

Silence to Sound: Narrating Hearing Loss and Beyond for Health Communication in Turkey

Sessizlikten Sese: Türkiye’de Sağlık İletişimi için İşitme Kaybını ve Ötesini Anlatmak

Burcu ŞİMŞEK*

Abstract

This paper, deriving its starting point from the studies that focus on digital storytelling and voice studies in the recent decade, discusses giving voice to personal experiences and listening as political action, focusing on the digital stories produced in a digital storytelling workshop that I facilitated with our facilitation team at Hacettepe University Faculty of Communication Digital Storytelling Unit in February 2014 in cooperation with the New Born Hearing Screening and Early Detection Research and Application Center at Hacettepe University in Turkey. This workshop was the first digital storytelling workshop facilitated in relation to health communication in Turkey. The digital stories from this workshop are collected under the name “First Steps to Sound Digital Stories” and have been in circulation for the promotion of newborn hearing screening since April 2014. The majority of the participants were women and their self-representations as mothers were very strong during the workshop. Focusing on the narratives of quest for sound, I discuss how these storytellers position themselves and their children in their narratives in relation to gaining access to sound and claiming their own voices. In this paper, my aim is to examine how motherhood and childhood are narrated in the digital stories of the participants.

Keywords: Digital storytelling, health promotion, hearing loss, voice

Öz

Bu makale, hareket noktasını dijital anlatımı ve ifade/ses üzerine çalışmalarından alarak, HÜ İletişim Fakültesi Dijital Hikaye Anlatımı Atölyesi ve HÜ Erken İşitme Tarama ve Erken Tanı Araştırma ve Uygulama Merkezi işbirliğiyle Şubat 2014 yılında yürüttüğüm dijital hikaye anlatımı atölyesinde ortaya çıkarılan dijital hikayelere odaklanarak kişisel deneyimlere ses vermek ve politik eylem için dinleme üzerine bir tartışma yapmaktadır. Bu dijital hikaye anlatımı atölyesi Türkiye’de sağlık iletişimi için gerçekleştirilmiş ilk çalışmaydı ve bu atölyede ortaya çıkarılan “Sese İlk Adımlar Dijital Hikayeleri adı altında yeni doğan işitme taramayı teşvik amacıyla Nisan 2014 tarihinden beri çevrimiçi dolaşımdadır. Atölye katılımcılarının çoğunluğu kendilerini anne olarak konumlandırımları kuvvetli olan kadınlardan oluşuyordu. Ses için katedilen yolculukta bu kadınların kendilerini ve çocuklarını anlatımlarından nasıl konumlandırımlarına odaklanan bu çalışma, dijital hikayelerde annelik ve çocukluğu nasıl yer aldığına da bakmaktadır.

Anahtar Kelime: Dijital hikaye anlatımı, sağlık gelişimi, işitme kaybı, ses

* Hacettepe University, Faculty of Communication, Ankara, Turkey, bsimsek03@gmail.com

Introduction

The idea of running a digital storytelling workshop for the promotion of newborn early hearing detection emerged out of a need of the Newborn Early Hearing Screening and Detection Research and Application Center at Hacettepe University. The research center was found in 2013 by a group of physicians who have been working in Audiology Department at Faculty of Medicine at Hacettepe University. As a member of the Advisory Board of that center, my contribution on health communication issues was expected. In addition to research in the area, the center aims to raise awareness among parents of the newborn in addition to the health technicians who apply the basic screenings in the institutions that are in the structure of Ministry of Health. In Turkey, the government runs the majority of the health promotion campaigns. However, the process with such health campaigns would get complicated and the center's priority was to make the voices of the patients heard and through that raise awareness. The center was not familiar with the digital story form but I introduced digital storytelling as an alternative way to circulate the messages of the patients and their parents who gained their hearing with hearing aid through the early hearing screening. Digital stories with their 2-2,5 minute long flows with the voiceover of their owners are digital forms that help circulating personal narratives. This description and the examples of digital stories shared with the center, convinced the physicians in the center to use digital storytelling for the promotion of early hearing screening and the first steps were taken. The center took the responsibility to gather a group of parents and their children with hearing loss in order to participate in a two-day-digital storytelling workshop during the winter break in February 2014, which also turned out to be the first digital storytelling workshop for health communication in Turkey.

