

RESEARCH

Women's Lived Experiences of Disabling Hearing Loss in Daily Life

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The aim of this study was to achieve a deeper understanding of what a moderate hearing loss means in daily life for middle-aged women. We used a phenomenological approach and interviewed ten women, 36–56 years old. From the analysis, one essential structure 'Keeping in touch with life – a strain but a vital necessity' and two interrelated themes – 'Performing on the social scene' and 'Living the internal life' emerged. The hearing loss changed their approach to daily life and relations to other people had become more demanding and challenging. Communication was interpreted by the women as their responsibility and involved feelings of unpredictability, uncertainty, stress and fatigue. The combination of the hearing loss, ill-health and the life situation at midlife, increased strains in daily life. Resources and competence in hearing rehabilitation need to be developed in order to meet the individual and long-term demands of these women and to prevent insufficient connections and ill-health.

Keywords: Hearing loss; lived experiences; midlife; phenomenology; women's health

Introduction

For most of us, sound is a natural part of life. Even before we were born, we had learned to recognize some common sounds. After birth, hearing is rapidly developed and differentiated to become necessary for survival and interaction with other. A few children are born with or develop severe hearing loss, but most hearing loss affects adults after they have been hearing well. A limited ability to hear is noticeable when conversations with other people become unclear and are no longer as easy to perceive. This also affects the relatives who can encourage the person with hearing loss to seek professional help (Getty and Héту 1991). Some degree of hearing loss (PTA 0.5–4 kHz \geq 25 dB HL) is a common obstacle to health and includes 16–17% of the population in Europe (Pascolini and Smith 2009). Most commonly, individuals over 65 years of age are affected. The number of individuals between 35 and 55 years of age is about 10% and has almost doubled over the past 20 years (Johansson and Arlinger 2003; Statistics Sweden 2009). As the connections between the audiometrically measured hearing ability and the individuals' own experiences of their difficulties are weak (Erdman and Demorest 1998; Hallberg, Hallberg and Kramer, 2008; Kramer et al. 1996), the effects of rehabilitation are more affected by non-audiological variables, such as gender, age, personality and social support (Kricos 2000).

Self-rating studies have shown that individuals with hearing loss often are restricted when it comes to activities and participation in society. They have difficulties to perceive speech, especially in competition with other sounds, and listening is exhausting. They may therefore find it difficult to participate in social situations with several people, and in noisy environments. They become more worried, tired and stressed than those with no hearing difficulties, and the quality of life is lower (Hallberg and Carlsson 1991; Helvik, Jacobsen and Hallberg 2006). People with severe hearing loss can today in many countries get cochlear implantation which can change not only their ability to hear and communicate but also increase their well-being and quality of life (Hogan et al. 2001; Hirschfelder, Gabel and Olze 2008).

A deeper understanding of what limited hearing means in daily life has emerged through qualitative studies where people indifferent ages and with different forms of hearing loss are allowed to express their experiences. Gullacksen (2002) studied recurrent life changes and phases of life in a longitudinal study of middle-aged persons. She described three interrelated phases – admitting, realizing what the consequences are and learning to deal with the problems, as well as maintaining a balance between demands of everyday life and personal limitations. Over time, the adaptation might swing back and forth between the phases. In a phenomenological study (Herth 1998), the core theme was formulated as the metaphor 'dance with...', i.e. an ongoing constant movement with different content and an uncertainty about the next step. The themes of the dance were constituted by loss, fear, fluctuating emotions and a changed perspective on

life. These were ways to integrate the hearing loss into life. For older people, the experiences of hearing loss could be connected to identity and existence. They protected their identity and their feeling of continuity in everyday life. Not until they had experienced the lack of sound as a lack of contact with life they were interested in seeking help (Karlsson Espmark and Hansson Scherman 2003).

