



Seeing My Journey Through New Eyes

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Chapter 10

Seeing My Journey With New Eyes: Therapeutic Life Story Work With Deaf People

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Being able to tell your life story is essential for understanding your identity and humanity and for coping with life transitions (Atkinson 1995; McAdams 2006; Bohlmeijer 2007). However, this fundamental aspect of being human is far from evident for deaf adults and young deaf people, who tend to be visually oriented (Hauser, Lukomski and Hillman 2008). For them, the emergence of a secure and healthy identity may be at risk due to limited access to resources for normal language development, whether spoken or signed (Young 2016; Zand and Pierce 2011). Life story work may ameliorate these experiences of exclusion and the negative consequences of barriers to identity-related resources; this work is also in a mutually beneficial symbiosis with the ongoing documentation of deaf communities’ emancipation around the world (Mathur and Napoli 2011; Cooper and Rashid 2015; De Clerck 2016). While this article introduces therapeutic deaf life story work to services of psychotherapy and wellbeing with the deaf community, it also supports the description of psychotherapy with diverse deaf clients (Leigh 2010).

Thus, as a Marie Skłodowska-Curie Fellow at the University of Manchester’s Social Research with Deaf People group (EU Horizon 2020 funding scheme, 2015-2017), I am exploring the potential of life story work for enriching the wellbeing of British deaf people and deaf migrants. This exploration aims to tailor this intervention to the unique linguistic-cultural experiences of deaf people, enabling them to strengthen their identities and gain resilience through employing creative and narrative methods.

To introduce the reader to the notion and incipient practice of life story work with deaf people, I will first sketch my personal journey as a deaf scholar who became fascinated by life story work with deaf people, and then describe the interdisciplinary perspective from which I examine this practice. I will also provide examples of recent life story work with the Ugandan deaf community and an ongoing project with British deaf migrants.

My own journey towards life story work

As an anthropologist, I bring to life story work more than a decade of ethnographic research with deaf communities around the world, a journey that has centred round the cultural practices of signed storytelling. These practices are transmitted intergenerationally and involve both personal life stories and collective storytelling. For my doctoral studies on deaf empowerment, I carried out life story research with deaf community members in Flanders (in the north of Belgium) and international deaf people at Gallaudet University (the world's only university designed expressly for deaf people, located in Washington, DC), reflecting on transitions in their identities. I continued this in my postdoctoral studies, focusing on emancipation with deaf communities in Cameroon and Uganda. My research has encompassed multimedia and produced documentaries in which deaf people in Flanders and Uganda tell their signed stories and those of their communities, and describe landmark moments in their empowerment (www.signlanguageprojects.com/en).

I recently wrote a book about this journey, titled *Deaf Epistemologies, Identity, and Learning* (De Clerck 2016), which presents a cross-cultural theoretical framework on deaf identity and the role of storytelling in identity formation. It explores the metaphor of 'deaf flourishing', i.e. deaf people's wellbeing and self-actualisation as it emerges in the variety of cultural practices, in each of the communities mentioned above, in both personal and collective identities. Scholars from various disciplines, such as positive psychology (Seligman 2011), ethics (Sandel 2009) and social justice (Nussbaum 2011), work on the notion of flourishing, which relates to the anthropological view of wellbeing as 'an optimal state for an individual, community, society, and the world as a whole' (Mathews and Izquierdo 2010, p.5). This refers to individual experience and recognises the interconnectivity of humans and interpersonal/intercultural aspects of wellbeing. It is also supported by theories of learning, which look at the interaction with resources available in the environment, as discussed below.

Looking back on this journey, it was during my work with international deaf people at Gallaudet that I became aware of the potential of therapeutic life story work. There were no life story work courses, but the notion of identity was in the foreground to a much greater extent at Gallaudet than in Flanders because of the university's unparalleled accessibility and intensive transnational contact, which offered the chance to investigate the budding of international deaf identities. I recall an African friend sharing a story that he wrote for a personal development class shortly after my arrival. It was a metaphorical story of his own life, about the necessity of roots and personal growth. It was a common practice for international deaf people to share their stories with each other, to reflect on what had happened in their lives and reframe them from a perspective of strength and possibility. We therefore told our stories frequently, and this practice inspired me to study what was happening within this storytelling, what deaf empowerment was, and how deaf identity formation could be seen as a learning process. This illuminated the roles of an accessible and sign-based learning environment, peer learning, deaf cultural rhetoric, community participation, and learning by doing (De Clerck 2007, 2009, 2016).

