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The Malta Journal of Health Sciences is a peer-reviewed, open access publication that promotes the sharing and exchange of knowledge in Health Sciences. It provides a platform for novice and established researchers to share their findings, insights and views within an inter-professional context. The Journal originates within the Faculty of Health Sciences, University of Malta.

The Malta Journal of Health Sciences disseminates research on a broad range of allied health disciplines. It publishes original research papers, review articles, short communications, commentaries, letters to the editor and book reviews. The readership of the journal consists of academics, practitioners and trainee health professionals across the disciplines of Applied Biomedical Science, Audiology, Communication Therapy, Community Nursing, Environmental Health, Food Science, Health Services Management, Medical Physics, Mental Health, Midwifery, Nursing, Occupational Therapy, Physiotherapy, Podiatry and Radiography.

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Neville (2010) argues that...

Book (two to three authors)

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In text:

Bradbury, Boyle and Morse (2002)...

Book (four or more authors)

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In text:

(Reece et al., 2012)...

Journal article (printed)

Trefts, K. & Blacksee, S. (2000) Did you hear the one about Boolean Operators? Incorporating comedy into the library induction. *Reference Services Review*, 28(4), pp. 369-378.

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Trefts and Blacksee (2000) argue that...

Journal article (electronic/online)

Wilson, J. (1995) Enter the Cyberpunk librarian: future directions in cyberspace. [Online] *Emerald Database* 44(8), pp. 63-72. Available from: <http://www.emeraldinsight.com>. [Accessed: 30th January 2012].

In text:

Wilson (1995) argues that...

Website

BBC News (2008) *Factory gloom worst since 1980*. [Online] Available from: <http://news.bbc.co.uk/1/hi/business/7681569.stm>. [Accessed: 19th June 2012].

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- (iii) providing final approval of the version to be submitted (or resubmitted) for publishing.

Authors are expected to meet all three criteria. Contributors who do not qualify under the authorship criteria should be included in the Acknowledgments section.

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Any acknowledgements should be included at the end of the article, prior to the declaration of conflicting interests and the reference list.

Funding

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Guest editorial

SOME THOUGHTS ON HEALTH AND SAFETY

Anton Pizzuto

Visiting Senior Lecturer, Department of Food Studies and Environmental Health, Faculty of Health Sciences, University of Malta, Msida, Malta

Director, Cleaner Technology Centre, University of Malta, Msida, Malta

“Workplace safety aims at eliminating the health risks involved in a particular job and hence makes the job profile a secure option for interested candidates.” (Shukor, 2014)

It is so saddening that since being invited to write this editorial at the beginning of 2016, we are recording the fourth fatality at the place of work. Statistics published by the National Statistics Office indicate a declining number of accidents being reported in Malta. From a high of nearly 5,000 cases reported in 2002, the number of cases reported to the Social Security Department last year went down to just over 3,000 (Occupational Health and Safety Authority (OHSA), Malta, 2016)

This persistent downward trend in occupational injury rates and numbers of fatalities can be attributed to activities which raise awareness and disseminate information. However, as George Robotham, a world leading Risk and Safety consultant, declared:

“A health & safety problem can be described by statistics but cannot be understood by statistics. It can only be understood by knowing and feeling the pain, anguish, and depression and shattered hopes of the victim and of wives, husbands, parents, children, grandparents and friends, and the hope, struggle and triumph of recovery and rehabilitation in a world often unsympathetic, ignorant, unfriendly and unsupportive, only those with close experience of life altering personal damage have this understanding.” (OHS Change, 2012)

Occupational health and safety is a complex subject which requires the cooperation of stakeholders and duty holders. It can only be improved through a self-regulating process where all duty holders recognise that it is in their best interest to adhere to their duties as imposed by law.

In Malta we have a well-developed legislative framework, but we do lack sufficient human resources to ensure implementation and enforcement. In this respect, the University of Malta has given an important contribution these last few years by offering a Diploma programme in Health and Safety through its Centre for Labour Studies. Recently, the same Centre has announced the launching of a degree programme in the subject. This should go some way to alleviate the problem of lack of more qualified personnel

in the Health and Safety inspectorates, a problem which appears to be present even among Member States of the European Union.

