2021). Despite the increased advocacy by the World Health Organization (WHO) for the promotion of Ear and hearing care (EHC) from the grassroots (World Health Organization, 2021) and the integration of EHC services into the primary health care package, many LMICs lack implemented policies addressing EHC and HL. As a result, unaddressed (World Health Organization, 2018, February) HL results in loneliness, social isolation, depression, and a poor quality of life among PWHL (Mick et al., 2014; World Health Organization, 2020).

A community's level of knowledge of HL may influence society's attitudes towards PWHL (Alsudays et al., 2020; Wong et al., 2019). Such attitudes may range from respectful and helpful to discrimination and stigma against PWHL (David & Werner, 2016; Masuku et al., 2021; Wallhagen, 2010). Negative attitudes towards PWHL can be fueled by a poor understanding of the causes of HL and its subsequent impact on PWHL[6] or by the existing cultural beliefs about HL (Ravi et al., 2016; Swanepoel & Almec, 2008).

The majority of the causes of HL in LMICs are preventable (World Health Organization, 2020). However, there is limited documentation on community knowledge about various causes of HL. This knowledge deficit may largely contribute to delays and reluctance in seeking care and promote resistance towards EHC services in communities. This study therefore set out to explore community knowledge of HL and attitudes towards PWHL in a local community.

MATERIALS AND METHODS

A cross-sectional mixed methods study design was employed in a rural community in southwestern Uganda. Using the Kish and Leslie (1965) formula for prevalence studies and assuming a 95% confidence interval, 5% margin of error, p=40% (for the level of knowledge about hearing loss) and a design effect of 1.0, a sample size of 364 participants was calculated. Participants were conveniently sampled and recruited from routine community gatherings and homesteads and were eligible for participation if aged ≥ 18 years and provided written informed consent.

Quantitative methods were used to assess community knowledge of the causes of HL using a questionnaire adopted from a study by Govender and Khan (2017) and modified to include culturally relevant questions on the causes of HL in a rural setting. In the responses 'Yes' was considered as the favourable response except for those items that were reverse scored (Table 3).

Community attitudes towards PWHL were assessed with a tool adopted from a study by Hughes *et al* (2014) which employed a modified forced-choice 4-point Likert scale to reduce social desirability bias. Responses of either 'Strongly Agree' or 'Agree' were grouped as a favourable attitude while

Article DOI: https://doi.org/10.37284/eajhs.8.1.2589

'Disagree' or 'Strongly Disagree' responses were considered unfavourable.

Qualitative methods were used to explain the findings on knowledge of HL and community attitude towards PWHL using four FGDs comprising 6-8 volunteer participants each with two groups of general community members, one group each for community leaders and community health workers.

Quantitative data was analysed using STATA version 16. Levels of knowledge and attitudes were reported as frequencies. Qualitative data were recorded, transcribed and analyzed for themes explaining influences on the community knowledge of HL and attitudes towards PWHL.

RESULTS

Participants' Demographics

Of the 370 participants, the majority were aged 18 to 35 years (74.32%), female (53.78%) and had attained secondary education 47.30% (**Table 1**)

Table 1: Socio-Demographic Characteristics of the Study Population

Characteristic	Category	N=370 (%)
Gender	Male	171 (46.22)
	Female	299 (53.78)
Level of Education	Primary	158 (42.70)
	Secondary	175 (47.30)
	Tertiary	37 (10.00)
Age categories	35 and below	275 (74.32)
	36 – 55	83 (22.43)
	56 and above	12 (3.24)

Community Knowledge and Beliefs about Causes of Hearing Loss

The highest knowledge on causes of HL was recorded for infective causes such as measles (84.32%) and meningitis (79.19%) and lowest for herbal medicines (17.30%) (Table 2), and low birth weight (17.57%) (Table 2). Whereas a small number of respondents attributed HL to cultural factors such as angry ancestors (21.89%), a larger proportion believed witchcraft causes HL (45.14%).

