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Research Article

Item Generation for a Music-related Quality of Life Questionnaire for Adult Cochlear Implant Users

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Abstract

Background

Existing music questionnaires designed for adult cochlear implant (CI) users are limited in their ability to measure real-world benefits of auditory music training and new technologies.

Aims

To investigate aspects of CI users' relationship with music that are relevant to quality of life (QoL) domains, with a view to generating items for a new questionnaire.

Methods

Thirty adult CI users participated in 1 of 6 focus groups about music in everyday life. The group discussion data were analyzed based on the theory of template analysis. The QoL domains of the Nijmegen Cochlear Implant Questionnaire were used as broad a priori categories to help with organizing associated themes. Participants also evaluated items of existing questionnaires.

Results

The themes identified in the discussion were organized into three main domains (music listening ability, attitude towards music, musical activity), which constituted the *music-related* quality of life (MuRQoL) of CI users. Fifty-three items were developed for a prototype questionnaire using a combination of these themes and items from existing questionnaires highly rated by participants.

Conclusion

The study highlights musical abilities, attitudes and activities of adult CI users poorly addressed or not addressed at all by previous questionnaires. By covering novel aspects of music experience, the MuRQoL questionnaire has the potential to be a more suitable measure of music-specific CI outcomes than previous questionnaires, which may open up new avenues for the assessment and provision of music rehabilitation in clinical settings. The MuRQoL questionnaire was optimized and validated in another study before becoming available for use.

Introduction

Cochlear implant (CI) users perceive most fundamental elements of music (pitch, timbre, melody) poorly, which can be attributed to the physical limitations of the implant (e.g., poor fundamental frequency coding) and to auditory deprivation as a result of the deafness (Drennan & Rubinstein, 2008). Moreover, studies assessing what is commonly referred to as *music appreciation* agree that CI users are disappointed with the music they perceive, have difficulty in enjoying it, and listen to it less with the implant than before their deafness (Looi et al., 2012). However, auditory music training and new CI technologies (e.g., novel implant types and processing strategies) may have the potential to improve music listening and satisfaction (Limb & Roy, 2013; van Besouw et al. 2016). In order to evaluate the effectiveness of such applications and technologies, reliable music-specific outcome measures are needed.

Although there are formal music perception tests that can be used in laboratory conditions (Looi, 2008), there is currently no measure that can reliably assess the effects of music rehabilitation for CI users. Music questionnaires have been designed for adult CI users, such as the Iowa Musical Background Questionnaire (IMBQ; Gfeller et al., 2000), the University of Canterbury Music Listening Questionnaire (UCMLQ; Looi & She, 2010) and the Music Munich questionnaire (MUMU; Brockmeier et al., 2002). However, these questionnaires have not been designed with the aim to assess rehabilitation outcomes. As a result, they do not cover aspects of CI users' relationship with music, such as their feelings about music or music-related social interaction. They are difficult to score and their

psychometric properties (reliability and validity) have not been assessed. We propose that an alternative questionnaire that (a) is a psychometric instrument and (b) assesses music experiences in everyday listening situations more broadly would be more appropriate to evaluate the real-world effects of various interventions on CI users' music experiences. This hypothesis is in line with van Besouw et al. (2016), who suggested that measures of music listening habits of CI users may not be sufficient to capture the impact of auditory music training on CI users' lives and that more holistic and sensitive measures are needed. There is evidence to suggest that music can have a strong impact on the quality of life[1] (QoL) of adult CI users (Calvino et al., 2016; Dritsakis et al., 2017). Calvino et al. (2016) showed significant positive correlations between perceived music sound quality and their QoL scores, whereas Dritsakis et al. (2017) demonstrated how music affects different aspects of the QoL of CI users. Although, studies assessing the music experiences of CI users have not taken into account the impact of music on QoL, music has sometimes been included in QoL questionnaires developed for CI users, such as the Nijmegen Cochlear Implant Questionnaire (NCIQ), where three items under the *physical functioning* domain ask about rhythm perception, melody perception and music enjoyment (Hinderink et al., 2000). Based on the above evidence, we propose that organizing music experiences of CI users according to QoL domains can enable the development of a measure that includes aspects not addressed by previous music questionnaires. We further suggest that the assessment of music experiences in QoL domains reflects the QoL of CI users to the extent that this is affected by music. Thus, we defined the concept of music-related quality of life (MuRQoL) as the QoL of CI users as a function of their relationship with music. The QoL model used for the development of the NCIQ (Figure 1) was used to develop the MuRQoL construct: The MuRQoL, therefore, refers to aspects of the relationship of CI users with music that are relevant to the physical, psychological and social QoL domains. This construct was used as a basis for the generation of items for a MuRQoL questionnaire.

The present paper describes the first stage of the development of the new questionnaire. The aims of the study were (a) to investigate aspects of adult CI users' relationship with music that are relevant to the physical, the psychological and the social QoL domains and (b) to generate items for the

