

# **The Patient Journey: Living With Hearing Impairment**

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Hearing impairment is a common chronic condition which is often poorly recognised and rarely acknowledged. People with acquired hearing impairment may begin a long journey of unknown consequences. This paper provides the narrative (personal accounts) of 2 adult patients with acquired hearing impairment about their experiences of living with this condition. The narrative is presented in a structured way with 7 main phases identified from our previous study on the patient journey (Manchaiah, Stephens, & Meredith, 2011). The journeys described by the patients highlight the individuality and uniqueness of each person facing the same challenge. They also illustrate the complexity of the psychosocial aspects of acquired hearing impairment.

Hearing impairment is a common chronic condition in middle-aged and elderly adults which is often poorly recognised and rarely acknowledged. Acquired hearing impairment can be due to a variety of causes including genetic factors, noise exposure, ear disease, and so on. Person with hearing impairment may experience poor health-related quality of life due to consequences in both physical and mental domains (Chia et al., 2007). Frequently, individuals may not be aware of the consequences they might face during this long journey of acquired hearing

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impairment. However, they will have various experiences and milestones before, during, and after the hearing healthcare assessment and/or rehabilitation sessions.

The natural course of the condition may vary and a wide range of long term experiences have been reported by individuals with hearing impairment (Edgett, 2002; Stephens & Kramer, 2009). Examples of this are: becoming aware of the problem; making a decision to seek help and achieving referral; understanding hearing loss and its impact. This information may be invaluable to hearing healthcare professionals when they consider how best to ensure meeting the individual needs with treatment and/or rehabilitation options available.

The course of illnesses related to various chronic conditions has been studied by medical anthropologists. Such examples of published case studies with emphasis on the patient journey have been reported in a number of medical conditions such as Parkinson's disease (Baker & Graham, 2004), Locked-in syndrome (Chisholm & Gillet, 2005), Pertussis (whooping cough; Levenson, 2007), and Rheumatoid arthritis (Oliver et al., 2008; Simpson, Franks, Morrison, & Lempp, 2005). The clinical healthcare literature usually focuses on technical and physiological aspects of chronic disease management. However, some studies by anthropologists have focused on understanding the social and cultural dimensions of the illness (Hahn, 1995). In recent years some healthcare professionals have attempted to better understand this process, which may help the development of a patient-centered treatment approach. For example, Englund (2006) studied the decision making process of hearing impaired people who seek help, a process which she termed the "time for hearing." She identified four main stages experienced by patient during this process which include: (a) attracting attention, (b) becoming suspicious, (c) sensing tribulation, and (d) jeopardising fundamental self.

The Ida Institute at Denmark developed a possible patient journey model using professionals' perspectives (Ida Institute, 2009). In our previous study we further developed the "patient journey model" for adults with acquired hearing impairment using the patients' perspectives (Manchiaiah, Stephens, & Meredith, 2011). Thirty-two adults with acquired hearing impairment (all hearing aid users) from two hearing impaired groups in Wales worked in small groups to describe their experiences through hearing loss. These data were used to develop a template of the patients' perspective of the journey. This was then compared with the professionals' perspective of the patient journey developed by the Ida Institute and a "patient journey template for adults with acquired hearing impairment" was developed. This model includes seven main phases: (a) pre-awareness, (b) awareness, (c) movement, (d) diagnostics, (e) rehabilitation, (f) self-evaluation, and (g) resolution. The study highlighted the differences and commonalities of perspectives of professionals and patients. In addition, the study also highlighted the fact that the professionals did not identify the stages the patients go through during the self-evaluation phase. Figure 1 shows the main phases of the model. In addition, on another pilot study we looked into the patient journey of sudden-onset ac-



Figure 1. Main phases of the patients' journey of adults with hearing impairment. From "The Patient Journey of Adults With Hearing Impairment: The Patients' View," by V.K.C. Manchaiah, D. Stephens, and R. Meredith, 2011, *Clinical Otolaryngology*, 36, p. 231. Copyright 2011 by Wiley-Blackwell. Reprinted with permission.

quired hearing impairment (Manchaiah & Stephens, 2012). In this study the professionals' perspectives were collected from 16 audiologists using the Ida template and patients' perspectives were collected from interviewing four patients with sudden-onset hearing impairment. The main differences between professionals' and patients' views were in the self-evaluation stage where the professionals did not recognize various stages. The absence of a pre-awareness stage was the main difference in sudden-onset patient journey when compared to journey of adults with gradual-onset acquired hearing impairment.