Including Children Voices in the Workshop

Having a daycare opportunity in order to have the chance to participate in an activity for one's self is not always available for woman. This is one of the main reasons that Fraser reminded us nearly two decades ago while she pointed to the counter publics in her opposition to the ideal Habermasian public sphere debates. In Turkey, welfare state daycare solutions for women are still very limited when they are in need to leave their children for some public engagements. In this respect, with its foundation in the gender studies, it is always a priority to facilitate the participation of women with children in the digital storytelling workshops.

Until First Steps to voice Digital Storytelling Workshop that we run in cooperation with New Born Hearing Screening and Early Detection Research and Application Center, in a facilitator training workshop, one of the participants three-year-old daughter accompanied her mother while she was doing her digital story. The significance of welcoming children lies in the understanding about inclusion and the nature of digital storytelling practice in relation to its potential for political communication in the new media era. New media technologies, such as digital cameras, computers, smart phones and the Internet, while used widely, as Gubrium cites from Wang, "these technologies also can potentially contribute to a digital divide separating those with access to technologies from those without access"(Gubrium, 2009:186). Corcoran states that "[d]espite the potential for IT a sense of realism needs to be maintained in order to include those who are unable to access IT and ensure it does not become an easy but ineffective way to reach target groups" (2013:111).

Digital literacy comes to play when we are talking about digital divide. Rather than using a negative term like divide then it would be helpful to use the term “digital inclusion” as suggested by Burgess.

In this respect, using digital storytelling workshops as a way of engaging the disadvantaged or marginalized groups such as LGBTI individuals, different feminist groups in addition to young people help these groups create their own digital content. Digital storytelling in that sense can be a good example to widen the options for digital inclusion as well as political inclusion. Jean Burgess in her article “Hearing Ordinary Voices: Cultural Studies, Vernacular Creativity and Digital Storytelling” (2006) defines digital storytelling as:

a workshop-based process by which ‘ordinary people’ create their own short autobiographical films that can be streamed on the Web or broadcast on television. This form of digital storytelling can be understood not only as a media form but also as a field of cultural practice: a dynamic site of relations between textual arrangements and symbolic conventions, technologies for production and conventions for their use; and collaborative social interaction (i.e. the workshops) that takes place in local and specific contexts. Digital storytelling as a ‘movement’ is explicitly designed to amplify the ordinary voice. (2006:207)

What gives the digital storytelling its power is the everyday ordinariness. “Narrative accessibility, warmth, and presence are prioritized over formal experimentation or innovative ‘new’ uses for technologies.” (Burgess 2006:207) Burgess also reminds us of another important aspect of digital storytelling: “Above all, digital storytelling is an example of creativity in the service of effective social communication, where communication is not to be understood narrowly as the exchange of information or ‘ideas’ but as the affective practice of the social” (Burgess, 2006:210). Gubrium also states that “[d]igital storytelling serves as a method for community participants to produce something concrete and tangible out of their experiences, thus being a forum for advocacy on issues of concern” (Gubrium, 2009:189). Burgess, Foth and Klaebe (2006) state that “bona fide citizenship is practiced as much through everyday life, leisure, critical consumption and popular entertainment as it is through debate and engagement with capital ‘P’ politics” (Burgess, Foth and Klaebe 2006:1) and later in the presentation add that “the significance of new media lies in the shift from a ‘common’ cultural public sphere (e.g. public service broadcasting) where politics and identity can be dramatised and affect can be politicised, to everyday active participation in a *networked*, highly heterogeneous and open cultural public sphere.” (Burgess, Foth and Klaebe 2006:4-5)

In an inclusive society, the value of speaking, giving a voice to the experiences of the ordinary people, the responsibility of listening arouses as Dreher points to.

The intention is rather to address the relative lack of attention to listening in order to better understand the possibilities for speaking and listening. It is therefore important to acknowledge the limits as well as the many achievements of the politics of voice (Dreher, 2009:447).

In reference to Bickford's focus on the everyday 'hierarchies of language' and 'linguistic conventions', Dreher states that "certain voices are undervalued or ignored highlights the gendered hierarchies of value which tend to hear masculine patterns of speech as confident and authoritative as opposed to feminine speaking styles which are often heard as warmer and less certain" (Dreher, 2009:445). Here it won't be wrong to add the voices of the children being undervalued or ignored. "An interest in political listening thus challenges us to understand when and how the media can facilitate difficult listening as well as encouraging openness and receptivity across difference" (Dreher, 2009:450). This is where it would be helpful to call for digital storytelling in order to facilitate encouraging openness in addition to digital stories' "being in general marked by their sincerity, warmth, and humanity" (Burgess, 2006:209). This warmth and presence as a real person is enhanced through the personal voiceover of the storyteller in a digital story.