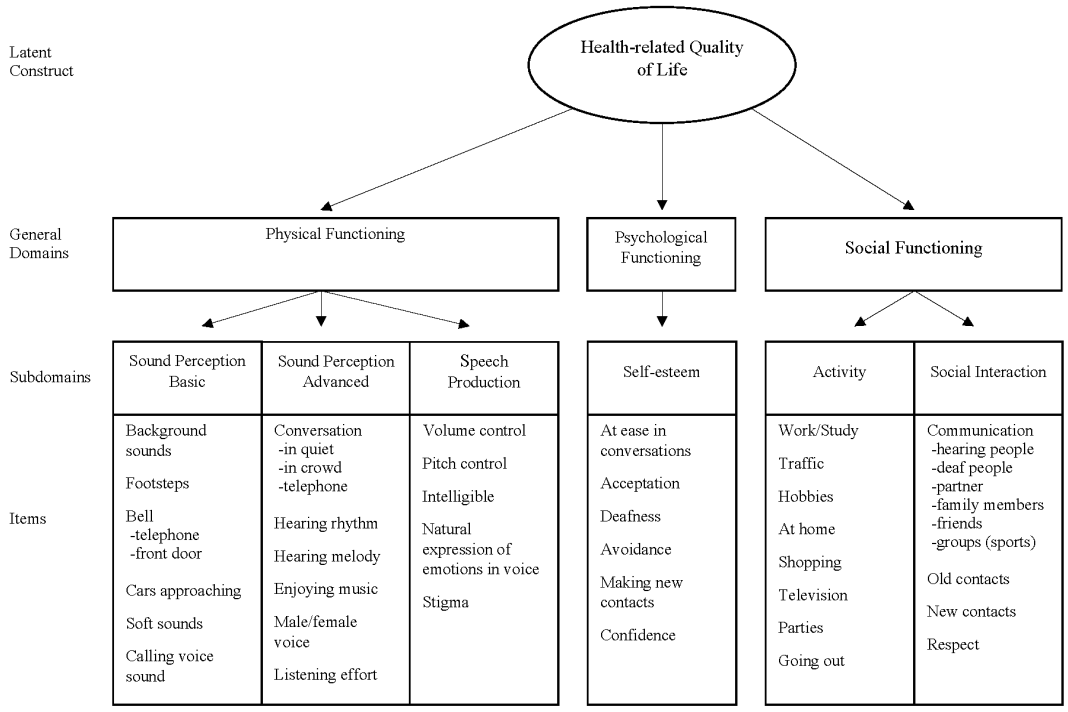

Figure 1. The Quality of Life (QoL) model used as a basis for the development of the Music-Related Quality of Life (MuRQoL) questionnaire. Originally published in: Hinderink, J.B., Krabbe, P.F., & Van Den Broek, P. (2000) Development and application of a health-related quality-of-life instrument for adults with cochlear implants: the Nijmegen cochlear implant questionnaire. Otolaryngology Head and Neck Surgery, *123*, 756–765.

MuRQoL questionnaire. To achieve these aims, focus groups with adult CI users were run and the data collected were used for the generation of questionnaire items.

Methods

Participants

The study was approved by the UK National Research Ethics Committee (14/EM/0140), the University of Southampton Ethics Committee and the University of Southampton Research Governance Office (8264). Thirty adult CI users (12 male, 18 female, *mean age* = 49.5 years, *age range* =18-81 years) participated in 1 of 6 focus groups about music in everyday life (4 to 6 participants/focus group). In order to recruit a wide range of participants to ensure that the results were representative of as many adult CI users as possible, our inclusion criteria were relatively loose: Potential participants had to be adult CI users and able to take part in a group discussion using spoken English. The latter was indicated by a score of 50% or higher in the BKB sentence test (Bench et al., 1979) or by self-report. No special interest in music or any music education were required. Five of the participants were pre-lingually deaf and 9 had received some form of music training (Table 1). Twenty-eight participants were recruited through the University of Southampton Auditory Implant Service (USAIS) using postal or email invitations. One participant was recruited through the UK National Cochlear Implant User Association after responding to a study advertisement and another participant, a student at the University of Southampton, expressed an interest to participate directly to the researcher.

The Focus Groups

Six focus group sessions were held. *Focus groups* are small discussion groups where participants focus on a specific topic by interacting with each other; this is their main advantage over interviews (Kitzinger, 2006). van Besouw et al. (2014) demonstrated that through interaction between participants in a focus group[2] setting, CI users could explore their own relationship with music and validate each other's experience. It also has been suggested that participants can benefit from feeling that their problems with music are common among CI users (Plant, 2012). Among the disadvantages of focus groups is the lack of confidentiality, which may cause embarrassment to some participants especially when discussing sensitive topics. In the present study we believed that interaction in a focus group setting would allow participants to reflect on their own music experiences of issues raised by others, which they could not do in a one-to-one setting. This would highlight a wider range of music experiences and would help us explore music experiences in more depth. The sessions were 2-hours long and divided into two parts.

The first part was a group discussion on music in everyday life. The first author acted as the focus group facilitator by asking broad open-ended questions (Appendix A) to stimulate discussion and ensure that issues relevant to all 3 QoL domains were covered. The discussion lasted approximately 45 minutes and was audio-recorded with participants' consent. The recordings were transcribed verbatim and anonymized by the first author. The discussion was followed by a written evaluation of 19 statements adapted from items of existing questionnaires designed for CI users (Appendix B). The statements described music listening tasks and activities, and participants were asked to rate how important they were for them on a 5-point, (Very important – Not important at all) scale, and to make optional comments on the phrasing of each statement.

The purpose was to assess the degree to which existing items were appropriate for use in the new instrument. The combination of both methods (discussion and ratings) ensured that the new questionnaire would address new dimensions of music experience but also build on existing instruments.

Data Analysis

The discussion data were analyzed based on the theory of template analysis, a particular type of thematic analysis of qualitative data where themes are organized into a coding template (King, 2012). The analysis often starts with a priori themes, reflecting areas expected to be important. Template analysis was preferred over purely inductive (e.g., original grounded theory; Glaser & Straus, 1976) or purely deductive (e.g., framework approach; Pope et al., 2006) thematic analysis techniques because it allowed for both the analysis to be based on a QoL model (Figure 1) and for new themes to arise from the data. It was considered more appropriate than modified grounded theory, for which theoretical sampling has been recommended (Pope et al., 2006), due to the flexibility in sampling. It also was considered more appropriate than the thematic analysis described by Braun and Clarke (2006) due to the use of hierarchical coding, a priori themes and an initial template. The use of a template allowed the development of a MuRQoL framework, which would be useful, not only for the development of the questionnaire, but also as a theoretical framework.