In working life, a hearing loss poses different problems depending on the nature and content of the work. The ability to have an influence on and to control their work situation was decisive for the degree of stress shown in a study by Danermark and Coniavitis Gellerstedt (2004). High demands on correct verbal communication combined with low control of the situation, for example in schools and health care, were found to lead to more unhealthy stress than low demands on the communication and high control. Recurring disruptions in communication between a person with noise-induced hearing loss and colleagues could lead to harassment of various kinds. To hide their hearing loss was then a way to maintain their social identity and avoid the risk of being excluded from the group. It meant to withdraw from many social activities and isolate themselves to avoid detection (Hétu, Getty and Quoc 1995; Hallberg and Jansson 1996; Hallberg 1999). A consequence of hearing loss for middle aged individuals is often reduced working capacity. Twice as many of them are on sick-leave for longer periods compared to people in the same age with other ill-health conditions and early retirement is also twice as common. The reasons for ill-health and sick leave have been fatigue and stress (Danermark and Coniavitis Gellerstedt 2004; Kramer, Kapteyn and Hougast 2006). Sick-leave increases with age, and more women than men in the general population is affected (Statistics Sweden 2003, 2009).

In social life gender, age and life situation are important, however, research concerning the consequences of disabling hearing loss have, to a large part, been based on the impairment as such. There are yet obvious differences in daily life between gender and age groups. In addition to their profession middle-aged women spend more time than men carrying out household tasks and have responsibility for the daily care of children. Their spare-time is more fragmented than men's are (Statistics Sweden 2009, 2012). The middle-age life span, 40–59 years of age, is in many ways different from other life phases according to Lachman (2004). It is an eventful period which includes the difficult task of a balancing between several different and complex roles, which might involve a professional career, growing children, ageing parents, and developing age-related ailments themselves.

During this period of life women and men experience and handle a hearing loss in different ways (Garstecki and Erler 1999; Hallberg and Jansson 1996; Hallberg 1999). Women assigned social communication greater importance than men did, which was the basis of the choice of coping strategy. They also experienced more anger and stress related to the hearing loss. Women used non-verbal coping to a larger extent than men. By selecting between verbal and non-verbal coping strategies women could control the social scene to a greater extent than men could, in difficult listening situations (Hallberg and Carlsson 1991; Hallberg 1999).

Few studies were found where middle-aged women or men with moderate hearing loss have shared, in their own words, their experiences of living with hearing loss. This would be valuable knowledge, as the mid-life period often contains many activities and responsibilities for others, and a hearing loss may have different consequences than during other life phases. The number of people in midlife who develop difficulties in hearing have increased dramatically during the past decades, at the same time when extensive and rapid changes in society and working-life also have taken place. The purpose of this study was to achieve a deeper understanding of what a hearing loss means in daily life for middle-aged women. A study of men's experiences is published (Jonsson and Hedelin 2012).

Method

The study has a qualitative, explorative design. The phenomenological approach was chosen as the purpose was to gain a deeper understanding of the phenomenon. The approach seeks to find the meaning of a phenomenon, its essence on an ontological level. The phenomenon appears in the life-world and shows itself through the subject's descriptions of their everyday life (Husserl 1989; Merleau-Ponty 2002/1945). In this study the phenomenon, living with a hearing loss, was elucidated through the women's descriptions of their lived experiences of everyday life. In order for the phenomenon to emerge, the researchers' pre-understanding have been identified and bridled (Dahlberg and Dahlberg 2004) to the greatest extent possible (cf. Colaizzi 1978).

Informants

The informants were chosen by purposive sampling (Polit and Beck 2012). The inclusion criteria were; Woman (35–55 years old), affected by a moderate hearing loss, which had arisen over the past few years; had been participating in group rehabilitation; participating in continuing individual consultation with a doctor, social worker and/or psychologist; users of technical aids. Exclusion criteria; non-Swedish speakers.

Names of possible informants were gathered from a center for hearing rehabilitation in central Sweden. We sent written information describing the purpose and the procedure of the study, as well as a request for consent to participate, to 12 women who matched the inclusion criteria. We also informed them that the interviews were to be tape-recorded, that the information they gave would be treated with confidentiality and that participation was voluntary. Ten women gave their consent to participate in the study. Three to six years before the study started, they had received their first hearing aids and had been offered rehabilitation. The informants' age, occupation, significant others, place of living, disease and hearing loss see **Table 1**.

Table 1: Description of informants.