During my postdoctoral studies, I became more interested in exploring the relationship between life storytelling and wellbeing, and in 2010–11 I took a postgraduate course called Coaching and Counseling in Existential Wellbeing at Leuven University. It encouraged me to reflect on my personal story, a strength-centred approach in ethnography, and the treasures in life story research (De Clerck

2016); it was during this time that I made the first notes on the proposal for the work I am doing now. The Cameroon context was particularly motivating since many of the deaf community members had never before been able to tell their life stories. They sometimes came to me with heartfelt questions about their lives, wellbeing, family and future, and I noticed the potential for finding answers through the strength that they built in the telling of their story. I wished to be able to support them in this process as well as in dealing with trauma, which is where my research tends at present.

Deaf life story work at an interdisciplinary crossroads

I am doing this work from a perspective that can be situated at the crossroads of narrative therapy, social work, cross-cultural human development, anthropology and deaf studies. The knowledge from these disciplines can support an emancipatory approach to life story work as an intervention that promotes empowerment and wellbeing by enabling deaf people and communities to tell their own stories and consider their past and future. Here I look briefly at the theoretical justification for this positioning, and then relate some interesting results of communal life story work with the Ugandan deaf community and from ongoing individual work with deaf migrants in the UK. These examples illustrate a practice that draws on these interdisciplinary perspectives.

A cross-cultural perspective on human development looks at identity formation and agency from a socio-cultural approach, understanding it as the result of learning through the internalization of social relations and cultural resources (Vygotsky 1978; Cole 1996). It can illuminate deaf processes of learning, growth and blossoming, which, as in the example of Gallaudet above, may be fostered by interaction with a deaf-friendly environment and peer contact. Centred around stories and autobiographical reflection, narrative therapy (Bohlmeijer 2007) fosters self-reflexive learning and strengthened social, psychological, cultural and linguistic capital in deaf people and communities, while the situated 'knowledges' (Haraway 1991) within deaf life stories may provide alternative pathways for deaf identity (Sheridan 2008).

The exploration of deaf selves and personal knowledge in relation to society and wellbeing is particularly important in the light of socio-political transitions in contemporary deaf communities (De Clerck and Paul 2016), but also in transitions, disempowerment and displacement not associated with being deaf (seen, for example, in the stories of deaf Ugandans and deaf migrants in the UK). For Hannah Arendt (1989), it is in showing who we are, in telling our story, instead of only being able to show our 'whatness' (for example, the physical passport made up by gender and deafness) that we become human and are born for the second time. This subjectivity is always interwoven with the stories of others (for deaf second birth stories, see De Clerck 2016). This process can be supported by life story work in which children and adolescents are able to develop a healthy sense of self in relation to their carers (Rees 2009; Rose 2012; Wrench and Naylor 2013).

Although storytelling has been explored as a linguistic and cultural practice of deaf signers (Metzger 1995; Mindess 2006), my research is the first attempt to harness the deaf life storytelling process as a deliberate and evidence-based means of supporting mental health and wellbeing. I also look at deaf life story work from a human rights angle: Article 24 in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) promotes 'the development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities,

to their fullest potential' (United Nations, n.d. p.17). Life story work can facilitate this learning, growth and blossoming and contribute to other human rights entitlements such as 'social development skills to facilitate their full and equal participation in education and as members of the community' (United Nations, n.d., p.17). As such, life story work could be an essential part of inclusive education and deaf rights, and each deaf person, including young learners and adults in lifelong learning, has the right to tell his or her own story (for further discussion of the UNRCPD and inclusive education, see Jokinen 2016).