The QoL subdomains of the NCIQ were adapted for music and were used as broad a priori categories to help with organizing associated themes. The NCIQ subdomains were considered appropriate due to their relevance with CI users. The six broad a priori categories used for the analysis of the focus group data were: basic music perception, advanced music perception, music production, music-related self-esteem (how CI users feel about themselves and other feelings about

Table 1. Focus Group Participant Demographics

Participant	Age	Gender	Implant type	Type of deafness	Duration of implant use	Implant manufacturer	Formal music training	Participated in music focus group before
1	75	Female	Contralateral HA	Post-lingual	1 year	Advanced Bionics (AB)	At college	Yes
2	60	Female	Unilateral	Post-lingual	1 year	AB	Piano lessons	No
3	66	Male	Contralateral HA	Post-lingual	15 months	Med-El	None	Yes
4	80	Female	Contralateral HA	Post-lingual	1 year	AB	None	Yes
5	37	Female	Contralateral HA	Pre-lingual	1 year	AB	None	No
6	53	Female	Unilateral	Pre-lingual	4 years	AB	None	Yes
7	42	Female	Unilateral	Post-lingual	4 years	Cochlear	None	Yes
8	64	Male	Unilateral	Post-lingual	8 years	AB	Choir, piano, flute and guitar lessons, music teacher	No
9	63	Male	Unilateral	Post-lingual	2 years	Med-El	None	No
10	68	Female	Unilateral	Post-lingual	2 years	AB	None	No
11	71	Female	Unilateral	Post-lingual	6 years	Cochlear	Piano lessons	Yes
12	67	Male	Contralateral HA	Post-lingual	2 years	Med-El	Self-taught, electronic organ	Yes
13	64	Female	Unilateral	Post-lingual	18 years	Not reported	None	No
14	57	Male	Contralateral HA	Post-lingual	1 year	AB	None	No
15	81	Male	Bilateral	Post-lingual	4 years	Cochlear	None	Yes
16	81	Male	Contralateral HA	Post-lingual	1 year	AB	None	No
17	66	Male	Contralateral HA	Post-lingual	1 year	AB	None	No
18	26	Male	Unilateral	Pre-lingual	13 years	Cochlear	None	No
19	68	Female	Unilateral	Post-lingual	2 years	Med-El	None	No
20	67	Female	Unilateral	Post-lingual	2 years	Med-El	Group training	Yes
21	80	Female	Unilateral	Post-lingual	1 year	AB	None	No
22	67	Female	Contralateral HA	Post-lingual	2 years	Med-El	None	No
23	62	Female	Unilateral	Pre-lingual	1 year	Cochlear	None	No
24	18	Male	Contralateral HA	Pre-lingual	7 years	Cochlear	Music degree	No
25	68	Male	Unilateral	Post-lingual	3 year	Med-El	None	No
26	77	Male	Unilateral	Post-lingual	2 years	Neurelec	Play piano by ear	No
27	67	Female	Contralateral HA	Post-lingual	1 year	Med-El	Piano lessons	No
28	43	Female	Unilateral	Post-lingual	5 years	Med-El	None	Yes
29	76	Female	Bilateral	Post-lingual	3 years	Neurelec	None	No
30	48	Female	Unilateral	Post-lingual	7 years	AB	None	Yes

music), musical activity and music-related social interaction (how music promotes social interaction). The use of a priori categories ensured that music experiences falling into important QoL domains were not overlooked and were consistent with our conceptualization of MuRQoL, whereby allowing music experiences to be mapped onto QoL domains. However, in order to avoid limiting the scope of the analysis, the categories were considered tentative and treated exactly as any other theme, and so could be merged, removed or redefined. For the same reason they also were kept to a limited number.

In thematic analysis, the importance of a theme does not necessarily depend on quantitative measures (e.g., the number of occurrences in the data) but rather on how well it captures something crucial in relation to the research question (Braun & Clarke, 2006). In the present study, because the aim of the focus group discussion was to cover as many areas of music experience as possible, the themes themselves were more of interest than the number of occurrences. We coded as themes comments that referred to experiences (a) particularly related to music, (b) that could be measured on a rating scale (because the new questionnaire would be a psychometric instrument), (c) that were related to limitations of the deafness or CI. We did not code statements that referred to music preferences, musical background or music listening strategies, (e.g., use of direct input).

Regarding the analysis of participants' feedback on items from previous questionnaires, for each item the percentage of respondents who rated it as important or very important was calculated. Participants' comments were used to interpret the ratings and informed the content and the wording of the new questionnaire items overall.

Producing the Template

The first author developed an initial template after coding the transcript of the first of six focus groups. Comments corresponding to one of the six a priori categories were coded as such and themes were identified within each category. The transcript was read again to identify new themes (comments that did not correspond to any of the a priori categories). The initial template was then used for coding the remaining five transcripts. During this process, the template was modified by the first author to better describe the new data (e.g., subdomains were added or deleted and themes moved across subdomains). After all the necessary changes to the initial template were made, a final template was developed.

The Quality of the Data Analysis

It has been argued that when qualitative analysis aims at practical applications, such as health policies, an assessment of the quality is necessary (Yardley, 2000). Quality checks that have been recommended for template analysis, in particular, are critical comparisons between researchers and the provision of a detailed report of the steps of the analysis (King, 2012). In the present study, quality checks were performed at all stages of the data analysis. First, specific coding criteria were used and the development of the template was documented in detail by the first author. This ensured the quality of the analysis by showing that certain steps were followed and that the analysis was done methodically. Second, throughout the coding process, the template was discussed with an expert in music and CIs who critically assessed whether the themes were coherent, appropriate and distinct from each other. As a result of this review, changes in the template were made. Finally, because the analysis of the focus group data aimed at the generation of questionnaire items, it was deemed necessary to ensure that all relevant themes were identified in the data. An independent researcher, with experience in qualitative research and with hearing-impaired adults, coded two transcripts using the final coding template with the code definitions. The independent researcher also assessed the template in terms of how well it represented the data. Issues raised by the independent researcher and potential changes to the template were discussed; we decided not to make any changes at this stage but consider these issues later in the questionnaire development together with feedback from professionals. Independent coding for the purpose of critical comparison between researchers is a common quality check in template analysis (Lewis, 2014). However, the calculation of inter-rater agreement has not been recommended, as it violates the assumption that qualitative data are open to a variety of interpretations. Therefore, it was not used in the present study.

Development of Questionnaire Items

Items for the new instrument were developed by the first author in two ways. New items were generated from the themes that were identified in the focus group discussion data. Items from previous questionnaires rated as *important* or *very important* by 80% of the participants or higher also were adapted for use. This percentage was decided by convention and was informed by questionnaire expert review studies (e.g., Hyrkäs et al., 2003).