	Age, years	occupation full-time	significant others	living	disease, actual	hearing loss ^{4/} dB
A	55	clerk ^{1/}	family	village	rheumatic, tinnitus	— ^{5/}
B	38	teacher	single ^{2/}	city	tinnitus	— ^{5/}
C	45	nurse	family	village	psoriasis	43
D	56	physiotherapy	family	city	arthrosis	— ^{5/}
E	36	nurse	family	city	—	47
F	53	retired	single ^{3/}	town	rheumatic	45
G	41	retired	family	town	rheumatic	41
H	54	musician ^{1/}	single ^{2/}	village	heart	47
I	41	teacher	single	city	—	48
J	54	student	family ^{3/}	city	diabetes, movement	42

^{1/} part-time on sick-leave; ^{2/} home living children; ^{3/} adult children;

^{4/} Hearing Level Better Ear; ^{5/} unilateral, severe hearing loss.

Data collection

To collect data, we used informal and conversational interviews (cf. Fog 2004). The informants were asked to freely describe everyday experiences from their lives at home, with family and friends, at work and in their spare-time. We asked follow-up questions to make the stories clearer. The informants had no problems following the conversations in a quiet room using their hearing aids and the interviewer had experiences of talking with people with hearing difficulties. The interviews took place on two occasions, two weeks apart, with each informant. In the second interview, we followed up and deepened topics/themes from the first interview. The interviews lasted about 60 minutes and were tape-recorded and transcribed verbatim by an independent transcriber. In total, the transcribed text corresponded to 278 pages with single spacing, size 12. The tapes were listened to and compared to the texts before the analysis began.

Data analysis

We analyzed the text from the transcribed interviews according to the seven steps described by Colaizzi (1978). (a) The text from each interview was read through in order to get a sense of the whole. (b) Significant statements relating to the current phenomenon were elucidated by moving back and forth between parts of meanings and the whole text. (c) Meanings were formulated based on the significant statements by using reflection, intuition and imaginative variation. (d) The formulated meanings were ordered into themes and comparisons were made between the transcriptions and themes in order to ensure a credibility. (e) Themes were integrated in an exhaustive description of the phenomenon. (f) The fundamental structure of the phenomenon was formulated. (g) Descriptions of themes were supported by quotes from the interview transcriptions.

When the first interview with an informant had been transcribed, we analyzed the first three steps (a–c) preliminary according to Colaizzi. The preliminary meaning analysis served as a base for deepening in the second interview. After the second interview had been performed and transcribed, we analyzed both interviews using all of Colaizzi's steps. The analysis procedure was repeated for the data of each informant. Finally, all interviews were woven together through a continuous process of comparisons between similarities and differences, between parts and the whole of the entire data text, and between the steps of analysis with the purpose to validate the analysis and understand the meaning of the phenomenon under study.

Trustworthiness

To ensure trustworthiness, standards for rigour in qualitative research – credibility, auditability and fittingness – were applied (Sandelowski 1986). We strove to hold back our own pre-understanding to ensure that the informants' lived experiences had precedence in the study (cf. credibility). We read through the interview texts separately and made a preliminary analysis, which was then compared and discussed until a mutual understanding of the text was agreed upon. Quotes are used in the findings to enhance the meaning of the themes. To facilitate review (cf. auditability), we described the research procedure and Colaizzi's method (1978) was followed as carefully as possible during analysis. The choice of informants was made based on working women of different ages, civil status, life situations and experiences in order to have a broad spectrum (cf. fittingness). In the discussion, the results of the study are compared and related to qualitative studies with similar focus.

Ethics

The study has been reviewed and approved by a Regional Ethical Review Board. Furthermore, ethical considerations were made regarding the informants' integrity, confidentiality and voluntariness guided by The World Medical Association Declaration of Helsinki <http://www.codex.vr.se/en/index.shtml>. The informants received oral and written information about the study and gave written informed consent to participate.

Findings

The informants' descriptions of everyday life with limited hearing emerged as one essential structure, *'Keeping in touch with life – a strain but a vital necessity'*. Taking responsibility for facilitating and maintaining daily life and relations to other people was experienced as a natural part in the women's life. After the onset of the hearing loss, this became more demanding and challenging. The consequences of an imperfect communication were interpreted as their own fault, which affected them in a negative way. The essential structure was built on two interrelated themes. One theme appeared as external, *'Performing on the social scene'*, and the other appeared as internal, *'Living the internal life'*.