To the beat of our own drum – life story work with the Ugandan deaf community

In 2015, as part of a research project on emancipation processes of the Ugandan deaf community, involving collaboration between the University of Manchester and Kyambogo University (funded by the British Academy), I worked with Dr Sam Lutalo-Kiingi to document Ugandan deaf heritage. This was a process which could be conceptualised as collective life story work in the form of a community profile, a picture that starts from the experiences of community members, is woven through their signed stories and contributes to collective wellbeing. Like individual life story work, a community profile juxtaposes diverse individual narratives with documented information (for example, on historical, demographic and socioeconomic evidence) and aims to raise consciousness and support members in their agency and plans for the future (Dominelli 2006; Ledwith 2012). Around the world, including in Uganda, these members often view their communities as an 'extended family' with whom they share a language, culture and experience of being deaf (Padden and Humphries 1988, 2005; Lutalo-Kiingi and De Clerck, in press). From this perspective, communal life story work is as vital as individual work to the wellbeing of deaf people.

This profile consisted of two major parts: 1) a visual timeline of key moments in the emancipation process and significant efforts toward the community's development; and 2) multimedia portraits entitled 'snapshots of the Ugandan deaf community', in which members look back on its early development and reflect on its present status and future perspectives. The timeline and snapshots were presented to the community during an exhibition at Kyambogo on 29 September 2015 and made available on the project website (www.signlanguageprojects.com/en).

For the video snapshots and the timeline, we worked through regional community meetings in Kampala (central Uganda) and Mbale (eastern Uganda) in which eight deaf Ugandans of diverse ages participated. In Kampala, they were held in the shade of a tree on the site of the Uganda School for the Deaf in Namirembe; in Mbale, members gathered outside on the platform of a large church near the unfinished foundations of what was once supposed to become their own deaf church building. Both sites had symbolic meaning: the former was the first deaf school in Uganda, founded in 1961 (a year before Uganda's independence), and the inception of Ugandan Sign Language (UgSL). It was also where the Ugandan National Association of the Deaf (UNAD) had its first offices and international development partnerships arose. The latter site attests to both the strength and vulnerability of the community, with members steadfastly gathering on Sundays despite the reminder of their shattered dreams of development, symbolised in the unfinished building.

During the four-day meetings, members were invited to explore key moments in their personal and communal lives (such as starting deaf or mainstream school, experiencing the death of a parent, getting married, participating in student strikes and

helping to establish the deaf association and launch development projects) through signed stories, photographs, performance and film. The meetings were held as signing circles with a drum and began with a discussion of the project's ethics, which continuously balanced an absolute protection of privacy for personal narratives (and confidentiality within the group) with public openness for aspects of community profiles which are intended for a broad audience. The intergenerational dialogue provided opportunities for young deaf people to learn about the history of their community from their elders, and deaf elders in turn had the chance to learn about the perspectives of deaf youth. This is exemplified in this excerpt from a community dialogue in the snapshot entitled 'A fruitful future?' in which a member from Mbale, which is a four-hour drive from Kampala, illustrates the community's vulnerability and restricted means:

It would be helpful if the UNAD would regularly visit and follow up our work. Then we can develop. If they come to guide us once and then stay in Kampala and forget about us, it discourages the membership. That is partly why the Mbale Deaf Association is declining... We have challenges in our families: our parents are poor and we have spouses and families to take care for. We failed to secure local government funds to run our deaf programmes. That is why deaf people are getting scattered. Some have resorted to farming in the villages and others are weaving. It is deaf elders who keep checking on us rather than the UNAD. It's been five years since the UNAD came here. That's a long time.

The perspectives of members in Kampala, the capital region where deaf people have been able to gain better access to resources, are more hopeful and confident regarding the future, as one young member relates:

We have had a group of deaf people [involved in establishing the deaf association and researching UgSL]; they had information that I didn't know before; it's been passed on to me now. This means that [they] planted a seed from which a tree has grown that now bears fruit. [We] youth are the fruit... We can gradually take the reins of older leaders...and use our strength to mobilise fellow deaf people to advocate for education and UgSL.

This is an example of how the life story of the Ugandan deaf community is told through a Ugandan metaphor of deaf flourishing, that of the tree.