Specific principles applied to the generation of questionnaire items: 1) All items would be phrased in a similar way and would be suitable for a frequency Likert-type scale *Never…Always*), 2) The same response options would be used throughout the questionnaire, 3) Items would be phrased as questions (and not statements), 4) The questions would be appropriate for both pre-lingually deaf and post-lingually deaf

CI users and for CI users with different degrees of music training and 5) It would be a current-state measure and would not ask respondents to make comparative judgments (e.g., compare with how music sounded before the implant).

Findings

The Final Template

The final template of the analysis of the focus group data can be seen in Figure 2. It consisted of three domains and nine subdomains. On the basis of this template, the MuRQoL of CI users included *music listening ability*, *attitude towards music* and *musical activity*; domains that correspond to the physical (ability to perceive the physical properties of the music), psychological (feelings) and social (participation and active engagement with music) QoL domains, respectively. The following presentation and discussion of the themes was organized around the three domains and illustrated with quotes from participants.

Domain: Music Listening Ability

This covers the ability of CI users to perceive specific features of music (subdomain: perception of elements of music) and to music perception in different everyday listening scenarios (subdomain: perception of music in particular listening scenarios).

Musical elements include what has been referred to as fundamental features of music, i.e., pitch, rhythm, melody, timbre (McDermott, 2004). The ability to detect musical pitch differences has been assessed by music perception tests (e.g., Kang et al., 2009) and by questionnaires, such as the MUMU (Brockmeier et al., 2002): "Can you distinguish between high and low notes?".

The difficulty to perceive pitch also may affect an individual's ability to sing or play an instrument in tune:

> "But I realize there are a lot of people who know the songs and we know we would love a chance to do it but we have to keep quiet because it's not in tune." (Participant 8)

Theme: ability to hear yourself singing in tune

The poor ability of CI users to sing in tune has been previously reported in the literature (Marozeau & Innes-Brown, 2014).

The *perception of elements of music* also may refer to other non-fundamental features of music:

> "…cause a lot of songs do have meanings. Whether it is a happy song or a sad song or about a topic in particular like you said singing on a football terrace is. And I think that's a thing you want to try and get from it isn't it? What the song is about? What kind of emotion you should be feeling. Just because it's got maybe enough beat doesn't mean it's a happy song. You know the lyrics can be downright depressing." (Participant 7)

Theme: ability to perceive the emotion of music

Emotion here refers to the emotional content of music, i.e., whether a piece of music sounds happy or sad (Volkova et al., 2013). The emotion of music has been highly correlated with inherent acoustic properties of music, such as the tempo (Brockmeier et al., 2011).

Other challenges of CI users with music are not related to specific elements but rather to the listening environment, the type of music or the attention or effort required by the listener (subdomain: perception of music in particular listening scenarios). For instance:

> "Well I really have to concentrate on listening to music. I don't just have the radio on music as I'm moving from room to room or working in the kitchen or anything like that. If I want to listen to music I might sit down and either watch and listen to it on television." (Participant 15)

Theme: ability to hear music casually without effort or concentration

In a study by Bartel et al. (2011), the attention CI users have to pay while listening to music was found to play an important role in the perception and enjoyment. In the same context, the MUMU asks respondents to indicate if they listen to music as their main focus of concentration (Brockmeier et al., 2002).

Domain: Attitude Towards Music

This covers the feelings of CI users about music as well as feelings about their own music listening abilities (subdomain: music-related self-esteem). Feelings about music may be positive, such as pleasure:

> "I have to say I've enjoyed 'Britain's got talent' recently cause it's, you know, there's a lot of people been singing on it and, like you say, it's something that I've been able to follow, it's been quite... [smiles]" (Participant 5)

Theme: enjoyment of music listening

The enjoyment CI users derive from music listening has been assessed by questions like "How much do you enjoy listening to music?" (Mirza et al., 2003). Music enjoyment in specific listening environments also has been included in previous questionnaires (Gfeller et al., 2000).

DOMAIN: MUSIC LISTENING ABILITY

A. Perception of elements of music

1. Ability to hear the musical beat
2. Ability to hear the words in music
3. Ability to determine the loudness of music
4. Ability to recognize musical instruments
5. Ability to follow the melody of music
6. Ability to hear differences in musical pitch
    - 6.1. When listening to music
    - 6.2. Ability to hear yourself singing in tune
    - 6.3. Ability to hear yourself playing a musical instrument in tune
7. Ability to perceive the emotion of music
8. Ability to understand the meaning of music
9. Ability to distinguish between different musical instruments in a mixture

B. Music perception in particular listening scenarios

1. Ability to understand music using audio-only media in noise
2. Ability to understand familiar music
3. Ability to understand new music
4. Ability to understand music in public music events
5. Ability to understand music using audio-visual media
6. Ability to hear music casually with little effort or concentration
7. Ability to recognize music-like everyday sounds
8. Ability to tell if a musical performance is good or bad
9. Ability to understand audio-only music in quiet

DOMAIN: ATTITUDE TOWARDS MUSIC

C. Music-related self-esteem

1. Confidence with music (with music listening and making)
2. Embarrassment with music

D. General attitude towards music

1. Avoidance of music
2. Perseverance with music

E. Feelings about music

1. Positive feelings
    - 1.1. Enjoyment of music
        - 1.1.1. Enjoyment of music listening
        - 1.1.2. Enjoyment of going to public music shows
        - 1.1.3. Enjoyment of music making
    - 1.2. Feeling at ease with music
2. Negative feelings
    - 2.1. Frustration with music
    - 2.2. Disappointment with music

F. Music appraisal

1. Annoyance by music sounds
    - 1.1. Annoyance by music-like everyday sounds
    - 1.2. Annoyance by background music in public places
    - 1.3. Annoyance by high-pitched music
2. Music sound quality
    - 2.1. Music sounds/does not sound clear
    - 2.2. Music sounds/does not sound pleasant
    - 2.3. Music sounds/does not sound discordant
    - 2.4. Music sounds/ does not sound "as it should"
    - 2.5. Music sounds/does not sound "like noise"
3. Music sounds comfortable/uncomfortable

DOMAIN: MUSICAL ACTIVITY

G. Music listening activity

1. Listening to music actively
2. Having/not having music in the background whilst doing something else
3. Listening to music whilst travelling
4. Listening to new music

H. Participation & Social interaction

1. Participation in music interest groups
2. Going to public musical events
3. Taking part in social events where music is potentially played
4. Talking about music to others
5. Participating in dances and fitness classes

I. Music making activity

1. Singing (alone or with others)
2. Playing a musical instrument (alone or with others)
3. Music lessons

Figure 2. The final template of the focus group discussion data analysis. The three main domains are in capitals, A to I are subdomains and the themes/subthemes are numbered within subdomains.