Table 2: Community Knowledge and Beliefs about Causes of Hearing Loss

Characteristic		Response (N=370)	
		Yes n (%)	No n (%)
Family-related factors	Family History of Hearing Loss	154 (41.62)	216 (58.38)
	Alcohol intake during Pregnancy	161 (43.51)	209 (56.49)
	Use of Traditional medicine during pregnancy	113 (30.54)	257 (69.46)
	Maternal infections during pregnancy	280 (75.68)	90 (24.32)
Intrinsic factors in a child	Low birth weight	65 (17.57)	305 (82.43)
	Prematurity causes hearing loss	164 (44.32)	206 (55.68)

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Characteristic		Response (N=370)	
	Meningitis causes hearing loss	293 (79.19)	77 (20.81)
	Measles	312 (84.32)	58 (15.68)
	Jaundice	82 (22.16)	288 (77.84)
	Defects on the head, face or neck cause hearing loss	286 (77.3)	84 (22.70)
Extrinsic factors	Head trauma causes hearing loss	336 (90.81)	34 (9.19)
	Recurrent or unmanaged ear infections cause hearing loss	360 (97.3)	10 (2.70)
	Some medicines cause hearing loss	285 (77.03)	85 (22.97)
	Prolonged exposure to noise causes hearing loss	341 (92.16)	29 (7.84)
	Talking for long on the mobile phone causes hearing loss*	343 (92.70)	27 (7.30)
	Using headphones causes hearing loss	340 (91.89)	20 (5.41)
	Comorbidities cause hearing loss such as DM, HTN, HIV	207 (54.95)	163 (44.05)
	The use of herbal medicines causes hearing loss	64 (17.30)	306 (82.70)
	Hearing loss is treatable	242 (65.41)	128 (34.59)
Cultural beliefs	Hearing loss is caused by angry ancestors*	81 (21.89)	289 (78.11)
	Engaging in witchcraft causes hearing loss*	167 (45.14)	203 (54.86)

Note.*Items were reverse scored during the analysis

Community Attitudes towards Persons with Hearing Loss

The majority of participants had favourable attitudes towards PWHL. Most Participants agreed that 'PWHL should talk to a doctor for help' (95.13%), 'the family of a PWHL should not keep him/her at home hidden from other community members (95%) 'It is not okay to make fun/tease PWHL' (93.78%) (Table 3). Unfavourable attitudes included beliefs in the inability of PWHL to attend mainstream schools and make friends with hearing peers (63.79% and 86.22%, respectively), and PLWH are emotionally disturbed (67.03%).

Table 3: Community Attitudes Towards Persons with Hearing Loss

	Characteristic	Responses (N=370)	
No	Item	Favorable Response n(%)	Unfavorable response n(%)
1	PWHL should talk to a doctor for help	352(95.13)	18(4.86)
2	PWHLs are likely to be as intelligent as their peers	269 (72.7)	101(27.3)

Article DOI: https://doi.org/10.37284/eajhs.8.1.2589

	Characteristic	Responses (N=370)	
3	PWHL should not go to a traditional healer	215 (58.11)	155(41.89)
4	PWHL can pursue their education in mainstream/public schools	134 (36.22)	236(63.79)
5	PWHL have trouble making friends	51(13.78)	319(86.22)
6	It's okay to make jokes about hearing loss	338 (91.35)	32(8.65)
7	PWHL have trouble getting married	309 (83.52)	61(16.48)
8	PWHL are being punished by God	303(81.89)	67(18.11)
9	PWHL could speak or hear better if they tried hard	153(43.71)	217(58.63)
10	The family of a PWHL should keep him/her at home to hide from other community members	352(95.14)	18(4.86)
11	It's okay to make fun of or tease PWHL	347(93.78)	20(6.22)
12	Many PWHLs are emotionally disturbed	122(32.97)	248(67.03)
13	PWHL should get help for their speech problem	30(8.11)	340(91.89)

Focus Group Discussion (FGD) Results

Five themes were derived from the FDGs: community understanding of HL, causes of HL, quality of life of PWHL, Challenges faced by PWHL and support systems for PWHL.

