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RESEARCH PAPER

From isolation and dependence to autonomy – expectations before and experiences after cochlear implantation in adult cochlear implant users and their significant others

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Abstract

Purpose: The aim of the study was to examine pre-operative expectations and the post-operative experiences related to cochlear implants (CI) in CI-users and their significant others. *Methods*: A questionnaire was used and the responses were analysed by means of The Qualitative Content Analysis. All adults implanted between 1992 and 2010, who had had their implants for a minimum of 12 months ($n = 120$) were contacted. Response rate was high (90.8%), and all-inclusive answers were received from 101 CI-users (84.2%). *Results*: The overall sense of increased *well-being and life satisfaction* was described as having lived in two different worlds, one with the auditory stimulation and one without. In the overall sense of increased well-being and satisfaction three interwoven subcategories, *alienation – normality, fear – autonomy*, and *living a social life* emerged. When CI-users and their significant others recalled the time prior to receiving the CI, a sense of fear was present with origins in the concern for the respondents' (CI-users) ability to cope and care independently in society. Conversely, after the implantation both parties emphasized the notion of a distinct transformation within the CI-user towards autonomy. Communication was highlighted as a large part of living social life. *Conclusion*: The CI increases well-being and satisfaction for both CI-users and their significant others, which is especially evident regarding enhanced autonomy, normality and living social life.

➤ Implications for Rehabilitation

- Before implantation it is important to discuss the fact that phone calls and listening to music are improvement expectations that might not be met by the CI.
- The perceived life changes affect the lives of both the CI-users and the significant others, a finding important to take into consideration before implantation and during rehabilitation after the implantation.
- Before implantation it is important to inform both CI-recipients and significant others about the length of time required to be able to hear selectively after the implantation and about past experiences of CI-users.

Keywords

Autonomy, cochlear implant, experience, hearing loss, well-being

History

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Introduction

A cochlear implant (CI) is a technical device that enables severely to profoundly hearing impaired individuals, both children and adults, to get access to the hearing world [1]. A hearing impaired individual who does not get enough benefit of amplification with acoustic hearing aids may be a candidate for CI [2]. The decision for cochlear implantation is made after a thorough assessment which considers hearing function, psychosocial status and general health condition. CIs have been available for more than 20 years, and numerous studies have shown that adults with acquired severe to profound hearing impairment (HI) benefit from CI regarding various measures of speech recognition ability and quality of life [e.g. 2–5]. However, the degree of benefit regarding hearing obtained with a CI, based on hearing measurements, varies between individuals [6,7]. There are reports from other specialities, such as ophthalmology and orthopaedics, saying that unrealistic or too high expectations tend to have negative effects on the self-reported benefit of interventions [8,9]. Thus, it is important to examine, what kind of expectations CI-candidates had, which of these came true and which did not.

Severe to profound HI also affects the individual patients' significant others, but this issue has been examined in relatively

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few studies. In the early years of the CI era, when simple single-electrode implants were used to stimulate the auditory nerve, Wexler et al. [10] designed a five-graded multiple-choice questionnaire to study the psychological effects of CI in a relatively small sample of patients ($n = 22$) and individuals in close relationship to the patients (index relatives; $n = 13$). The questionnaire included a pre-operative and a post-operative part and was used retrospectively, such that the patients and their index relatives answered the questionnaire after the implantation. The index relatives' responses were consistent with the patients' responses in that they experienced an increased sense of safety, considerably enhanced self-sufficiency, a significant decrease in the number of emotionally negative episodes, and a reduced feeling of being a burden to others [10]. Thus, the index relatives felt less burdened and responsible [10]. Stephens et al. [11] used an open-ended questionnaire to study benefits and shortcomings of CI among CI-users ($n = 94$) and their significant others ($n = 78$) in Wales and Sweden. The three most common benefits listed by the patients included improved conversation, hearing everyday sounds and being able to use the telephone. The benefits reported by the significant others were hearing what family members said, improved confidence and better communication. The most frequently reported shortcomings were, according to both CI-users and their significant others, hearing in the presence of background noise and telephone conversations.