There also are negative feelings (a) related to the difficulty to perceive and enjoy music that CI users want to hear and (b) caused by unwanted music, such as:

> "I shouldn't have music with other noise, with speech or whatever, I find that incredibly tiring and upsetting that you go into a restaurant and there's background noise. No one is listening to it. I want to say: 'One in six people have a hearing deficit. Why are you playing it when no one is listening to it?'. It doesn't give ambience to me. It actually causes me a lot of distress." (Participant 29)

Theme: frustration with music

The frustration or disappointment of CI users about how music sounds through the implant has been touched on by several authors (Gfeller et al., 2000; Mirza et al., 2003; Plant, 2012). With the exception of music enjoyment, the feelings of CI users about music have been poorly addressed by previous music questionnaires.

CI users' confidence with their ability to understand music is an example of a *music-related self-esteem* issue:

> "I still stand at the back of my gym class when the music is playing and people are doing the, you know, sort of keep fit stuff and there's Zumba dancing, because I need to watch everybody else, I'm not confident enough to… I hear it but I'm not sure I'm

hearing exactly the same as everybody else. And so I stand at the back as I've done for quite a lot of years now and just make sure that I can follow everybody else." (Participant 27)

Other statements of the focus groups participants do not refer to feelings but to more general attitudes (subdomain: general attitude towards music). Participant 9, for example, said:

"But I did not enjoy that carol service. And it put me off and I was a bit reluctant to go."

Although it is commonly reported that CI users listen to music less post-implantation than before deafness (Leal et al., 2003), no previous study has explicitly addressed the tendency of CI users to actively avoid music. The degree CI users persevere with music listening also was highlighted:

"I've not tried hard enough with music. I've been sort of concentrating on other things in my life rather than music. My husband bought me a radio which I'm ashamed to admit but I never turned it on but I'm going to now, sorry." (Participant 10)

Theme: perseverance with music

A similar concept was touched on before by Bartel et al. (2011) who identified *determination* as a theme in their interviews.

The *music appraisal* subdomain includes comments referring to how positively or negatively participants describe the way specific music sounds sound to them. In contrast with previous studies, here music appraisal is not related to music preferences or liking (Looi et al., 2012). The participants reported finding music annoying in certain listening situations, e.g.,

"High pitch irritates me." (Participant 6)

Theme: annoyance by high pitch

The sound quality of the music also affects CI users' enjoyment of and attitude towards music:

"But on the radio I switch it off because it sounds racket, that's the best word I could use." (Participant 20)

Theme: music sounds/does not sound like noise

"If it sounds discordant, which it often does particularly if there's a lot of strings, then I switch it off." (Participant 29)

Theme: music sounds/does not sound discordant

In studies where perceived *musical harmony* (i.e., the quality of music that determines how discordant it sounds) has been assessed before, CI users were asked to rate musical chords from *harsh (dissonant)* to *melodious (consonant)* (Rosslau et al., 2012).

The extent to which *music sounds as it should* also is related to music sound quality. It corresponds to what has been referred to elsewhere as *naturalness* of the music or whether music sounds "as before" (Looi et al., 2011):

"I think this is maybe why I don't listen it, because not how I feel it should sound." (Participant 10)

Theme: music sounds/does not sound "as it should"

The purpose of the phrasing ("as it should") was to make the theme and the relevant questionnaire item appropriate to both post-lingually deaf and pre-lingually deafened CI users.

Domain: musical activity

This domain covers, among others, what is commonly referred to in the music-CI literature as music listening habits (Looi et al., 2012). It also roughly corresponds to what has been referred to elsewhere as *active music engagement* (Müllensiefen et al., 2014). The CI users' music listening habits have been assessed in previous music questionnaires with broad questions about the frequency ["How often do you listen to music now?" (Mirza et al., 2003)], the amount ["When you are/were listening to music, how long do/did you listen?" (Brockmeier et al., 2002)] or the environment of music listening ["Where have you listened to or do you currently listen to music?" (Brockmeier et al., 2002)].

Musical activity can be music listening, music making or participation in music-related social activities. Music listening activities were grouped here according to the reason for listening. Participants reported actively listening to specific pieces of music, often their music of preference. In this case, CI users listen to music carefully and usually pay effort. Music, here, may have various functions, e.g., it may be used for entertainment or as a link to the past:

"Well at Christmas time, from you know from sort of 12 days before Christmas every single day I put Nat King Cole, I've got a record of Nat King Cole and that's what I'm doing all day, all week. You know up to Christmas and in Christmas morning I've got Nat King Cole again..." (Participant 13)

"…one of my pieces that I know in my head is…Elgar's cello concerto. And I can hear that in my head…I put on a CD of Elgar's cello concerto and just sat down to listen to it." (Participant 22)

Theme: listening to music actively

Participants reported listening to music while they were travelling (e.g., in the car), in order to make journeys more pleasant:

> "I listen to it in the car all the time, how to pass the journey." (Participant 18)

Theme: listening to music whilst travelling

Some of the participants also reported having music on in the background when doing other non-musical activities, whereas others reported that they would like to but they find it difficult:

> "But I just want to, you want to listen to music and do other things. But you can't if you are connected with the headphones. You just have to sit there and listen to it. As you said, we don't just want to sit there. And I would like to just turn the radio on and do other things and be listening to them." (Participant 4)

Theme: having/not having music on in the background while doing something else

In contrast with active listening, having music in the background does not involve effort or attention. It is used for relaxation, it accompanies everyday activities (such as cooking, painting etc.) or simply, as Participant 11 explained:

> "It's noise, it's something in the house."