The present paper is aimed at understanding the patient journey using the patient journey model as the baseline and also provides some insight into the life story of two adults with acquired hearing impairment.

## METHOD

### *Data Collection*

A purposeful sampling strategy (Patton, 1990) was used in order to recruit the individuals with different onsets and courses of the impairment. This research was approved by the Research Ethics Committee, College of Human and Health Sciences, Swansea University. The biographic-narrative interview method (Wen- graf, 2001) was used to gather the data from two adult patients with acquired hearing impairment who were recruited from the hard of hearing support groups based in South Wales. The biographic-narrative interview method is a method to explore "lived" experiences of individuals or collectives through biographic narrative interviews. This approach focuses on eliciting the narratives of past and present experiences rather than on explicit statements. The interview protocol involves three stages which include: (a) non-interrupted initial narrative, (b) internal questioning of the points raised in the initial interview, and (c) further questioning to explore the areas relevant to the particular area of research.

Interviews were conducted by the first author. The participants were asked to narrate their journey (tell their story) with hearing impairment. The interview was initiated by asking questions related to topics that arose during the narrative. This was followed by some general questions to explore the patient's problems broadly and finally, more directed questions were asked to get an in-depth understanding of their experiences. The Appendix provides information about some of

the questions used during the interview. The interviews were recorded using portable digital recorders to recheck the notes taken by the researcher.

### *Data Analysis*

The notes and the voice recordings were further analysed using qualitative analytic methods such as narrative analysis (Lieblich, Tuval-Mahiach, & Zilber, 1998; Riessman, 2005) and thematic analysis (Braun & Clarke, 2006) to identify the meaning and essence of the participants' experiences and to assign them to appropriate phases of the patient journey model. Narrative analysis uses a positivist approach, focuses on the way in which people make use of stories to interpret the world, and attempts to provide an account of change over time. The narratives can help the individual define their own identity by attempting to link their unbiased views of the past and present experiences. Overall, the storyteller interprets the world and their experiences in it and the researcher selects, organizes, and connects the events and evaluates the meaning associated with it to report to a particular audience. In contrast, thematic analysis involves identification, analysis, and reporting patterns (themes) within data.

Thematic analysis was used to identify an adequate number of themes which effectively reflect the data, while narrative analysis was used to link their past and present experiences and to interpret the meaning to the experiences described. Adults with hearing impairment go through various experiences with their hearing loss during the course of their condition and treatment. We would argue that the narrative models are useful in gaining in-depth understanding of the meaning and the contextual issues of their experiences and to connect their experiences which are described in the form of time-line.

## RESULTS

The following life stories describe the impact of hearing impairment on the participant's life. The main issues pointed out by the individuals have been described in seven main phases identified in the patient journey model of adults with acquired hearing impairment (Manchaiah et al., 2011).

### *Jenny's Story*

**Background.** Jenny is a 59-year-old female who has bilateral bone-anchored hearing aids (BAHA). She has retired and lives in South Wales. She first experienced hearing impairment when she was a little girl (about 5-6 years of age). This was caused by chronic ear infections and she underwent several ear operations (mastoidectomies) during her childhood. Having to take a lot of time off from school to go for treatment caused many problems for her schooling. She reports that she had a very understanding family who supported her well during her childhood. She discontinued schooling at the age of 15 years and went on to become a hair-dresser. She travelled widely and also worked abroad. Her ear in-

fections continued and she suffered difficulty with her hearing. However, she was not able to use hearing aids due to constant active ear infections.