Theme: Performing on the social scene

The women were constantly reminded of their hearing limitation when meeting and interacting with other people in different environments. It also impaired their ability to interpret and locate sounds in their surroundings, for example from emergency vehicles. The articulation and strength of voice of others, as well as the presence of background noise, affected the women's ability to hear and participate in conversation. The problems varied depending on whether the conversations took place one-on-one or with several participants, and whether the conversations were formal or consisted of more informal chit-chat. The informal conversations made the women especially worried, as there was an increased risk of misunderstanding:

I have difficulties to hear and I become very tired. I try to participate in the conversation and I usually have to ask for repetitions. That makes me feel as if I am causing the conversation to stop, that I am breaking the flow. I sense that people are offended, and that's what makes it difficult.

Usually, the women felt that it was their sole responsibility to understand correctly and give an adequate answer. One woman described her encounters with others:

I usually inform people that I am hearing-impaired, so they won't be offended if I get very close to them or have to ask them to repeat. Otherwise, people might get stressed and think that I'm a bit stupid or lost, or misinterpret it.

All informants had hearing aids, and some even had special aids for telephony and conferencing. Sometimes they had trouble using the aids because of noise, loud everyday sounds or environments with a high moisture level. Also, they felt that in most situations, hearing aids could not replace their own hearing. 'It is a wonderful complement. I mean that life is much better with the hearing aids and the assistance they give, but it is not like hearing well myself.' The disabling hearing loss decreased the women's autonomy. The need for well-functioning hearing aids was a daily concern and very time-consuming. It restricted the informants' social spontaneity such as going to a restaurant or taking a trip somewhere. Also, in order for the aids to be effective, people with no hearing loss had to adapt to the informants. For example, they could speak in a way that made it easier for the person with hearing difficulties to hear, or they could take note of whether the women had heard what was being said, and if not, they could repeat themselves or lean in closer. When people around them did not adapt, it could mean that 'people with bad hearing are ignored. Large public spaces usually include an amplifier. It works most of the time, but when it is broken, it is not always fixed right away... it becomes uncertain.'

In the workplace it was often easier to hear formal conversation rather than informal chit-chat. New information, given at meetings in the workplace, brought extra tension. The women felt uneasy about asking questions in those situations, as the information may not become understandable anyway. Telephone conversations with unknown people posed difficulties, especially if the topic was unknown. It was easier when the informants could use e-mail instead of a telephone, and also have access to written material. This also gave them an increased sense of participation. Other strategies could include being active and talking, thereby establishing eye contact with the person in charge of the meeting. If the women no longer were able to participate in a work environment, they expressed feelings like; 'I'm ashamed and I don't really want to say that I'm on disability leave. I have tried, but there are no jobs for me.' In order to handle the strain that everyday noises and conversations bring, the informants used different approaches. One recurring strategy was to save energy by for example retreating somewhere else.

In a family situation, the hearing difficulties and misunderstandings could lead both to irritation and to jokes. Informants mentioned that they worried when they did not hear soft-spoken words said in confidence by their children, if the situation did not make it possible for them to ask for a repetition. It became especially worrisome if they had to give an adequate response in order for the conversation to continue. When family members needed support from the

women, such as at doctors' appointments, it could be difficult for them to stress their own need of hearing. Their ability to meet new people and make new acquaintances outside of work or in relation to their children had decreased. They preferred to meet a small number of people, preferably in the home.

Theme: Living the internal life

The hearing loss meant a process of change with different phases. It forced the women to make priorities in life and make life changes accordingly. Changes in everyday life could be demanding. 'I have changed, I can tell because I am backing down. I didn't use to be like that. I think my self-esteem is low. A hearing loss makes you shrink a little bit.'

Periods of balance, acceptance and confidence were replaced by periods of emptiness, worry and lack of satisfaction. Some chose to challenge the situation by taking a completely new direction in life, for example by starting a new education, despite age and hearing difficulties. Others felt it was important to stick to a hobby that was crucial to them. 'The hardest part was not being able to sing in the choir. I decided I had to sing, so I had to work hard to keep my pitch.'