As shown above, there are only a limited number of studies [10,11] where adult CI-users and their significant others have participated in order to elucidate their pre-operative expectations, the effects of modern multi-electrode CIs on their lives and important factors related to pre-operative information. Further, these studies include relatively small sample sizes.

The aim of the present qualitative study was, by using an open-ended questionnaire, to examine both pre-operative expectations and the impact of CI on the lives of adult CI-users and their family members or close friends.

Participants and methods

Participants

All adults (18 years or older at the time of the implantation), unilaterally implanted between February of 1992 and January of 2010, who had received their implants at a minimum of 12 months earlier in the CI programme at the Department of Otorhinolaryngology at Linköping University hospital in Sweden, were invited to participate in the study ($n = 120$). An invitation letter and a questionnaire were mailed to the CI-users by the research group (first author). The CI-user was asked to choose a significant other from family members or close friends to participate.

All CI-users were operated unilaterally with Nucleus implant from the Cochlear. The CI-users' mean age at implantation was 61.1 years (SD 14.9, min 25.6, max 86.6) and the mean time since implantation at the time they participated in the study was 4.9 years (SD 3.8, min 1.2, max 16.9 years). Only 20 of them had received their implants in the 1990s, indicating that the majority of the participants (80%) used modern CI technology. The mean age of the CI-users was 66.0 years (SD 14.3, min 27.1, max 91.7 years) at the time of participation. Roughly 50% had retired from working life. Phonemically balanced monosyllabic words presented without noise (Swedish speech audiometry, [12]) are routinely used to measure maximum speech recognition score. Individuals who have normal hearing score 90–100% in this test. Pre-operative speech recognition score with hearing aid in the ear to be implanted was 2% (SD 6%, range 0–38%) and the best post-operative score with CI was 68% (SD 20%, range 10–98%).

Questionnaire

The CI-user's part of the questionnaire included 18 questions, and the ''significant other''-part of the questionnaire included nine questions. The questions covered areas such as pre-operative expectations that either became fulfilled or fell short after the implantation, and the positive and negative factors related to the implantation (Appendix A). The letters, with pre-paid response envelopes, were sent to the CI-users between November of 2008 and April of 2011. A reminder was sent to non-respondents about 4 weeks after the first letter resulting in 109 (90.8%) responses.

All-inclusive answers were received from 101 CI-users (84.2%), 40 males and 61 females. Eighty-seven (86.1%) family members or close friends answered the ''significant other''-part of the questionnaire.

Analysis

To capture the perceptions of the participants (CI-users and their significant others) the qualitative form of content analysis was chosen [13,14]. The qualitative approach is well suited when the aim is to examine peoples' perceptions and experiences, and enables descriptions of the CI-users' expectations and perceptions of the impact on their lives. The analysis was conducted inductively which means that theory emerges from the data, as opposed to the deductive approach where the theory forms the basis for the analysis. The inductive approach facilitated in capturing the respondents' perspective by allowing the categories to emerge from the data. The focus of the analysis was in the respondents' written perceptions. The analysis started with a preparation of the data, the first step being repeated readings of the responses in the questionnaires to build up a sense of the comprehensive picture. Responses concerning the experiences of the CI-users and their significant others were extracted and gathered as the unit of analysis. The unit of analysis was then, in the second step, divided into meaning units. These are, more specifically, words and sentences with a common content relevant to the aim of the study (e.g. *Since the fear of mishearing is lesser now, conversations with neighbours, shop staff, agencies are possible*). The third step in the analysis process was to extract the core meaning from the meaning units to create condensed meaning units (*decrease in fear of social interaction*). The fourth and last step in preparing the data consisted of abstracting and labelling the condensed meaning units with a code (*decreased fear*). Subsequently, the data were organized through comparing the codes based on their similarities and differences, and gathered under categories based on recurring patterns of meaning. The continuous comparison within and between the emerging categories resulted in some initial categories merging and others being divided. When no new categories emerged from the material data saturation was considered achieved. These categories are what Graneheim and Lundman [14] label ''manifest content''. The latent content, the theme or main category, *well-being and life satisfaction*, was formulated on an abstract level through the content of the categories. Descriptions and explanations of the expectations and experiences in relation to receiving a CI were created from the categories that emerged from the data. The most frequent results from the analysis were illustrated with excerpts from the data. The excerpts were translated from Swedish to English by the authors. To reassure that the core meaning of the excerpts was not lost in the process four people not related to the study retranslated them back to Swedish.