She was advised that she would be a good candidate for BAHAs when she was in her early 30s. However, it was 10 years later before she was implanted. The BAHAs helped her to hear better and made a significant difference to her quality of life. She managed to keep her job until her early 50s even though she had considerable problems hearing her customers. She has faced various challenges due to her hearing loss. The following sections provide insight into some of the key stages and/or experiences through the journey with hearing impairment.

***Pre-awareness and awareness.*** She was born and grew-up in the South Wales Valleys. She underwent several ear operations during her childhood. She remembers this as a distressing time.

When I was a child I had lots and lots of mastoid operations. I used to scream in pain.

The nurse who attended the school for regular health checks first identified that she might have a hearing loss. Her words describe the problems she faced during the initial stages of hearing loss. She notes her senses of “otherness” and isolation from peers impacted on her education.

Your schooling becomes affected, because you have taken so much time off to go for these operations. Even though they educated us in the school. . . . you don’t make the contact with the school-friends. Because by the time you gone back to school they have either gone better . . . your schooling does become affected. . . . Even though I think I could have done better as I went on to do other things and my education came when I went to work. . . . I learnt more when I left school than when I ever did in school.

There was hearing impairment in her family. Her mother and her brother both had similar problems. She feels that, because of this, they were able to better understand the problems she faced and supported her. She reports that communicating when at home was not a big problem as they all spoke to each other loudly.

TV and radios were always loud at my home. My mother and brother had hearing problems and we spoke very loudly. . . . We were a loud family.

***Movement.*** The problems in communication continued and caused her more difficulties when she went on to take up her job as hair-dresser. She also needed to take time off to visit the doctors regularly and while undergoing ear surgery, which created problems with employment.

When I started my job as a hair-dresser, there were things I used to get wrong what people have said. I was not wearing hearing aids. I found it very difficult.

She mainly relied on information from the doctors about her ear disease and also about the treatment options.

***Diagnosics.*** She visited ENT specialists mainly for treatment of her ear in-

fection. However, she also had hearing tests routinely. She was not able to use hearing aids because of her ear infections. One of the ENT specialists recommended a BAHA for her.

When I found out about this bone-anchored hearing aids, I wanted one. . . . I heard about the BAHA from this American doctor in London.

**Rehabilitation.** Regular attendance with the hearing clinic has been a constant feature throughout her life. In the initial stages she mainly sought medical help from hearing healthcare professionals.

Up until 30 I have had about four ear operations.

However, she has been using BAHAs since she was in her late 30s.

My hearing went right down. I went to see ENT. He was trying to get me to wear hearing aids. I couldn't wear the hearing aids due to infections. I was having recurring ear infections. I was deaf.

I waited for about 10 years before having BAHAs . . . When I came to Wales. I kept saying about it. When the funding came through. There was a nice lady who showed the video. I really didn't care. I felt this is the way forward for my life.

Having a BAHA inserted was a major transition in her journey. Currently she reports that she is doing well with the BAHA and manages well in most situations.

This is one of the best things that has happened to me in my life.

**Self-evaluation.** She reported having missed all sorts of sounds when she was not able to use any amplification devices because of her ear infections. She understood what she was missing only after she started using the BAHA.

I never heard water running through pipes for long time. . . . Rain . . . rain on the windows I never heard unless it is very very loud.

While she had experienced various difficulties in communication at school and work, her emphasis during the interview was on the emotional disturbances she experienced, mainly due to people not understanding her difficulties. A sense of stigma was also evident.

People tend to think you are daft when you don't hear well.

Even though the hearing impairment caused various challenges in physical and emotional terms, she was able to identify some positive aspects of hearing loss.

I travelled a lot because of deafness and . . . Because of my hearing I became more visual and I got better at my job. I was used to watching people . . . People watching. . . . and get things right by watching and guessing . . . I also bluffed a lot. . . . It also made me more determined and I think it did make me stronger.

By travelling . . . you meet different people and nobody knew about my hard of hearing and I got by better.

**Resolution.** The life adjustment she has had to make due to hearing impairment has resulted in a poor quality of life.