In terms of the Occupational Health and Safety Authority Act XXVII of 2000 and other subsidiary regulations, employers have various legal obligations that must be fulfilled in order to manage health and safety at the place of work. Employers have the general duty of ensuring the health and safety at all times of all persons who may be affected by the work being carried out for such employers. This duty is considered to be wide in its scope and encompasses a series of other obligations intended to fulfil such a general duty.

On their part, workers have the duty to safeguard one's own health and safety and that of other persons who can be affected by reason of the works carried out. Workers must also cooperate with the employer and with the Health and Safety Representative or Representatives at the work place on all matters relating to health and safety.

In a health care setting, the issue of health and safety is even more complex than in other workplaces due to the “biological component”, meaning the handling of potentially infective body fluids. Other risks facing health care workers stem from specific hazards connected with their professions. These include the possible exposure to ionising radiation, back injuries connected with manual handling, the stressful situations due to pressure of work in Accident and Emergency Departments, the exposure to high levels of anaesthetic gases in operating theatre air, and the handling of cytotoxic medications. All these contribute to a high level of risk if the right precautions are not taken.

As George Robotham aptly noted, “*Health & Safety is about change for the future NOT blame for the past*” (OHS Change, 2012). Indeed, the greatest threat to our safety is complacency in the face of new and emerging risks associated with our economic growth, competitiveness and long-term sustainable employment.

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Research paper

COMPARISON OF HEARING AID OUTCOME MEASURES IN ADULT HEARING AID USERS

Pauline Miggiani, Nadine Tabone

Department of Communication Therapy, Faculty of Health Sciences, University of Malta, Msida, Malta

Abstract. Hearing aid outcome measures have become an essential part of audiological intervention. This study aimed to explore hearing aid benefit in Maltese hearing aid users through subjective and objective outcome measures. The *Profil Imqassar dwar il-Benefiċċju tal-Hearing Aids (PIBHA)*, a translated version of the Abbreviated Profile of Hearing Aid Benefit (APHAB) questionnaire, was used to subjectively examine hearing aid benefit in 56 adult hearing aid users falling in the 20- to 60-year age range. Thirty of these hearing aid users subsequently participated in clinical testing to evaluate hearing aid benefit objectively. Real ear measurements (REMs) and two non-word repetition tests, the Maltese Non-Words in Quiet (MNWQ) and the Maltese Non-Words in Noise (MNWN), were used in the study. Analysis aimed to identify which factors correlated with hearing aid benefit. It also explored the extent to which subjective perception of hearing aid benefit correlated with performance on non-word repetition and REMs in the local population. Daily use was associated with gender and hearing aid type. Non-word repetition scores were correlated with the PIBHA scores and with REMs. Unlike findings reported in the literature, REMs were not correlated with the self-reported measures of the PIBHA. Implications for including both subjective and objective measures in hearing aid fitting protocols are addressed.

Keywords: APHAB, outcome measures, hearing aid benefit, questionnaires

1 Introduction

The most common rehabilitation options for adults with hearing impairment include hearing aid provision and communication programmes (Hickson, Laplante-Lévesque & Wong, 2013).

Correspondence to Pauline Miggiani
(paulinemig@gmail.com)

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Positive outcomes have been reported for adults with a mild to moderate sensorineural hearing impairment fitted with bilateral hearing aids (Humes & Krull, 2012). In their systematic review of 33 research articles, Humes and Krull (2012) reported (i) reductions in activity limitations and participation restrictions, (ii) satisfaction with the hearing aids, (iii) hearing aid usage 75% of the time, and (iv) improved speech recognition scores when using a hearing aid. Audiologists and other researchers in fact use a combination of outcome measures that are either hearing aid-focused (objective) or patient-focused (subjective) in order to support evidence-based practice.