Hearing limitations were experienced differently depending on whether the on-set was gradual or sudden deafness in one ear. Problems with following a conversation could be interpreted as attention issues, or mumbling on the part of the speaker. When the women sought help, the limitations had become noticeable in situations important to them, such as at work or during contact with family members. The need for social interaction took precedence over the feeling of old age that disabling hearing loss and hearing aids might imply. Other illnesses or life events could sometimes disguise the hearing problems for a long time, while, at the same time, things such as medical examinations might require active listening. If hearing was drastically deteriorated it could be experienced as 'it has ruined my life, I had hit rock bottom. How will I spend my time, how am I going to fix it? My life sort of fell apart, both privately and professionally.'

Daily life with difficulties to hear could mean a great deal of insecurity and worry about daily interaction, about different kinds of changes and about the future. Some worries could be dispelled with planning and preparation, while others would not lend themselves to control. Uncertainty about what had been said and what the women had been agreeing to caused constant stress. Not participating in a conversation 'felt rude' and meant that others could 'be offended'. Especially significant was worry about one's own body and impaired hearing; 'Sometimes I become frightened and think 'Please God, don't let me lose my hearing on both ears'. Of course I go on like before, but it almost causes... a panic attack.' Informants with children were worried that their hearing loss would be inherited, and for some of those with grown-up children, their fears had already come true.

Listening intently in different situations was trying and brought on loss of energy and fatigue. A mutual effect could be seen. 'I'm so tired that I hear even less... they intensify each other... hearing and mood.' Recurring or constant body ache, as with different rheumatic illnesses, affected the ability to focus on listening and caused fatigue. Migraines and tinnitus often also brought on sensitivity to sound, which made it difficult to use hearing aids. Every day could feel like a struggle. In addition to the personal illness, significant events in one's life or in the lives of family members put a certain strain on the informants, as emotional commitment got in the way of listening:

My hearing is worse now that I have been sad [death in the family]. You shut off many senses and don't want to hear. Then I take my hearing aid off as well, because then I am alone in my own little world.

Accepting as well as living with the hearing loss could mean that 'I mourn that I can't live life to the full, of course that brings grief.' The sight of interaction between others could often remind the women of what they had once had, but now lost. 'I am jealous of people with normal hearing, in particular the everyday life that people see as natural.'

When stimulating interaction with others did not work as before, solitary nature walks or personal activities became important. Usually, this included creative activities like music, painting, working with animals or gardening. Unemployed women could experience better cohesion through these activities, and sometimes their financial situation even improved. However, it could require great determination to claim a right to personal time and plan the day. 'I have learned to say no, but then I feel guilty. I think I'm raised to always be there for others. Then it is difficult to put yourself first.' Another lesson for the women was to accept that they could not hear everything and that they might not be in full control, especially if they had previously always placed high demands on themselves.

Discussion

The purpose of this study was to gain a deeper understanding of what a moderate hearing loss meant in daily life for middle-aged women. The informants in the study constituted an ordinary group of women regarding education, occupation, living and family relations and health problems (Statistics Sweden 2009, 2012; see also Table). On the surface, their lives were similar to other women's lives, with duties to family and society (cf. Lachman 2004). What distinguished them from most women were their disabling hearing loss and the consequences it entailed. When the hearing loss appeared, from nowhere for some of them, they were unprepared. The hearing difficulties and their consequences were not part of their life plan and the purpose they had given their lives. In calm environments and in one-on-one encounters, the hearing loss was hardly noticeable, especially when aids were used. However, the conditions might change rapidly due to noise and complicate hearing. They had learned a lot about their disabling hearing loss and technical aids and found different coping strategies after they were diagnosed. Among other things, the women

experienced the benefit to participate in group rehabilitation with information and shared experiences with others, which is proved valuable in other studies (Getty and Héту 1991; Preminger and Yoo 2010).