Listening to music in the background has previously been addressed in the MUMU with a question asking whether CI users listen to music as their main focus of concentration or in the background (Brockmeier et al., 2002).

The *music making* subdomain includes comments about activities such as singing (alone or with others):

> "I keep wishing I would have a terrible cold and recover from this cold and then I find my voice… I just love it but that's my disappointment in life, not being able to sing." (Participant 13)

or playing a musical instrument:

> "And yeah sometimes I try to play keyboard myself and I find the time." (Participant 11)

Musical instrument playing and singing also have been covered by previous questionnaires: "Do/did you sing/play a musical instrument?", "What/where do you sing?", "What instrument do you play?" (Brockmeier et al., 2002; Mirza et al., 2003).

In addition to the above activities, participants brought up another dimension of music listening, that had not been explored by previous studies:

> "There's a social side to it too. You can go out with somebody and listen to music or talk about music." (Participant 11)

The subdomain *participation & social interaction* refers to the function of music as a means for socializing, communication, development of interpersonal relationships and relationships with the environment in general. Several themes were identified here and are related to participation in public musical events or participation in social activities where music might be played in the background. For example:

> "But having said that, I love going to anything to do with music. We've been to a couple of concerts since I've had the, and it's been a magic experience. We went to the opera - that was absolutely splendid." (Participant 1)

Theme: going to public music events

> "I've been finding myself - you're probably going to laugh - having two young children - I've got a 7- and a 4-year-old, they quite like watching the music channels on the TV - and because now that I'm starting to hear the beat, I will be mucking about with them, just starting to, not really dancing, but just mucking about with them, and that's now becoming part of our weekend and stuff, and there's laughing and 'mummy's being silly', but yeah I think that's quite good though." (Participant 5)

Theme: taking part in social activities where music is potentially played

Finally, music as a source of social interaction also was highlighted:

> And sometimes I said 'oh I don't think it's a happy song'. And they said 'oh why'? So it's good to talk about it. (Participant 6)

Theme: talking about music to others

The Development of Items for the Prototype MuRQoL Questionnaire

Items for the new questionnaire were subsequently developed using a combination of (a) the themes of the final template and (b) the ratings on existing items. The resulting prototype MuRQoL questionnaire was comprised of 53 items grouped under the 3 domains and 9 subdomains (Table 2). The phrasing of the questions followed the NCIQ and also was informed by the participant's comments to the existing items and by the vocabulary used in the focus groups (e.g., the word *understand*, Table 2, subdomain B). In most cases 1 theme was transformed into 1 questionnaire item based on the criteria explained earlier, but some themes were split into 2 items and others were merged into 1. In broad themes, e.g., avoidance of music, examples were added in the question

Table 2. The items of the prototype music-related quality of life (MuRQoL) questionnaire and comparison with four previous music questionnaires developed for CI users: the Music Munich questionnaire (MUMU), the Iowa Musical Background Questionnaire (IMBQ), the University of Canterbury Music Listening Questionnaire (UCMLQ) and the questionnaire used by Mirza et al. (2003). For each item, previous questionnaires including the same or a similar item are given.

Prototype MuRQoL items	Previous questionnaires
1. Can you hear the beat in music?	MUMU
2. Can you hear the words in music?	
3. Can you tell how loud or quiet music is?	
4. Can you recognize the sounds of musical instruments?	MUMU, UCMLQ
5. Can you follow the melody in music (e.g., follow the melody of a song or a familiar tune)?	UCMLQ
6. Can you hear differences in musical pitch?	MUMU
7. Can you hear whether you are singing or playing a musical instrument in tune (in tune with the music or with others)?	
8. Can you hear the emotion in music (e.g., when a piece of music is happy or sad)?	
9. Can you understand the meaning of music (i.e., why it was created or what message it is trying to get across)?	
10. Can you distinguish between different musical instruments when they play together?	
11. Can you distinguish between different rhythmic patterns in music?	
12. Can you understand music using audio-only media (without visual cues) in noisy environments (e.g., in the car over the engine/road noise or at a party)?	UCMLQ, IMBQ
13. Can you understand music that you know (e.g., a familiar song, singer, tune or musical play)?	UCMLQ
14. Can you understand music that you have never heard before?	UCMLQ
15. Can you understand music at public music events (e.g., at a theatre, cinema, concert, music festival or church service)?	UCMLQ, IMBQ
16. Can you understand music using audio-visual media (e.g., music on TV, DVD or on the computer) with subtitles?	UCMLQ
17. Can you understand music using audio-visual media (e.g., on TV, DVD or on the computer) without subtitles?	UCMLQ
18. Can you hear music casually without effort or having to concentrate?	
19. Can you recognize music-like every-day sounds such as the ringing of your phone, the doorbell or different bird songs?	
20. Can you tell when a musical performance (singing, musical instrument playing) is good or bad?	
21. Can you understand music using audio-only media in quiet environments, e.g., music on the radio or CD player at home?	UCMLQ, IMBQ
22. Do you feel confident about your ability to hear music that you listen to (e.g., confident that you hear it correctly and understand it)?	
23. Do you feel confident about your ability to sing, play a musical instrument or dance to music?	
24. Do you feel embarrassed with music, (e.g., when you cannot sing in tune with others)?	
25. Do you avoid music (e.g., avoid listening to music, avoid public music shows or social events where music is played)?	
26. Do you persevere with music (e.g., continue to attempt to listen when music is hard to recognize, follow or understand)?	MUMU
27. Do you feel at ease in places where music is playing?	
28. Do you enjoy listening to music?	MUMU, UCMLQ, IMBQ, Mirza et al. (2003)
29. Do you enjoy going to public/live music events (e.g., theatre, concert, opera, church service, cinema, recital, gig)?	
30. Do you enjoy making music (e.g., singing, whistling or playing a musical instrument)?	IMBQ
31. Do you feel frustrated with music (e.g., when music is hard to recognize or understand, when music does not sound as it should or when there is background music in a restaurant or pub)?	
32. Do you feel disappointed with music (e.g., when you cannot understand music, when it does not sound as before, when you cannot sing in tune)?	
33. Do you find music-like every-day sounds (e.g., bird songs or church bells) annoying?	
34. Do you find background music in public places (e.g., background music in a shop, restaurant or pub) annoying?	IMBQ
35. Do you find high-pitched music (e.g., soprano singing, whistling or flute playing) annoying?	UCMLQ
36. Does music sound uncomfortable?	
37. Does music sound clear?	IMBQ
38. Does music sound pleasant?	MUMU, UCMLQ, IMBQ
39. Does music sound discordant?	
40. Does music sound 'like noise'?	UCMLQ
41. Does music sound as you think it should sound?	MUMU, UCMLQ, IMBQ
42. Do you put music on to listen to (e.g., watch a musical show on TV or DVD, listen to a CD or to music on the radio)?	MUMU
43. Do you have music on in the background while doing something else (e.g., while reading, painting, doing gardening, exercising or just relaxing)?	MUMU
44. Do you listen to music whilst travelling (e.g., in the car)?	MUMU
45. Do you listen to music that you have never heard before?	MUMU
46. Do you participate in 'music interest' groups (e.g., music workshops or music clubs)?	
47. Do you participate in public music events (e.g., musicals, concerts or music festivals)?	MUMU
48. Do you participate in social events or activities where music is played (e.g., parties or getting together with the family)?	
49. Do you talk about music to others?	
50. Do you dance or participate in music fitness classes?	
51. Do you sing, whistle or play a musical instrument when you are alone?	MUMU, Mirza et al. (2003)
52. Do you sing or play a musical instrument when others are singing/playing at the same time?	MUMU, UCMLQ, Mirza et al. (2003)
53. Do you participate in music classes (e.g., singing lessons)?	MUMU, IMBQ, UCMLQ