It affected my job and affected my self confidence. Luckily, I kept my self-confidence keep going until my last job . . . it did get me down so much that I suffered from depression.

People not understanding the hearing impairment was very frustrating.

Oh. . . Don't worry. . . She is deaf . . . you look back, you look at that and think . . . hang on. . . I am not able to hear so much but there are ways in which they need to be educated not me . . .

Hearing impairment can also act as a barrier when it comes to relationships and making friends.

People been saying to me I called you the other day and you ignored me . . . You can lose friends unless they can understand . . . you can lose people . . . You know . . . that you would like . . . But they think you are rude . . . Because you have not heard . . .

Deafness is an unseen disability. . . You don't carry anything to say you have it.

The other important issue which was identified was that people with acquired hearing impairment may not have an easy access to support networks.

But maybe when you get deaf when you are young . . . you have a network you learn sign language . . . I am not saying it's a lucky thing . . . but when you caught in the middle and can't wear hearing aids due to infections . . . It saps your confidence so much . . . You feel like a non person.

Having faced the hearing impairment most of her life, she had several comments and recommendations which need serious consideration.

I think what needs to happen is that . . . there needs to be somewhere where a people can go and have support and counselling, not just for them and for the family, so they can handle it and through the family handling it the society can handle it.

### *Alan's Story*

Alan is an 83-year-old man who developed hearing loss as he became older. He started noticing hearing difficulties when he was in his early 60s. He initially complained that his family members were mumbling and managed hearing loss for a few years without any help. However, due to family pressure, and also with the increase in the amount of difficulty he was facing, he consulted hearing healthcare professionals. He has been using hearing aids since he was in his early 70s. Currently he manages well with his hearing aids in quiet situations, but finds

it challenging to hear in situations with background noise present (e.g., restaurants, supermarkets). He is dependent on his wife, to some extent, for communicating in challenging situations, especially when using the telephone.

**Pre-awareness.** During the initial days of facing hearing difficulties he expressed denial and also blamed his family for not speaking clearly. However, with repeated complaints from family members he began to become aware of his hearing loss.

First of all . . . My wife and my children . . . Who said . . . You are getting deaf. We are not mumbling . . . You can't hear us. It's your fault.

**Awareness.** He reported that he started going deaf in his 60s. His hearing impairment was confirmed when he had a hearing test.

Specialists come and tested me at home . . . Commercial . . . Exactly when and what happened . . . I am not sure. They said . . . yes . . . you needed a hearing aid. They fitted me with one.

**Movement and diagnostics.** He was first tested and fitted with hearing aids by a private hearing aid dispenser. He does not remember whether he consulted any other services. However, later he was referred from his family doctor to visit the Audiology clinic in the National Health Service. He has been receiving services from them ever since.

Later . . . after a few years. In 1993, I must have gone to Singleton Hospital. Because, I have a book with the record. They tested me and I started getting National Health hearing aids.

**Rehabilitation.** He started noticing immediate benefits from hearing aids.

I went home and I said to my wife, I have been hearing better than I have heard for years.

At present he is very dependent on his hearing aids.

If I switch my hearing aid off . . . I can't really say what you are saying . . . I can't lip read either. I am in trouble.

**Self-evaluation.** He wears his hearing aids all day and finds it hard to manage without them.

Sometime I can't understand my wife, particularly in bed at night . . . She speaks and I have to go face to face and watch her mouth. I can't lip read . . . But it helps.

He also avoids conversations with visitors, especially if they speak quickly or have a strong accent.

If we have visitors very often I sit back and I let them talk. I can't follow con-



versation.

He reported the following positive and negative experiences with hearing impairment.

The main positive experience is that it's quite nice to switch them off and listen to the silence. It's peaceful . . . It can be . . . But the real trouble is of course I might miss hearing things and I can't follow . . . Particularly if we are visiting someone or travelling or something. . . . I miss picking up pieces of information . . . I do rely on my wife.

**Resolution.** He reported having difficulty with television and films.

Films . . . I often can't often follow dialogue, in TV. I can usually follow the news readers . . . they are nice and clear . . . Otherwise . . . in plays and so on . . . and quiz, shows, and so on . . . I have to use text at the bottom to follow what is happening.