When we take a look at the use of digital storytelling for health promotion, two articles open leading discussions for both the process of production of the digital stories in the workshop and the output serving a messenger for individual concerns to be circulated in their own words and expressions regardless of the linguistic conventions and differences in cultural aspects. Gubrium's *Digital Storytelling: An Emergent Method for Health Promotion Research and Practice* (2009) and Haigh and Hardy's *Tell Me a Story- a conceptual exploration of storytelling in healthcare education* (2011) draw attention to both the integration of digital storytelling as a research component and a health promotion strategy. Gubrium reminds us that "[a]ctions that address disparities can take different forms, from increasing participants' feelings of control over their lives to reversing structures of health promotion and practice that have historically excluded or placed them at the bottom of institutional priorities" (Gubrium, 2009:186). On the hand, as the experience of Pip Hardy in *Patient Voices Project* tells:

Many storytellers who have participated in the Patient Voices Programme (www.patientvoices.org.uk) report an increased sense of well-being, as well as greater confidence gained through the process of creating their 'digital stories' of healthcare. Patients comment on the sense of solidarity generated by being part of a group of storytellers with a shared experience of a particular condition, and comment on the satisfaction of feeling that sharing their story might help someone else — their experiences and comments might be characterized as a stronger feeling of shared humanity (O'Neill and Hardy, 2008) (Haigh & Hardy, 2011: 410).

Digital storytelling workshops also provide the ground to "become actively involved in choosing between alternative ways of framing experience" (Gubrium, 2009:190) especially for women who are most of the time excluded from public debates because of their language. On the other hand, the workshop environment encourages participants to make decisions about positions in narrative.

Participants' digital stories clearly stood out as a set of interpretive choices as they represented themselves as certain kinds of women with particular types of experiences depending on the story they wished to produce.[...] Because the story circle process works from a participant-generated agenda, the indigenous nuances of personal identity are encouraged and vividly featured(-Gubrium, 2009:189-190).

Especially the story circle phase, which is a discursive phase where the connections are formed among the participants and the facilitators “allow participants to come together as a community in discussing and mutually mentoring each other in story construction” (Gubrium, 2009:188).

First Steps to Sound Digital Stories- Narratives of gaining sound

“[A]ll identity is relational”. (Eakin 1999: 43)

During the two-day flow of the First Steps to Sound Digital Storytelling workshop, seven digital stories were produced. The seven stories can be found in the digital Storytelling workshop website in English subtitles at <http://www.digitalstoryhub.org/filter/health/Sese-Ilk-Adimlar>. Two of these stories were by the professionals who have been playing an active role in the treatment processes of the infants or young patients with hearing loss and in supporting the families of the patients. The rest of the digital stories were by young patients with hearing loss who have been using a hearing aid and their parents who have been present during the treatment period. These five digital stories hosted two narratives, two voices at a practical level telling their experience of the process, from their own perspective. The tellers of these two narratives in each digital story were either mother and daughter, or mother and son, or mother and father, if the patient was an infant. From the first moment of morning greetings, emotions were very strong all through the workshop and were reflected strongly in the digital stories conveyed by the voices of the participants.

The point that this workshop was open to the participation of the children and was especially organized for the parents to share their experiences with their children were emphasized when the participants were approached. In the first workshop morning, in total there were four children in the workshop. Two 10 year-olds, Nisa, a girl who was the sister of a boy with hearing loss and Bugra, a boy who has been using hearing aid since he was six months old were very active storytellers. Another participant child, the three year-old Bugra became the mascot of the workshop with his gaming on his Ipad while his parents were making their digital story about Buğra’s journey to sound. The youngest participant of the workshop was Defne, a six-month old baby who was recently detected with hearing loss and has been using the hearing aid for the past month. Defne’s parents were concerned when they first arrived to the workshop. They expressed their despair about the whole process that they have been going through for the past few months.

For most of these participants, the main motivation was to share experiences, to give an idea about the importance of early detection of hearing loss through the reflection of their own stories. However, during the course of the workshop while creating their digital stories, the participants formed friendships and gave each other supportive feedback about their children. In this regard, the digital storytelling workshop facilitated supporting networks to emerge not only for the patients but also for their families, which highlights the significance of sharing experiences through collective work.