Written informed consent was obtained from all the subjects and the study was approved by the regional Ethical review board at Linköping University.

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Results

The result section is organized in three subcategories (described briefly in the subsequent paragraph), representing the respondents' (i.e. the CI-users and their significant others) perceptions of their expectations and experiences of the CI, which evolved from the analysis. The three subcategories, *alienation – normality, fear – autonomy*, and *living social life*, are interwoven and are all part of the overall sense of increased *well-being and life satisfaction*. An important finding that emerged from the data was that the life-changes subsequent to the implantation not only brought about change for the CI-user. The perceived life-changes also affected the lives of the significant others, and brought about change in their everyday life. In accounts from both the CI-users and the significant others the CI was expected before and reported after the implantation to increase well-being and life satisfaction. This was described as living in two different worlds, one with the auditory stimulation and one without.

The subcategory *alienation – normality* consists of accounts from the respondents indicating a transformation for the CI-user from a state of alienation to a state of normality. The state of normality was perceived to affect the CI-users and their significant others in the second category, *fear – autonomy*. In the respondents' accounts there was evidence of a more general sense of fear prior to receiving the CI. This fear arose from concerns about their ability to cope and function in society. Conversely, respondents emphasized the notion that the CI-users, after the implantation, had a transformation towards autonomy. The state of normality and perceived autonomy facilitated the interaction between the CI-user and other people, enabling communication with society, thus increasing their social mobility. Communication was highlighted as a fundamental part of the third and last subcategory, *living social life*. Living social life was described as renewed membership in the social context, that is, interaction with individuals and groups, and becoming an agent in social life (external part of life constituted by activities, places, people, etc.). Additionally, two further categories emerged from the data, *shortcomings*, and *information*. These two categories include the respondents' accounts of the weaknesses of the CI and facts they wished to have received, and considered to be important to give others in the same situation in the future, prior to the implantation. Below, the results are outlined through the categories in the above-described order and illustrated by excerpts from the questionnaires.

Alienation – normality

Respondents' accounts of experiences pre- and post-implantation indicated a transformation from alienation to a state of normality. One of the most fundamental changes of receiving the implant was the perception of not being seen as different from everyone else, the ''hearing people''. The most obvious outcomes of the implantation are explicitly related to the CI-users. However, the change for the CI-user also affected people around them, such as family, friends and colleagues. One of the respondents stated that after the implantation her children no longer had a parent that was, by others, seen as odd. The state of normality was expressed by being seen by colleagues and others as normal, and to be treated accordingly.

> I don't need to be treated differently to the same extent as before. Am more one of the crowd (CI-user, female, age 62, working, implant since 2006)
>
> He doesn't have to feel left out (Significant other, family member female, age 69)

The normality, enabling increased engagement was emphasized by both CI-users and their significant others, as opposed to pre-implantation alienation and isolation. The concept of normality, being like any other, also facilitated relations at the workplace. In contrast to, as before the implantation, being ''an outsider'', some accounts from CI-users showed that they were, after the implantation, more involved and able to perform work tasks just like anyone else. Participating on the same terms increased perceived self-value, empowered the CI-users, and made them feel more important. There were also accounts from the CI-users that emphasized the importance of being able to hear and control their own voice. The ability to hear one's own voice enabled the capability to adjust the volume according to the current situation and to speak more clearly. In other words, the CI-user was no longer regarded as slurred and loud, and, thus, facilitated participation in dialogue on the same terms as hearing people. Being regarded as normal was also seen to affect the way and how often others initiated conversation and interacted with the CI-user. In accounts from the CI-users there was a perception that others, after the implantation, turned directly to them in conversation or when they wanted something, in contrast to pre-implantation when they turned to and used significant others as interpreters even though not always needed. This in turn, brought about change in the everyday life of the significant others, such as the CI-user and other people not being dependent on them to function as a bridge for communication.