Experiences of living with the hearing limitation, how life had previously turned out and how changes had affected the women were well described in the interviews. They had no problems hearing the questions during the interviews and they freely shared their experiences and thoughts. Out of the women's lived experience, the meaning of the phenomenon living with hearing loss emerged as 'Keeping in touch with life – a strain but a vital necessity'. Their living situation brought on many different encounters and conversations daily, especially for those who had an occupation and children who still lived at home. In many cases they had personal, actual responsibility for children or unhealthy adults. The responsibility to facilitate and maintain communication and relationships with people was a task that fell on them just as much now as when they had been hearing well. Encounters with others demanded preparations for the task and for the unexpected. This was seen as taxing and burdensome. This could be compared to the kind of 'double work' that other hearing impaired women and men described when they had to compensate for their hearing loss. This work was not obvious to others, but it was energy consuming and tiring for them (Gullacksen 2002; Jonsson and Hedelin 2012). Since woman with hearing difficulties as well as women with good hearing have shown to be more prone to stay in touch and not interrupt the flow of conversation by, for instance, asking for a repetition, this meant increased stress (Coates 2004; Garsteki and Erler 1999; Hallberg and Carlsson 1996; Hallberg 1999).

The human basic need to be in touch with one's surroundings can be highlighted and understood through a phenomenologic approach. Merleau-Ponty (2002/1945) claims that we are in the world through our lived body. The lived body gives access to the world through our senses, and our surroundings reach us through our lived body, an interconnectedness Merleau-Ponty called *embodiment*. When we are affected by ill health, it causes a disruption in our lived body, which not only affects us physically, but also in our core self. This leads to a loss of wholeness, certainty, control and freedom to act, as well as a loss of the familiar world (Toombs 1993). For women in this study, as well as for others with a disabling hearing loss, it might mean that what they do, want and are able to is altered, i.e. the subjective lived space is reduced. Furthermore, daily activities take longer time and their options are limited, i.e. their lived time is changed, which the informants also told us about. This can be seen as an unhomelike being-in-the-world (Svenaues 2000) which affects the entire existence.

Embodiment (Merleau-Ponty 2002) is also a central concept for the philosophers Corker and Shakespeare (2002) in their efforts to conform disability to postmodernist theory, like the theory of gender and ethnicity, in order to create a coherent theory. They want to problematize the concept of disability and focus on normality by highlighting the important aspects of disabled peoples' lives and experiences, which they mean is not made in sufficient extent within the dominant medical and social sciences. They also stress the changes that occur at different times and over a lifetime. The findings in the present study are supported by the theory by Corker and Shakespeare, since the women's lives are similar to other women's, that is normal, and that their hearing difficulties shifts from one situation to another and over time.

In order to facilitate and continue interaction with others, the women in the present study used, besides technical aids, different coping strategies appropriate to the situation. The strategies include among other things to be prepared for the tasks and to choose between different verbal and non-verbal approaches in the conversation in order to stay in touch and have a place in the community. Women use non-verbal coping to a larger extent than men (Coates 2004; cf. Garsteki and Erler 1999) and are better decoders and encoders of non-verbal communication than men (Hall 2006) which probably facilitates their connections to others. This approach is generally similar to the action of 'controlling the social scene' in demanding auditory situations by using different tools (cf. Hallberg and Carlsson 1991). They give priority to meetings with a few people, for better interchange, instead of participation in larger groups. The women in this study did not withdraw from social activities like other persons with hearing difficulties have been reported to do (cf. Getty and Hetu, 1991; Hallberg and Jansson 1996). The women's own resources and education levels probably helped them to make choices in their work and leisure that eased their strain. They had experiences of normal hearing and knew what meaningful conversations with others might be like, which could help them perceive messages and even affect their expectations when performing on the social scene. The difficulties and problems that the informants often encountered in their daily lives because of the hearing limitation gave rise to many different emotions. In the beginning, it was new and unknown to them, and they had difficulty understanding that this might be because of their hearing. They had chosen their profession, for many of them teaching or care-giving, based on an interest in human beings and had developed professional skills over the years. These encounters now came to be characterized by uncertainty and worry about not being able to perform their tasks the way themselves or people around them expected them to. The women in the study experienced stress in everyday situations and in interaction with others (cf. Danermark and Coniavitis Gellerstedt 2004). Unpredictable situations in the family's daily life could also cause stress and worry and interfere with the ability to listen, but required commitment. At times when technical aids did not work and if repairs took longer than expected, the informants' ability to be in touch with others was reduced and they could feel ignored. At those occasions, they were also in greater need for help, which made them feel less independent and valued. Many encounters and activities that required listening and adaptation were straining and resulted in tiredness at the end of the day, or accumulated to exhaustion. According to Toombs (1993) this could lead to an existential fatigue.