In the design of this digital storytelling workshop, it was aimed to open a space for narrative of both the child and the parent. Telling the story of the experience with hearing loss was a challenge by itself. Another challenge was to work on their little individual digital story while contributing to the other’s story. There are lot of sources to consult, in regards to storytelling. Here I refer to Eakin in his account of autobiography, as it is very common to call digital stories as autobiographic digital forms. Eakin draws attention to how self is positioned by its narrator in the narrative:

[A]utobiography promotes an illusion of self-determination: *I write my story; I say who I am; I create myself.* The myth of autonomy dies hard, and autobiography criticism has not yet fully addressed the extent to which the self is defined by- and lives in terms of- its relations with others (Eakin, 1999: 43).

“All selfhood” he states “is relational despite differences that fall out along gender lines”(Eakin 1999:50). Telling their struggles and achievements these parents, children and physicians experienced a sense of fulfillment. In addition, they felt themselves as responsible citizens to attract attention of the parents of the newborn. Telling their stories in order to help others to raise awareness for hearing detection constructed them as active agents. The widely circulated concern was the treat of exclusion in the society for the parents of these children with hearing loss. The source of this concern was mainly the hearing aid, which was not found as an object for being excluded but a part of the body by the child, whereas the parents expressed the difficulty of accepting the aid as a part of their child’s body that enables their child to hear. The digital stories by children in this workshop, reversed the assertion “children are always episodes in someone else’s narrative” that was made by Steedman, referred by Eakin (1999:61). Children were well aware of the concerns of their parents and their narratives have strong statements about being successful. Such a statement as “I write my story; I say who I am” (Eakin 1999: 62) was valid in the construction of the self in the digital stories of these children.

On the other hand, the relation with the mothers and their relations with their children deserve to take a closer look, as Bora (2011), reminds us that motherhood is one of the most problematic issues of feminisms. “Without the approval of the children, mothering is not a source of power, but guilt” (Bora 2011: 147). Feeling powerless was one of the most common emotions when the parents were confronted with the news about their child’s hearing loss. However, as the digital stories by the children reflected, children were critical of the reasons for this state of being powerless and they position themselves as being powerful with their hearing aids and supportive parents.

Positioning oneself in a power state in the struggle for gaining hearing is in the core of the stories by the participant children, just like in the story of Zübeyde. This strong positioning of Zübeyde and her mother in their digital story named *Sessizlikten Sese -From Silence to Sound* (<http://vimeo.com/album/2739818/video/87071730>) gave the inspiration for the title of this paper. Most probably, in addition to the other participants of the workshop, Zübeyde’s journey will inspire and motivate others as well.



Image 1. A photo of Zübeyde in her story



Image 2. Zübeyde with her mother Nurten from Nurten’s story

Zübeyde starts her story by introducing herself. “I am Zübeyde Yaşam Ateş. I am 17 years old. When I was 6 months old, I was diagnosed as hearing loss. I had an operation when I was 14 months old and a bionic ear was implanted”. Through her story, Zübeyde expressed a strong sense of belonging to her family and draw relationship between her success as a young person and their support. She also states how she internalized living with hearing aid and developed a peaceful self. Zübeyde concludes her story with a strong statement positioning herself in the future: “And also I want to work voluntarily for the ones like me”.

Following Zübeyde’s story, in her part, Nurten, her mother tells the story of how Zübeyde was diagnosed with hearing loss. She says “I gave birth to twins by vitro-fertilization. During the routine examinations, I learnt that my daughter Zübeyde could not hear. The whole world came down on me, I was buried in the wreckage. We didn’t know what to do.” Nurten makes the point clear that the most difficult part of that process was accessing information up until the family found Hacettepe University Hospitals. “My daughter was growing up and we have to create a solution without wasting time.” Nurten develops her story with the details of their journey to the treatment at Hacettepe University Hospitals acknowledging the support of the physicians.

While Zübeyde’s story reflects a longer journey, Bugra and her mother Yasemin *Benim hikayem duyuyorum- My story I am hearing* tell us about a more recent history with gaining hearing . (<http://vimeo.com/album/2739818/video/87071732>)



Image 3. A photo of Bugra in his story



Image 4. A photo of Bugra and her mother From Yasemin’s story

Just like Zübeyde, Bugra begins his story introducing himself. Bugra tells that in the hearing screening they told his mother that “He will never hear, his memory will be very bad.” Bugra tells about her mother’s sadness and states that “But that was not what happened. What happened was just the opposite of what they said.” Bugra draws our attention to the education he took and acknowledges the support of his physician Dr. Aydan with sincerely addressing her as Aunt Aydan. Then he lines up his fields of interest. Bugra ends his part of the digital story with a message for the other children in his story. “Dear kids, don’t be sorry for having hearing loss. You’re human too. Just don’t be ashamed of it. Just be yourselves.” With this last remark, Bugra aims to attract the attention of others to the inclusion of disabilities in the ordinary cycle of life.