for clarity. From the 19 statements (corresponding to existing items) given to participants for evaluation, 9 were rated as important or very important by 80% of the participants or more. From the existing items to which these statements corresponded, 7 were adapted for use in the new MuRQoL questionnaire, 1 was not included as not relevant and another was already covered by other items (Appendix B). Finally, a 5-point frequency Likert-type scale was adopted for the MuRQoL questionnaire with the same response options as in the NCIQ: 1: Never, 2: Sometimes, 3: Regularly, 4: Usually, 5: Always.

Discussion

Previous music questionnaires developed for CI users (e.g., the IMBQ (Gfeller et al., 2000), UCMLQ (Looi & She, 2010) or MUMU Brockmeier et al., 2002)) do not capture aspects of the music experiences of CI users, such as feelings about music and music-related social interaction. Furthermore, they have not been designed as measurement scales and have not been psychometrically validated. It is therefore, unknown whether they are appropriate, reliable and sensitive to measure changes after music interventions. An alternative measure was needed to evaluate the real-world benefits of auditory music training and new CI technologies. The present study was carried out to investigate aspects of music experience that fall under physical, psychological and social QoL domains with the aim to generate items for a new psychometric instrument. This approach towards CI users' music experiences allowed the study to explore psycho-social aspects of music experience in more depth than previous studies.

The generation of questionnaire items based on qualitative data is an advantage of the present study over previous questionnaire studies, where CI users either were consulted in order to modify already existing questionnaires (Brockmeier et al., 2002; Gfeller et al., 2000) or were not involved at all with items based on expert judgment (Amann & Anderson, 2014). The involvement of CI users in the item generation phase of the questionnaire development ensures content validity[3]. Where CI users were involved in previous studies, individual interviews were used (Looi & She, 2010). However, the use of focus groups in the present study offers a more comprehensive insight into CI users' relationship with music and feelings about music. The advantages of music focus groups with adult CI users have been reported elsewhere (Plant, 2012; van Besouw et al., 2014). It is acknowledged that some of the participants may have felt inhibited to talk in front of others, although no participant showed distress or reported feeling uncomfortable.

Many of the findings of the present study are in agreement with previous studies. Certain elements of music (e.g., timbre, pitch), music sound quality attributes (e.g., pleasantness) and musical activities (e.g., singing, participating in concerts), which have been reported in the literature as important for CI users' (e.g., Gfeller et al., 2000), were raised by participants in the present study. Also, the enjoyment of music and the recognition of familiar songs, assessed by previous music questionnaires and music perception tests (Gfeller et al., 2005; Migirov et al., 2009), were identified in our focus group data.

To the best of our knowledge this study is the first to map music experiences onto a QoL model. The findings confirm our hypothesis that a QoL model can be used to organize the music experiences of CI users, although it should be noted that the domains and subdomains need to be carefully adapted to be music-specific. This approach allowed for dimensions of CI users' relationship with music inadequately addressed by previous studies to be highlighted. For example, the study clearly distinguishes between two different types of music listening: listening actively and having music in the background. The study also addresses the effort or concentration needed for music listening, which only were touched on by previous studies (Bartel et al., 2011) and music questionnaires, such as the MUMU (Brockmeier et al., 2002). Our approach also was successful in identifying aspects of CI users' relationship with music that, to our knowledge, had not been explored at all by previous studies. Novel dimensions of the music experiences of CI users were identified as themes in all three MuRQoL domains:

Ability: "ability to understand the meaning of music", "ability to hear the words in music", "ability to hear yourself singing/ playing a musical instrument in tune", "ability to tell if a musical performance is good or bad"

Attitude: "embarrassment with music", "feeling at ease at places where music is played", "enjoyment of going to public music events", "music sounds or does not sound comfortable", "annoyance by music-like every-day sounds (such as bird singing)", "confidence with music"

Activity: "talking about music to others", "participation in music interest groups", "participation in dances or fitness classes", "listening to music whilst travelling", "taking part in social activities where music is potentially played"

These findings improve the understanding of CI users' everyday music experiences and challenges with music. The assessment of novel abilities, attitudes and activities gives greater content validity to the new measure and may enable a more complete measurement of music-related CI outcomes.

With these properties the new questionnaire has the potential to assess the effect of various interventions including aural training on adult CI users' music experiences more accurately than existing outcome measures (van Besouw et al., 2016). A comparison between the items of the prototype MuRQoL questionnaire and four existing music questionnaires developed for CI users illustrates the potential advantage of the new instrument (Table 2).