In the snapshot called 'Ugandan deaf culture: taught as our drum', members creatively employ a drum motif to weave aspects of deaf and indigenous Ugandan cultural practices into their exploration of a deaf engagement ceremony. This topic had organically emerged from the meetings and illustrates a life transition that relates to both the family of origin and the 'deaf family'. In a performance, the participants creatively blended personal experiences and fiction, with the aim of educating young deaf people about this important time in their lives. Since deaf Ugandans often grow up with limited communication within their home environments, vital information on these cultural practices, which is passed on intergenerationally among families and ethnic groups, may not reach them. This knowledge is currently not part of curricula in deaf schools, which makes it difficult for young deaf people to gain access to it, even at the age of dating. This may become traumatic, for example when young deaf Ugandans end up unknowingly dating their close relatives, i.e. members of the same clan. Through co-operating in a video snapshot on a signed deaf engagement ceremony with representatives from both their biological family and the deaf

community, and adding a touch of joy and laughter, deaf elders and young deaf people have been able to draw on their experiences to meet this need and to generate awareness about communication and cultural transmission among families of young deaf people.

Moreover, this communal life story work was in many ways a 'road less travelled' (Peck 1990), and required far more pioneering than we had foreseen. It invited us to explore alternative pathways, for example due to the scarcity of archives and written resources that could be consulted (in part because of Uganda's civil war from 1973 to 1986). For the timeline, we had gathered over 150 pictures, which were generously shared from personal and non-governmental organisations' collections. We also did life story research with 16 deaf Ugandans in the two regions, to capture more oral/signed historical evidence. We did not necessarily assess impacts on wellbeing, but we could observe how members in Mbale gained resilience and joy throughout the process, which differed from the collective sense of depression and stress at the beginning of the project (expressed as 'not feeling well'). All participants were able to contribute to the intergenerational dialogue and associated pride through beating the drum, sharing pictures, memories and stories, and working together in a filmed performance. The drama also enabled participants in both Kampala and Mbale to relive their experiences of the past while simultaneously reconstructing their communal life story, and taking the role of the audience (Smeysters 2008).

I felt very grateful seeing deaf Ugandans looking at their pictures on the timeline during the Kyambogo exhibition, some of which had survived the war but never seen the light. They were fascinated to see the milestones of their community, recognising themselves in the pictures, and realising their unique place in the collective history. The exhibition also attracted attention from the university, schools, non-governmental organisations, and wider society with coverage on national television (UBC and Bukedde TV) and in newspapers (*New Vision* and *The Observer*). Moreover, the timeline and snapshots are to be used as educational materials in the Deaf Studies Diploma Course at Kyambogo, which is particularly oriented towards deaf adults. Securing resources to continue deaf life story work in Uganda, communal as well as individual, is an important goal given how vital this work is for sustainability and wellbeing (see Lutalo-Kiingi and De Clerck, in press).

Deaf life narratives in times of transition: towards a cross-cultural instrument for life storytelling

When I came to the UK for this project, I was very interested in the existing legislation on life story work and associated services for children who are adopted or in foster care, and I was especially eager to partake in the therapeutic life story work training course at the Institute for Arts in Therapy and Education in London. To date there are no life story work services that are tailored to deaf children, youth or adults, and no specialised training for the professionals working with them. I intend for my study with deaf adolescents and adults to advance the development of life story work as a new intervention in deaf wellbeing. The aim is to develop a cross-cultural approach that is sensitive to both British deaf people and deaf migrants in the UK. I focus here on the latter group, which have been my initial focus in the project.

A very large percentage of the world's population today is comprised of migrants, who often face challenges in terms of wellbeing (World Migration Report 2013). In this project I work with deaf signers using various languages (signed and/or written) and participating in multiple communities. Those who have recently arrived

may have limited knowledge of British Sign Language and English. The cross-linguistic and cross-cultural skills I acquired around the world help me to ensure that deaf people can access information on this project, and the study also explicitly draws on my own and the participants' multimodal bilingual/multilingual competences, factors described by Quinto-Pozos and Adam (2015) as constituting 'a fertile landscape for the creation of contact phenomena' (p.53). This may include International Sign, a contact language among signers of 'mutually unintelligible language boundaries' (ibid), and is supported by visual methods of storytelling. A shared basis of language and experience is therefore developed during the life story work process. The motivation for participating in the project varies from simply making a book of their life, to seeking self-esteem and resilience, to being able to share their story with their (future) children.