Bugra’s mother Yasemin, first introduces herself in her part of the digital story. Then she continues, positioning Bugra in relation to herself:

As my Bugra said, I felt deeply sorry when I heard that Bugra has hearing loss. My husband and I kept asking the same question, “Why did it happen to us?” We cried, we didn’t want to see anyone. We thought that this was the worst thing ever happened to us.

Then Yasemin tells about the process of finding a solution and starting to use the hearing aid. She expresses her concerns for the hearing aid. “But I saw that Bugra was very happy with those devices we called ‘cici’ (dinky), and he was reacting very well” she stated. Yasemin mentioned about the “devastation” of getting the hearing aid trainings and how slowly Bugra claimed words, but how successful he was and how happy she got as a result. She concludes her story as: “My son is now attending the 4th class, at the same level with his equals. He has some abilities and fields of interest. Fortunately, we have Bugra. I love him so much.”

These stories of success had healing effect on a particular couple. The mother and father of Defne, Alpaslan and Ozge came to the workshop with a lot of questions about why they were there, most of which were not asked yet. They were at a stage where most of the parents had left behind long ago. Their daughter was only six months old and she was in the process of getting used to the hearing aid. During the story circle of this workshop, expressing the moments of despair was not easy for all of the participants. However, for Alpaslan and Ozge, who came to the digital storytelling workshop in order to spend more time with the physicians of Defne and to learn how to cope with some difficulties, the workshop turned out to be a speeded up healing process. Gubrium's statement "[t]he story circle serves as an opportunity for storytellers to find a way to resolve issues they may be facing in telling their stories" (Gubrium, 2009:188) was proved to work for Alpaslan and Ozge. The whole workshop process, building up connections with other parents and children as well was an empowering experience for them. This also demonstrates that when digital storytelling is used as a medium in health communication, the patients and their families are able to pass their experiences to those who experience the early stages of the illness through the workshop process. This eventually raises awareness about the illness among the patients' families fast and forward.

Conclusion

"First Steps to Sound Digital Stories" prioritized the voices of children with hearing loss. "For the storyteller, the digital story is a means of 'becoming real' to others, on the basis of shared experience and affective resonances" (Burgess ,2006: 211). These child participants in the presence of their parents told their stories of having hearing loss but being successful and having interests just like other children. They connected with each other, played with the ipad and draw pictures together.

Learning to listen to the struggles of the ordinary people is essential for health professionals as well as the politicians who are making health policies. "Learning to listen means 'learning to stay with the hard questions'" (Thompson 2003, 91). This is possible only when those accustomed to setting the agenda and to having their interests shape the interactions are prepared to put those expectations aside" (Dreher, 2009:451). More of digital storytelling is needed for health communication in Turkey for inclusion as well as for support.

Stories provide the grounds to build up connections. "What Schmidt calls 'the human mind' that produces civilization is of course a network of externally linked minds, which connect with one another and interact with circumstances, natural and political (demic), via storytelling" (Hartley, 2013:94).

References

- Eakin, P.J. 1999. *How our lives become stories: Making Selves*. New York: Cornell University Press.
- Bora, A. 2011. *Feminizm Kendi Arasında*. Ankara: Ayizi Kitap.
- Burgess, J. 2006. *Hearing Ordinary Voices: Cultural Studies, Vernacular Creativity and Digital Storytelling*, Continuum: Journal of Media and Culture Studies, Vol.20, No.2, pp.201-214.
- Dreher, T. 2009. *Listening across difference: Media and multiculturalism beyond the politics of voice*. Continuum: Journal of Media & Cultural Studies, Vol. 23, No. 4, August 2009, p. 445–458
- Gubrium, A. 2009. *Digital Storytelling: An Emergent Method for Health Promotion Research and Promotion*. Health Promotion Practice. Vol.10, No.2, p. 186-191.
- Haig, C., Hardy, P. 2011. *Tell me a story- a conceptual exploration of storytelling in healthcare education*. Nurse Education Today (31). P.408-411.
- Hartley, J. 2013, *A Trojan Horse in the Citadel of Stories? Storytelling and the Creation of the Polity-From Göbekli Tepe to Gallipoli*. Journal of Cultural Science. Vol 6, No.1, Community Uses of Co-Creative Media, p.71-105.
- Corcoran, N. 2013. *Communicating Health: strategies for Health Promotion*. London: Sage.