Community Understanding of the Meaning of HL

Community members described HL as a condition that is either congenital or acquired, total or partial or even seasonal while a community leader defined HL based on experiences relating to PWHL:

> *"If you live with a person or they are your neighbours, if you tell them to do something, it takes a while before they understand what you are telling them and so you have to repeat for them several times" (Community leader FGD).*

Causes of HL as Understood by the Community

Diverse opinions were noted with measles and chronic ear infections or genetic predisposition as the commonest causes of HL in children. One participant had this to say:

> *"It is a gene that is carried from the past, from grandparents and great grandparents" (Village Health Team FGD)'*

Among adults, poor immunity secondary to poor nutrition making individuals vulnerable to infections and eventually hearing loss, accumulation of ear wax and loud noise exposure were identified. One participant attributed HL to poor hygiene:

> *"…once an unhygienic 25-year-old had his hearing improve after he was forcefully washed and taken to the health centre for ear cleaning".*

Other non-age specific causes of HL noted included medications such as quinine, comorbidities such as stroke, syphilis and trauma from road traffic accidents and assault. Participants' narratives were however marred by some misconceptions about the

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causes of HL. For example, the notion that HL is a punishment from the ancestors, a result of witchcraft or the accidental drop of breast milk in an infant's ear did not go without contention from fellow discussants as impossibilities.

Perspectives on the Quality of Life of PWHL

Some respondents believed that with support, PWHL is capable of performing normal social functions like their counterparts with normal hearing. Perspectives on the quality of life of PWHL were constructed across two dimensions: cognitive/intellectual abilities and social relations and participation as illustrated below.

Cognitive/ intellectual capabilities of PWHL.

Some participants believed that PWHL is intellectually capable of independently navigating different life situations, arguing that HL has no bearing on mental state and aptitude. They cited an important example that legally, PWHL are punished to the same extent as their normal hearing peers since they can equally discern right from wrong.

Discussants further said the academic performance of PWHL could be even better than that of people with normal hearing. However, it was stressed that the educational success of PWHL was dependent on enrolment in appropriate institutions with teachers trained to educate learners with HL. One participant shared a personal experience:

> *"I have a child at home who became ill from birth and started developing HL gradually and so her academic achievement was not that good. I tried to tell the teachers that she could not hear what the teachers said when they were teaching. So that is why I am of the view that those children go to special schools where there are teachers that are well trained to teach them. (Village Health Team FGD)"*

Social Relations and Participation of PWHL in the Community.

Some participants were sceptical about the cognitive abilities of PWHL labelling them as 'mentally unstable' or 'cognitively impaired'. They further indicated that the mental instability of PWHL generally limited their social engagement and access to job opportunities beyond casual labour and exposed them to labour exploitation. One community member shared that his son with HL gave up on school and opted to graze animals for a small pay and even then, he is not paid as well as his hearing peers.

Notably, all groups believed that PWHL can only hold leadership roles within their special community and are incapable of adequately representing the whole community. On the other hand, the groups indicated PWHL are not limited to establishing and maintaining social and romantic relationships. However, it was pointed out that the social engagement of PWHL is negatively influenced by the lack of empathy from the community which may trigger a sense of rejection, paranoia and aggression towards the hearing community.

Challenges Faced by PWHL in the Community

The challenges were stratified under the following three categories:

Individual and family-level challenges. The FGDs agreed that in society, PWHLs are usually reluctant to disclose their disability even to family members for fear of shame and discrimination. Members cited that in some parts of the region, disability is culturally frowned upon and grossly affects family social status. However, a good number of participants thought this was due to a lack of adequate knowledge of HL and preexisting cultural bias.

Healthcare challenges. Participants had a general limitation in knowledge about healthcare service options available for PWHL. Some participants were unaware that certain types of HL can be treated. The healthcare workers FGD highlighted the discrimination experienced by PWHL within the

Article DOI: https://doi.org/10.37284/eajhs.8.1.2589

healthcare system, causing inequitable access to services for example PWHL had to wait longer at health centres because communication with them is challenging and a few staff know sign language while others have social biases towards PWHL. This experience is likely to deter and frustrate PWHL from seeking healthcare services even for life-threatening conditions. One health worker said:

> *"When a mother with HL comes to deliver and I tell her "push the baby'" forgetting that she doesn't hear. << [All laugh]>>. It is even worse when the mother is delivering for the first time. You might lose the baby." (Health care worker FGD)*

Community-level challenges. These mainly stem from the community's attitude towards PWHL. Experiences of direct and indirect discrimination against PWHL and their families were reported, with examples of different insults and derogatory local terms used to refer to PWHL. Everyone agreed that it is unfair to treat PWHL as lesser human beings. Participants agreed that such poor attitudes make optimum social integration of PWHL difficult and deny the community any growth PWHL would have otherwise contributed.