Most accounts from the respondents showed that the auditory stimulation provided by the CI made everyday life easier and enhanced participation in social contexts. However, there were indications in some accounts from the respondents that the way to normality was not entirely without difficulties.

> Everyone takes for granted that I'm hearing like a normal hearing (CI-user, female, age 69, retired, implant since 2002)

After receiving the CI some respondents experienced some problems, such as being taken for granted to be normal-hearing, even though they had to, for example, learn or re-learn how to differentiate between sounds. Participants reported that adjusting to a hearing life was energy consuming, and even though others have the best intentions this may increase the CI-user's stress. Furthermore, some of the CI-users experienced unforeseen difficulties as a result of their newly found empowerment related to the CI. The empowerment lead to a new balance in personal relationships affecting both the CI-user and individuals around them, that is, a transformation from someone in need of help to an independent human being.

> Feel much more secure. Am much better at speaking my mind in large gatherings such as at work, and that feels so good. (CI-user, female, age 52, working, implant since 2009)
>
> She manages better on her own and is more confident in herself. (Significant other, family member, female, age 56.)

The normality through increased empowerment and ability to communicate reduced the CI-users' fear of ''making a fool of oneself'', thus increasing the perception of autonomy.

Fear – autonomy

The process of going from fear of not being able to cope in society to experiencing autonomy is elucidated in the category *fear – autonomy*. Both the CI-users and their significant others described a fear, prior to the implantation, concerning the patients' ability to communicate with others. The inability to communicate with others was perceived to affect the patients' capability to manage

in everyday life, thereby relying heavily on the people close to them, that is, on their significant others. As a consequence of the fear, CI-users' accounts showed that they receded into the background leaving the communication and interaction with other people to someone else, most often to a significant other. As noted above, the fear was not only present among the patients. Significant others reported that they had worried that the CI-user would not be able to deal with social encounters and everyday social situations, such as grocery shopping on their own or managing contacts with agencies.

> When he's going to get the car serviced at the garage I don't have to be there. I don't have to be there when he's going shopping at the store. When someone asks him I don't have to be there... (Significant other, female, age 50)

The change from fear to autonomy therefore gave some significant others their own renewed autonomy as evidenced from the above quote. No longer required to function as a social bridge, or constantly worrying about the CI-users' ability to manage their everyday social life, lead to decreased stress in the everyday lives of significant others. The fear described in some accounts from the respondents had its origins in yet another source, ''the other people''. People outside the immediate family and circle of friends were perceived as being afraid to make contact with the CI-users due to their disability, further adding to the feeling of alienation. The fear present prior to the implantation decreased after the implantation. The fear among the CI-users was transformed into autonomy, and in the significant others peace arose with knowing that CI-users were able to cope on their own. Further, the confidence was also shown by reports of significant others encouraging the CI-users to seek out new challenges in life post-implantation.

After receiving the implant CI-users managed social situations on their own without having to rely on someone taking the role as the interpreter. Their confidence in interacting increased and the CI-users were more prone to take initiatives in communication.

> My loved one dares to take more contacts than before (Significant other, family member, female, age 55)

The post-implantation taking of initiatives was by the CI-users perceived to be of reciprocal nature. Friends and colleagues were perceived as taking more initiatives in starting conversations after the implantation.

> A key difference, before only a few, that is to say the closest relatives, dared to take the initiative, afterwards most do it (CI-user, female, age 56, working, implant since 1994)

Reduced fear and enhanced autonomy were also experienced as a result of greater participation in life and changed interactions (described further in *Living social life*). The reinforced autonomy and taking of initiatives were reported to lead to the CI-users undertaking more responsibilities, and also being assigned more responsibilities, at work. Some of the CI-users engaged in work tasks impossible to perform pre-implantation, such as working at the information desk. Being trusted with more responsibility further added to the CI-users' increased autonomy and self-efficacy.