This project works around three building blocks of present, past and future (Rose 2012; Wrench and Naylor 2013). Starting with the present, in the first session I provide coloured paper, craft materials, glue and pens and ask them to imagine how the first page of their book would look, for example their name and a list of the important people in their lives, or a drawing of a childhood memory. The page does not necessarily need to end up in the book, but it enables them to make a start. Across the various sessions, the papers are kept in a folder or display book, which helps them to select the documents or pictures they would like to include in the book or share with friends or relatives. It is important that they are able to take this home, and that they have craft materials there with which to continue the creative process. During the first sessions, participants have mentioned understanding how the life story work guides them (for example, while doing some artwork, a participant said that he suddenly understood how the drawing was like a mental warm-up, helping him to recall memories), and that it equips them with the belief in their own ability and in the value of the process. The initial sessions also include establishing a safe place (Wrench and Naylor 2013) for each participant psychologically, and anchoring this place so they can recall it at any time during the life story work, whether in a session or at home.

The project provides iPads on loan to participants, which enables them to build skills in the use of digital devices and make pictures and videos of their life world (for example, their home) and who they are (for example, their favourite activities, what they like and dislike, what makes them angry, happy and sad; for more on digital life story work, see Hammond and Cooper 2013). The possibility of telling their story visually and in sign language helps to circumvent language issues and avoid the stress that may be experienced in multilingual communication (for example, what happens when I write in my own language; would you understand it? What does this English word mean?). Participants have mentioned gaining pride in acquiring digital skills that they are able transfer to other domains (for example, a participant mentioned that the ability to use an iPad combined with increased confidence and assurance about his identity would be helpful in his employment).

Since this digital pathway supplies such advantages, we are devising the first-ever life storytelling app that is tailored to the visual strengths of deaf signers. The app includes tools to create timelines with pictures and videos, map and track users' life journeys; and highlight the treasures, discoveries, heroes/heroines, and supporters that they have collected on the way. The emphasis is on deaf-friendly features, including a strongly visual design and minimal written language.

In addition, narrative and culturally sensitive play therapy methods such as working with miniature animals are helpful for participants to reflect on their different

selves (sub-personalities) and the important people in their lives (and sometimes the interaction with the different selves of these people) (Gill and Dewes 2015; Riedel Bowers 2013). To support deaf people in visual and symbolic exploration of themes in their lives and compiling family trees and personal trajectories, I also work with puppets (McMahon 2009; also Diekmann, Schoemaker & van der Veer, 2003, the method of Marleen Diekmann, titled 'An extra language' which uses duplo puppets and is well-known in social and mental care in the Dutch language area, as well as being used with migrant populations and in war-torn areas). In the transitional space of life story work, these methods, as well as visual and digital timelines, enable the participants to gain insight into the relations with their family of origin and their 'deaf family', including movement to different physical and temporal locations in their life journey, and to identify and mobilise resources.

Throughout the life story work, the participants' strengths and resources are consciously recognised, ranging from their own virtues, to people who have supported them, to stories, images, or films that have inspired them in difficult moments. In the end, the book that is created might be paper-based or digital, and could be comprised of drawings, collages, paintings, videos of signed stories, or a mixture of these.

Conclusion

This chapter described a new intervention which has the potential to enhance deaf people's wellbeing. A cross-cultural approach for life story work is being honed to determine how it may contribute to deaf people's sense of identity, resilience and agency. Contributions toward this endeavour have included my personal journey as well as ethnographic life story research on 'deaf flourishing' around the world. I sketched the interdisciplinary crossroads from which I approach this, offering the examples of communal life story work with the Ugandan deaf community and individual work in the UK with deaf migrants. Communal life story work is vital to the wellbeing and empowerment of deaf signers, who participate in multiple communities, including their family of origin and one or more deaf communities with whom they share a signed language and deaf culture. I employ creative and pictorial methods, befitting the visual orientation of deaf signers and the established cultural storytelling practices of sign language communities. The work with deaf migrants also involves an emancipatory stance which fosters self-reflective learning and resilience. The strengths of signers are further exploited through digital storytelling, leading to an ultimate aim of producing a deaf-friendly app which, in concert with the other emerging innovations described here, is intended to contribute sustainably to specialised services and training in deaf life story work.

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