Support systems for PWHL in the community

All FDGs generally concurred that it is important for communities to promote and improve the well-being of PWHL through sensitization about HL, provision of specialized services towards EHC and establishment of dedicated accessible and affordable schools for PWHL. The current available resources in the community were deemed insufficient for the needs of PWHL.

DISCUSSION

Overall, the participants were knowledgeable about the common causes of HL and this information was acquired either through personal experiences and associations with PWHL or health education. It is worth noting that although disabilities like HL have high prevalence rates in LMICs, most community health programs focus on infectious diseases like malaria and more recently some non-communicable diseases, keeping preventable disabilities like HL under-acknowledged (Basañez et al., 2015; Hrapcak et al., 2016).

The majority of the causes of HL were known to the community however, although ototoxicity is a well-known side effect of many drugs, ototoxicity of herbal medications is under-researched in our setting (Crabb, 2004; Tugume & Nyakoojo, 2019). The use of herbal remedies for several ailments aligns with the community's social, cultural, religious and economic values regarding disease management (James et al., 2018), and since there are limited pharmacodynamics and toxicity studies in the region, this might explain the reluctance to attribute HL to herbal medicine use (Kayne & Kayne, 2010). Cultural conceptions and misconceptions are also key factors in how the community explains otherwise poorly understood disorders. It is therefore not surprising that witchcraft and angry ancestors were believed to be a cause of HL.

HL as a covert disability exposes PWHL to stigma and alienation (Wallhagen, 2010). The attitude of a community towards PWHL plays a key role in how PWHL are integrated and supported in the community for positive contribution to society's growth and development. The attitude may be influenced highly by community understanding and acceptance of PWHL, availability of infrastructure to support PWHL such as deaf schools and general cultural beliefs on disability (Mugeere et al., 2015). Unfortunately, there is a significant paucity of knowledge or neglect of the needs of PWHL by the hearing community with regard to resource allocation (Davis & Hoffman, 2019; Fausti et al., 2005).

The emerging FGD themes shed more light on the plight of PWHL in their day-to-day lives and suggested that the community's knowledge of HL is largely informed by interactions with PWHL, lived experiences and minimally by health education

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(Fadnes et al., 2011; Lasak et al., 2014). This low lack of health information risks community misdiagnosis of HL when they fail to differentiate it from mental illness and other similar comorbidities. Care should therefore be taken to provide the right and relevant information to communities and relevant stakeholders on the causes, prevention and management of HL. This has equally been employed and recommended in settings with similar findings to ours (Barnett, 2002; Bunning et al., 2017; Davids et al., 2021; Govender & Khan, 2017; Hallam et al., 2008; Shaw et al., 2013). The fact that several respondents believed that PWHL could not lead lives comparable in achievement to their hearing counterparts suggested community stigma, poor acceptance of PWHL and threatened the quality of life of PWHL. Similarly, a study in 2002 exploring communication with people with hearing loss reported that despite the steadily increasing prevalence of HL, few healthcare providers were prepared to work with PWHL leading to restricted access to healthcare service access by PWHL (Barnett, 2002). It is important not to simply assume or estimate the abilities of PWHL but instead to provide means for them to explore their potential and abilities (Wallhagen, 2010).

Challenges experienced by PWHL are generally more compared to their normal hearing peers and range from individual to systemic with potential spillover to involve family and friends (Bunning et al., 2017; Davids et al., 2021; Hallam et al., 2008). One of the systemic challenges reported is workplace discrimination and in-service delivery, fuelled by social stigma and the absence of accommodative infrastructures for PWHL. Shaw *et al* (2013) found that to cope with workplace disparities, some PWHLs tasked themselves with making the workplace and service areas more conducive, shouldering financial and physical demands to achieve this, including hiring interpreters which also happens locally (Shaw et al., 2013). Even though sign language is internationally recognized, it is not adequately promoted in Uganda and comparable settings and unless this is rectified, PWHL will continue to struggle to communicate effectively with hearing peers.

CONCLUSIONS AND RECOMMENDATIONS

There is good community knowledge of the causes of HL. However, there is a need for education to correct misinformation if any community-based interventional programs for HL are to be embraced, and attitudes towards PWHL improved. It is recommended, therefore, that for successful interventional or support programs aimed towards HL, communities must be involved from inception with the active participation of PWHL as key stakeholders.