Aside from the development of items for the new questionnaire, the final template also can be used as a conceptual framework to fully study the relationship of CI users with music. It addresses limitations of previous classifications of music in the adult CI literature, which do not fully cover aspects of music experience such as feelings and participation (see the issues under the "Appraisal and quality ratings" section in Looi, 2012) and which also used terms inconsistently (e.g., the use of music appraisal in Wright & Uchanski, 2012). The new framework could structure previous and future research in the area of music and CIs. Studies and the issues they address could be classified according to the domains and subdomains of the framework. This, together with the use of the terminology of the framework could make communication among researchers and comparison between relevant studies easier.

The assessment of music experiences on a QoL scale also is novel among music questionnaires developed for CI users. It will make the new questionnaire easier for researchers or clinicians to score and analyze as compared to previous music questionnaires, which have used different question types within the same questionnaire, such as visual analog scales, multiple-choice or open questions (e.g., UCMLQ).

When the MuRQoL questionnaire will be given to adult CI users for completion, additional questions assessing the importance of each ability, attitude and activity will be included. The combination of the frequency and the importance ratings will produce a MuRQoL score for each item. The assessment of importance is supported by individual differences between participants in our focus group discussions with regards to the role of music in life, for example:

> "I think I'm a music nerd. I think music is so important in my life and the emotional movements are so… [smiles]. It's something I've really missed with becoming deaf." (Participant 8)

> "Music's never been the part of my life." (Participant 10)

The approach of the present study was based on evidence for the effects of music on the QoL of CI users Calvino et al., 2016; Dritsakis et al., 2017). Participants' comments illustrated this, especially in the psychological dimension:

> "It makes me feel happy, it can make me feel sad. I like listening to the lyrics and sometimes if it's a new piece I'll have to read the lyrics first but once I've made a match and the connection then the next time I hear it I can make that. It just releases a lot of emotion, different emotions and listening to music can make me 'Oh, so many changes in my life'. It can inspire me make decisions. It just touches me somewhere." (Participant 28)

The subjective nature of the qualitative data analysis techniques employed for the development of the questionnaire items is a limitation of the study. More objective techniques that could be used, e.g. the statistical calculation of inter-rater reliability coefficient or the generation of items based on the number of occurrences of the themes in the data, were rejected as inappropriate for the chosen technique. However, not only the method was considered the most appropriate for the purpose of the study but also the quality of the analysis was ensured (see *Methods*). Regarding the study sample, although we tried to recruit a wide range of participants, it is acknowledged that the sample and the results of the study are by no means representative of the whole adult CI population. For example, although no formal experience with music was required, it is likely that CI users with a musical background were more inclined to participate than others. It is also acknowledged that, although every effort was made to consider the a priori categories as flexible and subject to changes when necessary, they may have been a source of potential bias.

Conclusions and Further Research

To the knowledge of the authors this study is the first in the CI-related literature to map the music experiences of CI users onto a QoL model. This approach allowed for music listening abilities, attitudes towards music and musical activities to be identified that had not been addressed or fully addressed by previous studies, which broadened our knowledge of the music experiences of CI users. The measurement of these abilities, attitudes and activities may result in a more accurate and holistic evaluation of the real-world effects of auditory music training and CI technologies than with previous music questionnaires. An important next step is the refinement of the questionnaire using expert feedback and psychometric techniques and the assessment of its reliability and validity when completed by adult CI users and NH adults. The use of psychometric techniques for the validation of the questionnaire is novel among music

questionnaires for CI users. The MuRQoL questionnaire may serve as an alternative measure of CI outcomes in research and in clinic, with potential subsequent benefits for the patients.

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Footnotes

[1] "An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL, 1993).

[2] In the music rehabilitation literature the term *music focus group* usually refers to sessions of musical activities where group discussion may be included as well. This should not be confused with the use of the term focus group as a qualitative research method (Kitzinger, 2006), which was adopted throughout the present article.

[3] It is acknowledged, however, that music experiences prior to implantation may affect music perception, enjoyment or activities with the implant. To account for this, the relative importance of the different music experiences for each CI user will be considered in the new questionnaire (see Discussion).

[4] The extent to which the items of a questionnaire are sufficient and relevant for the population it is intended to cover (Streiner et al., 2015, pp. 25).

Data Access Statement

The focus group data (transcripts of focus group discussions and forms of existing items' ratings) is available online: http://dx.doi.org/10.5258/SOTON/377895. The data has been anonymized and there are no ethical issues associated with or restrictions to making the data available.

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Appendix A

Focus group questions

- Where and why do you listen to music? For example, do you listen to music at home, in the car, at work? Do you listen to music to relax, to improve your mood, to dance?
- What are your everyday activities that are related to music? For example, do you go to concerts, do you watch videos on YouTube, do you play a musical instrument, do you buy CDs? Tell us about activities that you do not do at the moment but you would like to do.
- What is important for you to get from music? For instance, to recognize songs you know, to distinguish between notes when playing a musical instrument or just listening to music to relax
- How satisfied are you with the music you hear? Is there something that you can perceive from music and you are happy about it? Is there something that you find difficult or you don't like in the music you hear and it bothers you?
- How do you feel about music in general? You might say for instance: 'I feel confident when I listen to music', 'I like it' or 'I avoid listening to music'.

Appendix B

Statements addressing items from previous questionnaires used with CI users that were rated as 'Important' or 'Very important' by 80% of the participants or more and the item of the prototype questionnaire to which each statement corresponded.

Existing items	MuRQoL item
Being able to recognize your favorite song/singer (UCMLQ)	Question 13
Being able to recognize the ringing of your phone (Hearing Implant Sound Quality Index; ($HISQUI_{19}$))	Question 19
Being able to distinguish between different rhythms (NCIQ)	Question 11
Being able to recognize a movie's dialogue when music is playing in the background ($HISQUI_{19}$)	It was considered unsuitable and was not included
Hearing music that sounds natural (IMBQ, UCMLQ, MUMU)	Question 41
Hearing music that sounds clear (same as above)	Question 13
Hearing music that sounds pleasant (same as above)	Question 37
Feeling comfortable in a place where music is played (NCIQ)	Question 38
Being patient when trying to understand a song (NCIQ)	Covered by questions 27 and 31