As shown in the findings, the women grieved for they had lost the ability to spontaneously chat with others and to be a part of the working life because of sick-leave. This was experienced as a basic emotion or connected to certain situations. The loss could sometimes be diminished through the women's own efforts or through the environment, but they were still reminded about the difference between then and now. This could be seen as a threat to their existence and a changed life world (cf. Karlsson Espmark and Hansson Scherman 2003).

Finding ways of being in the world meant a continuous process to the women. Days or periods of being able to handle everyday life issues and being in touch with the surrounding world could be rapidly changed by outer circumstances, such as changes in the work life or in the family, or because of other illnesses. This meant a constant swinging between feelings of insecurity, worry and despondency, and feelings of relative harmony and well-being in the search for new ways of being in the world. Feelings of well-being presented themselves to the informants when they became absorbed in something that engaged them, such a creativity, being in nature or interacting with animals. Then they felt whole and connected to the world and the interactional demands of everyday life had been temporarily eliminated. For women with younger children such spare-time could be difficult to find. To reduce demands on themselves could provide a relief. Incorporating the unpredictability of the hearing loss or an illness into everyday life has also been shown to be a prerequisite for the sense of well-being (Fredriksson 2001; Mishel 2008). This oscillation of clear and different ways of being in the world was also found by Gullacksen (2002) and Herth (1998).

Differences in the communication style have been shown in women and men with hearing loss (Garsteki and Erler, 1999; Hallberg and Jansson 1996; Hallberg 1999), and are supported by studies of normal hearing (Coates 2004). In the study of middle-aged men with hearing disability (Jonsson and Hedelin 2012) the essential structure emerged as 'striving for genuine connections'. Many similarities were found between the women's and the men's experiences of living with a hearing limitation such as daily stress, uncertainty and unpredictability. However, the men were more focused on carrying out a conversation with others while the women strove to take part, verbally and non-verbally. For men, substantial changes in the work situation or worsening of hearing capacity gave rise to concerns, sadness and a threatened existence. This also affected the women but they were more worried, sad and concerned about every day issues than the men were. The present study gives us a deeper understanding of what a disabling hearing loss means in middle-aged men's and women's daily life.

Hearing rehabilitation needs increased knowledge of the complex and eventful daily lives of women in midlife with a moderate hearing loss, as well as resources to meet the demands that arise. Above all, the current and the referenced studies show that daily life with a hearing loss is a strenuous, complex and life-long process. Rehabilitation processes need to be developed in the direction of 'lifeworld- led care' as described by Dahlberg, Todres and Galvin (2009), and also need to apply a broad approach based on the experiences of the individual focusing on well-being. However, there is a lack of expertise regarding how to live with the loss, both in Sweden and in most other countries (Danermark 2005). Women and men (Jonsson and Hedelin 2012) in midlife with a hearing loss, about 10% of the population, may at different points in life have a need for psychological and psychosocial competence in order to handle the vulnerability documented in the present and referenced studies, in order to promote well-being, health and participation in working life and society during the entire life span.

Methodological considerations

As in other phenomenological research, the sample in this study was small and purposely selected. The informants chosen were willing and able to share their daily experiences and the interviews provided rich data. The intention was to capture an essential structure of lived experiences of the phenomenon and we mean that the study is consistent in the meaning that the aim, the approach chosen and presentation of findings is coherent (cf. Holloway and Todres 2005). We cannot claim that we have captured all possible perspectives of the phenomenon but according to the sampling process, we assume that the findings can be applicable to other women in the same life situation.

Conclusion

The experiences of the phenomenon living with a moderate hearing loss in middle-aged women emerge as a strain but a vital necessity to be able to keep in touch with life. Mutual, meaningful encounters with other people are uncertain and unpredictable in daily life. To maintain a meaningful conversation is mentally demanding and result in stress and fatigue even if own cognitive approaches and technical aids are helpful. When a disabling hearing loss coincides with illnesses and common life events in midlife, the demands of daily life sometimes increased dramatically, affecting both family life and working life (external) and the informants' own existence (internal). Hearing rehabilitation needs to develop competence to meet the demands in order to prevent insufficient connection and ill-health.

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Competing Interests

The authors have no competing interests to declare.

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