Living social life

The implantation was expected, by both the CI-users and their significant others, to increase the perceived value of life. Further, they expected that communication and interaction would be facilitated, enabling the CI-users to be more involved in life, especially in the social life.

> The isolation is broken /.../ possibilities to participate in family and friend activities have increased (Significant other, family member, male, age 60)

Communication and interaction are seen as essential parts of life. This does not only involve being able to express oneself, adapting one's own speech by speaking clearly and adjusting the volume of one's voice. A fundamental part of communication and interaction is to be able to listen. The ability to listen to significant others was emphasized as something desired before and expected after the implantation among CI-users.

> Much easier to communicate, less misunderstandings (Significant other, family member, female, age 67)

In addition, the nature of interaction changed as a result of the CI. As opposed to pre-implantation contact characterized by a distant nature, such as communication via e-mail, the interaction post-implantation was illustrated as more direct, face-to-face. This decreased the distance between individuals, allowing increased closeness, participation and involvement, hence reducing the fear and enhancing the autonomy. This in turn relieved the significant others from the added responsibility they had before implantation due to the CI-users' inability to manage social situations on their own. The CI facilitated participation in the social arena in yet another way, namely enabling the CI-user to socially interact without being forced to see the other party face to face.

> They speak and I answer without actually seeing them (CI-user, female, age 53, working, implant since 2005)

Respondents experienced a positive increase in social exchange post-implantation, and emphasized the value of being able to listen to significant others and carry out conversations, for example while driving or in the dark. Furthermore, the way other people listen to the CI-user was perceived to change to the better, contributing to a richer social life for the CI-users. The enrichment of the social life, illuminated through the categories described above, strongly affected and contributed to increased pleasure in all sections of the social life for the CI-user, and, not least important, for the significant others.

Shortcomings

Accounts of perceived shortcomings of the CI involved technology. Some respondents reported that their expectations of being able to make phone calls and listen to music were not fulfilled. There were also experienced limitations with the perception of certain sounds and thereby certain types of music. This created disappointment related to not being able to fully enjoy these everyday life sounds. However, the batteries were considered to be the main problem with the CIs. The short battery life made the consumption high, hence, leading to a high cost. Further, reported issues related to the batteries also consisted of the lack of device indicating when the battery was running low.

> When the batteries are dead and you don't have any available, you become deaf and you really feel your vulnerability (CI-user, female, age 49, working, implant 2003)

This created a stressful situation for the CI-users due to the risk of abruptly losing their hearing. This stress was also found in accounts from significant others who worried that the CI-users,

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out on their own, would suddenly become deaf, isolated, and alienated due to lack of battery power.

Information

Timescale and past experiences were the most important types of information desired pre-implantation by both the CI-users and the significant others. Timescale referred to the length of time required between the implantation and actually being able to differentiate between sounds, that is, the ability to hear selectively.

> Not having too high expectations understanding that the hearing doesn't immediately get perfect, but rather develops gradually (Significant other, close friend, female, age 69)

Acquiring this information pre-implantation was seen as a way to decrease the disappointment concerning the time and effort needed to gain hearing. Also, it would prevent others taking for granted that the CI-user would hear immediately after the implantation. First-hand information from someone who already received a CI was seen as important, not least in learning what to expect before, during, and after implantation.

Discussion

The study aimed to examine pre-operative expectations and the possible impact of CI on the lives of adult CI-users and their significant others (family members or close friends). According to our knowledge, this is the first time both expectations before implantation and effects after the implantation have been studied in populations of CI-users and their significant others. Both the CI-users and the significant others expected before and reported after the implantation of the CI increases in well-being and life satisfaction, which was an overall sense found in the present study. More specifically, the CI-users expressed a decrease in their perception of being seen as different, and experienced fewer feelings of isolation after receiving CI. The CI-users as well as their significant others emphasized an increase in normality, autonomy and satisfaction in social life after the implantation. Considering that all CI-users in the present study had lost their hearing after acquiring spoken language they all had a previous hearing identity. In addition, the CI-users were seen by the significant others as belonging to the hearing world. Thus, respondents indicated a transformation for the CI-user from a state of alienation (not hearing) to a state of normality (hearing). In his sense, the results of the current study are directly applicable in clinical work when future CI-candidates and their significant others are informed about expectations and experiences related to CI.