He also experiences difficulty understanding people in challenging situations.

If I go into a shop I can't always say what the shopkeeper is saying . . . Particularly if there other noise in the shop. . . . My wife is an interpreter for me.

When questioned directly he thinks that hearing impairment did not interfere with his quality of life. However, during the interview several statements he made clearly identify the life adjustments and compromises he has had to make. Also, he identified the fact that hearing impairment is not easily recognised and/or acknowledged by other people.

If you are blind you have a white stick and they know you are blind. But when you are being deaf . . . unless you have a little sign saying "I am deaf" . . . they don't do anything about it.

## DISCUSSION AND CONCLUSION

In this study information about the patient journey of two hearing impaired individuals, collected using qualitative methods, has been presented in a structured way with the seven main identified themes from our previous study (Manchiah et al., 2011). It provides an overview of the patients' view on "how it feels for an individual to face a hearing impairment," "how a person with hearing impairment adapts their life to manage such a condition," "positive and negative experiences," and "its relationship to quality of life." Even though the data does not reflect the experiences of all adults with acquired hearing impairment, the journeys described by the patients highlight the individuality and uniqueness of each person facing the same challenge. Moreover, the experiences reported by the participants were consistent with our previous study where the patients' responses emphasised more on the later phases of the journey (self-evaluation and resolution).

From the patient narratives it is clear that the individuals may experience various stages and/or milestones at different intervals of time. For this reason we suggest adopting some amount of flexibility in the boundaries of the phases of the patient journey model. Even though the nature and onset of hearing loss were different in two of these case examples, it clearly demonstrates the complexity of the psychosocial aspects of acquired hearing impairment.

In an era where healthcare is driven by evidence-based practice and service user satisfaction, better understanding of the journey through illness could provide clinicians with the opportunity to tailor the process of diagnosis, treatment, and management to suit the individual's needs (patient-centred approach). One way of understanding the journey of the patient is by using the approach of narrative based medicine. Greenhalgh and Hurwitz (1999) argued that "narratives of illness provide a framework for approaching a patient's problems holistically, and may uncover diagnostic and therapeutic options" (p. 48).

Such an approach in studying the patient journey places emphasis on the skills of listening, appreciating, and interpreting the patient's stories, which are key functions during the clinical encounter. It provides very useful anecdotal information at the expense of a structured approach and can be useful in understanding the complex processes underlying acquired hearing impairment. A recent study by Berg, Canellas, Salbod, and Velayo (2008) shows that exposure to disability and hearing loss narratives are effective in increasing the affective elements in undergraduate students' technical/informational responses. This would suggest that the patient narrative of the course of illness could be usefully incorporated into the training curriculum. In clinical situations identifying the experiences the patients go through and their psychological state of mind may help the clinician in planning the treatment strategies. For this reason obtaining detailed information about psychosocial aspects of hearing impairment additional to the routine objective data obtained through clinical investigations should be encouraged in clinical practice. In addition, studying the patient journey could be very useful in developing care pathways (Layton, Moss, & Morgan, 1998). However, the main drawback of the narrative approach is that, due to the small sample numbers, the results may not be generalizable.

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### **DECLARATION OF INTEREST**

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this paper.

## DISCLAIMER

The authors have not used participants' real names to maintain their anonymity.

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**APPENDIX*****INTERVIEW QUESTIONNAIRE***

1. Tell me about yourself and also tell me the story of your journey through hearing loss.
2. What was your initial reaction to your hearing loss?
3. What were your immediate emotional reactions to your hearing loss?
4. What were the reactions of your family members/friends?
5. What life adjustments did you have to make because of your hearing loss?
6. What are your strategies to cope with hearing loss?
7. What effects does the hearing loss have on your quality of life?
8. What are the main stages/phases you went through with your hearing loss?
9. Have you had any positive experiences due to your hearing loss?
10. Is there anything else you would like to tell me about your hearing loss?