Limitations

This study explored the objectives only within a rural setting. Similar information at different socio-economic levels is essential for adequate planning of services and interventions for PWHL at a country level.

It would also be more informative to explore the personal opinions of PWHL in the community in relation to the community attitudes they experience. Such information would be helpful in the social integration of PWHL.

Acknowledgements

We are grateful to the Mbarara University of Science and Technology First Mile Capacity Building Project for providing funding for this research project and to the community members and leaders served by Bwizibwera Health Center IV. Your participation ensured the successful completion of this research project.

Ethical clearance

This was received from the Mbarara University of Science and Technology REC (study no: 06/07-19) and the Uganda National Council of Science and Technology (study no: HS 549ES).

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Source of Funding: First Mile capacity building project at Mbarara University of Science and Technology.

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Age categories	35 and below	275 (74.32)
	36 – 55	83 (22.43)
	56 and above	12 (3.24)

Table 2: Community Knowledge and Beliefs about Causes of Hearing Loss

Characteristic		Response (N=370)	
		Yes n (%)	No n (%)
Family-related factors	Family History of Hearing Loss	154 (41.62)	216 (58.38)
	Alcohol intake during Pregnancy	161 (43.51)	209 (56.49)
	Use of Traditional medicine during pregnancy	113 (30.54)	257 (69.46)
	Maternal infections during pregnancy	280 (75.68)	90 (24.32)
Intrinsic factors in a child	Low birth weight	65 (17.57)	305 (82.43)
	Prematurity causes hearing loss	164 (44.32)	206 (55.68)
	Meningitis causes hearing loss	293 (79.19)	77 (20.81)
	Measles	312 (84.32)	58 (15.68)
	Jaundice	82 (22.16)	288 (77.84)
	Defects on the head, face or neck cause hearing loss	286 (77.3)	84 (22.70)
Extrinsic factors	Head trauma causes hearing loss	336 (90.81)	34 (9.19)
	Recurrent or unmanaged ear infections cause hearing loss	360 (97.3)	10 (2.70)
	Some medicines cause hearing loss	285 (77.03)	85 (22.97)
	Prolonged exposure to noise causes hearing loss	341 (92.16)	29 (7.84)
	Talking for long on the mobile phone causes hearing loss*	343 (92.70)	27 (7.30)
	Using headphones causes hearing loss	340 (91.89)	20 (5.41)

Article DOI: https://doi.org/10.37284/eajhs.8.1.2589

Characteristic		Response (N=370)	
	Comorbidities cause hearing loss such as DM, HTN, HIV	207 (54.95)	163 (44.05)
	The use of herbal medicines causes hearing loss	64 (17.30)	306 (82.70)
	Hearing loss is treatable	242 (65.41)	128 (34.59)
Cultural beliefs	Hearing loss is caused by angry ancestors*	81 (21.89)	289 (78.11)
	Engaging in witchcraft causes hearing loss*	167 (45.14)	203 (54.86)

Note. *Items were reverse-scored during the analysis

Table 3: Community Attitudes towards Persons with Hearing Loss

	Characteristic	Responses (N=370)	
No	Item	Favorable Response n(%)	Unfavorable response n(%)
1	PWHL should talk to a doctor for help	352(95.13)	18(4.86)
2	PWHLs are likely to be as intelligent as their peers	269 (72.7)	101(27.3)
3	PWHL should not go to a traditional healer	215 (58.11)	155(41.89)
4	PWHL can pursue their education in mainstream/public schools	134 (36.22)	236(63.79)
5	PWHL have trouble making friends	51(13.78)	319(86.22)
6	It's okay to make jokes about hearing loss	338 (91.35)	32(8.65)
7	PWHL have trouble getting married	309 (83.52)	61(16.48)
8	PWHL are being punished by God	303(81.89)	67(18.11)
9	PWHL could speak or hear better if they tried hard	153(43.71)	217(58.63)
10	The family of a PWHL should keep him/her at home to hide from other community members	352(95.14)	18(4.86)
11	It's okay to make fun of or tease PWHL	347(93.78)	20(6.22)
12	Many PWHLs are emotionally disturbed	122(32.97)	248(67.03)
13	PWHL should get help for their speech problem	30(8.11)	340(91.89)