Even if the effects of severe to profound HI on significant others have been recognized [15–17], there is a limited number of previous studies examining this issue in relation to CI-users. In an evaluation of outcomes of CI in children, Archbold et al. [18] used a questionnaire with the aim to capture the parental perspective of CI in children. The parents perceived improvement in the children's communication, sociability, confidence and independence 3 years after receiving the implant, that is, factors that affect relations with peers and significant others. In the present study on adults, we found similar improvements, such as increased autonomy and improved social interaction reported by significant others.

Hallberg and Ringdahl [19] used a qualitative approach with interviews to elucidate CI-patients' experiences post-implantation. The results from the present study are in accordance with their finding, that a CI facilitated individuals' social life by decreasing the dependence on others and increasing their participation in the social life, hence raising their sense of self-worth. The results of the present study are also in line with the qualitative study conducted by Rembar et al. [20], who used open-ended questions in order to investigate the effects of CI on emotional well-being, general benefits and shortcomings among 74 adult CI-recipients. They found categories such as a new life, interacting with the world, hearing the world and experience of oneself, which are all related to life and well-being. In the present study, we found that the above mentioned experiences reported on CI-users were extended to the significant others' experiences.

The decision of whether or not to undergo cochlear implantation is preceded by extensive multi-professional evaluation. The possibility to meet other CI-users was one of the most important factors related to pre-operative information reported by both the CI-users and their significant others in the present study. This is also in line with the results of an audit conducted by the Manchester CI Programme as early as in the mid-1990s [21], and is similar to the clinical practice adopted by CI-teams worldwide. Moreover, both the CI-users and their significant others in our study emphasized specifically the importance of information related to the time it takes before the CI-user has learned to hear with the implant. This is a valuable finding as concerns future CI-candidates, their significant others and clinicians working with individuals who have severe to profound HI and are considering implantation. Furthermore, based on the participants' accounts we find it important to note that even though the implant provides auditory stimulation enabling the CI-users to perceive sounds, they are still to some degree hearing-impaired.

Even if some CI-users and their significant others in the present study reported shortcomings in telephone conversation compared to the expectations, the shortcomings or limitations reported were mostly related to batteries. Short implant battery time and high costs of the batteries caused stress in both CI-users and their significant others. This is in line with the study conducted by Hallberg and Ringdahl [19], in which the CI-users expressed worries about the capacity of the batteries and forgetting or dropping the processor. Furthermore, when the most common shortcomings reported by both CI-users and their significant others were investigated by Stephens et al. [11], ''batteries running out of power'' was third on the list after ''difficulties in hearing in background noise'' and ''telephone conversation''.

In the present study, the participants reported their expectations regarding the outcome retrospectively, and expressed increased well-being and life satisfaction. It should be pointed out that all participants in the present study had modern CIs and the majority of them received their implants in the year 2000 or later. Knutson et al. [22] compared expectations related to prospective outcome in a consecutive series of adult CI candidates assessed before implantation in 1981–1999 ($n = 178$). The authors found increasing optimism over time regarding the outcome of the implantation, such that the CI candidates assessed in the 1980s had less expectations than those in the 1990s.

An open-ended questionnaire enabled us to receive more detailed information than a structured multiple-choice questionnaire would have provided. Even if possibilities to gather deeper information are limited in a questionnaire the method enabled inclusion of a larger group of participants compared to interviews. Consequently, the method in the present study increased the possibility, in a broader sense, to generalize the results into the target population. The possibility of studying large clinical populations is especially important considering the fact that CI-users are a very heterogeneous group regarding their age, social background and hearing history [23]. Further research is needed in order to analyse in depth especially those individuals, although few, who do not experience the expected benefit.

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It could be done by means of in-depth interviews. This approach would also enable exploring family dynamics, an issue highlighted in a recent study on CI-users [24]. The response rate was high which indicates that we were able to include a wide range of CI-users and their significant others, thus further increasing the possibility to generalize the results. The data were collected retrospectively, and in many cases some years had passed since the implantation. Thus, the reported expectations may have been affected by the perceived outcomes of the implantation. The expectations reported might reflect what the CI-users and their significant others experienced as outcomes from the implantation, overlooking expectations not met due to all the positive outcomes. Furthermore, the significant others may reflect the CI-users' views instead of their own, as discussed by Stephens et al. [11].

The improved implant technology, good results of CIs and relaxing audiological criteria have already resulted in a new group of CI candidates who have more residual hearing than previous candidates [25]. Consequently, both their and their significant others' expectations regarding the outcome of implantation may be higher and the experienced benefit of CI less than indicated in the present study where the CI-users' pre-implantation hearing was minimal. In addition, there is an increasing number of elderly (80 years and older) who are referred for CI. Thus, future studies should aim at examining the effect of new technology and changed indications.

Conclusion

The CI increases well-being and satisfaction in life for both CI-users and their significant others, especially regarding enhanced autonomy, normality and everyday social life. The results from the present study could be used to inform candidates, significant others as well as hearing health care practitioners about previous patients' experiences with CI. The study did not aim at generating a theory, and cannot be generalized to other contexts.

Declaration of interest

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Appendix A

The questionnaire

(1) What expectations did you have regarding the implant before you got it?
(2) What expectations according to your opinion have been met? What expectations according to your opinion have not been met?
(3) What expectations of the result or outcomes of your implant do you know/think that others (e.g. relatives, close friends, colleagues) had before you got your implant?
(4) When it comes to understanding speech, describe briefly a few situations where you experience that there has been an improvement.
(5) Do you think that you are taking more initiative to communicate with others after the implant than before? Please describe how.
(6) Do you experience that others are taking more initiative to communicate now than before you got your implant? Please describe how.
(7) Can you hear your own voice when you speak and the implant is on? If yes – please describe briefly your experiences of this and how it affects your communication with others.

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(8) Receiving an implant means in many cases some form of change in the individual's way to relate to significant others (e.g. family members, close friends, colleagues, or fellow club members). Do you recognize the situation? If so, describe briefly how.
(9) Do you think that others in the family see you differently after the implantation? If that is the case – who (all, or any particular person)?
(10) In what situations do you notice this most clearly?
(11) What type of information do you think is important to give to significant others before the implantation?
(12) How do you think your colleagues view you after the implant operation? Do you experience any change compared to before the operation?
(13) Generally, do you think that your situation in the workplace has changed after you received your implant? Describe briefly how.
(14) What do you experience as most favourable with your implant in relation to your work?
(15) Is there anything in your work situation that you think has become worse as a result of receiving your implant?
(16) What are the most positive changes you have experienced with the implant?
(17) What are the most negative experiences with the implant?

Please note that family members/close friends of the implant operated are to answer the following questions. Mark if you are □ family member □ close friend

Receiving an implant means in most cases some kind of change to the people living close to the implant operated as well. The questions below aim to identify family members'/close friends' experiences of someone close to them receiving an implant. We believe that the information revealed in such a mapping can be, for example, used in order to give significant others information about what the implant may mean for them.

(1) Has the implant operation led to any changes for you as a family member/close friend to the implant operated? If yes – try to rank the top three changes that you value the most.
(2) Is there any kind of change that you experience or have experienced as negative?
(3) In what areas do you think you see the most and the least change?
(4) What expectations about how it would be with the implant did you have before your family member/close friend received it?
(5) Which of these expectations do you think have been met?
(6) What expectations do you think not have been met?
(7) What type of information do you think is important that family members/close friends to implant operated receives before the operation?

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