Humes and Krull's review (2012) also points out the lack of high-level evidence in this research area. In Malta, a lack of research on hearing aid outcome measures in both the paediatric and adult populations is evident. The domain of hearing aid outcome measures has received increasing attention in the last decades. This is so as health care has moved towards an outcome-based design in which audiologists have to document the efficacy of hearing aid intervention, not just to policy makers but also to the persons with hearing impairment themselves (Cox, 2003). The shift embraces a change in focus from disorder to person. Hearing aid users' point of view has become ever more accepted as a valid and crucial gauge of treatment success. While self-report data is slowly becoming the gold standard in evaluating hearing aid intervention, Mendel (2007) advocates the use of self-report data alongside other objective clinical measures which can help in validating the hearing aid user's subjective impressions.

The purpose of this study was to evaluate hearing aid benefit in Maltese adults through the use of subjective and objective outcome measures. It aimed to give more insight into the factors that are associated with hearing aid benefit and to evaluate the correlation between subjective and objective hearing aid outcome measures.

	Bil-hearing aids	Mingħajr il-hearing aids
1. Meta nkun f'hanut tal-merċa mimli nies u nkun qed inkellem lill-kaxxiera, nkun nista' nifhimha.	A B Ċ D E F Ġ	A B Ċ D E F Ġ
2. Nitlef ħafna mill-informazzjoni meta nkun qed insegwi <i>lecture</i> .	A B Ċ D E F Ġ	A B Ċ D E F Ġ

A Dejjem (99%)
 B Kwazi dejjem (87%)
 Ċ Ġeneralment (75%)
 D Ġieli iva, ġieli le (50%)
 E Xi kultant (25%)
 F Rari (12%)
 Ġ Qatt (1%)

Figure 1. Excerpt from the PIBHA, the Maltese translated version of the APHAB

2 Methods

The study incorporated a quantitative research design. Multiple measures were obtained through self-report, non-word repetition testing and real ear measurements (REMs). Ethical approval for implementation of the study was obtained from the University of Malta's Research Ethics Committee.

2.1 Participants

Participants were selected from the Ear, Nose and Throat (ENT) Department of a state general hospital. They were all adult hearing aid users in possession of a hearing aid, and between 20 and 60 years of age. Older adults were excluded from the study in order to limit the presence of confounding factors, such as cognitive and physical difficulties, which may affect performance. According to the hospital's database, 230 adults were in the specified age range and possessed a hearing aid or were waiting for their initial fitting appointment. A questionnaire (see Section 2.2) was sent to all 230 individuals in order to increase the response rate. In total, 85 questionnaires were returned by mail, which is equivalent to a 37% response rate. Exclusion criteria were applied after questionnaire completion and clinical testing. These included invalid/empty questionnaires¹, non-verbal hearing aid users, individuals not yet fitted with a hearing aid, Bone-Anchored Hearing Aid users and individuals currently presenting with middle ear infections.

Valid questionnaires were returned by a total of 56 participants, out of whom 29 (15 females and 14 males) volunteered to undergo the non-word repetition test. REMs were carried out on 28 participants (15 females and 13 males), 19 of whom were unilateral users and 10 were bilateral users. Fifteen users wore digital aids whilst 14 had analogue hearing aids. Participant age ranged from 22 to 60 years (Mean (M) = 44.82, Standard Deviation (SD) = 13.32). Age was non-normally distributed, with just over half of the participants being between 50 and 60 years of age. Skewness of the age distribution was -.238 (Standard Error (SE) = 0.33) and kurtosis was -1.33 (SE = 0.65).

¹ A questionnaire was considered to be invalid when responses to all statements were marked as 'Always' or 'Never'.

2.2 Questionnaire

The Abbreviated Profile of Hearing Aid Benefit (APHAB) questionnaire has been proven to be a good self-report outcome measure of hearing aid benefit for adult hearing aid users, and was therefore selected for adaptation in this study (Cox, 2005; Paul & Cox, 1995). Norms and data on its psychometric properties are also available for cross-cultural comparison (Cox & Alexander, 1995; Johnson, Cox & Alexander, 2010; Kochkin, 1997), making it a useful tool in this research study. It is estimated that the APHAB can be completed in five to ten minutes (Cox & Alexander, 1995). It consists of 24 items that describe possible situations the subject may find him/herself in, for example, 'I can understand my family at the dinner table'. The subject has to select a response from a list of seven alternatives (ranging from *always* to *never*) in order to show how often the statement is true for him/her. For each item, two responses are required by the hearing aid user, one for 'without my hearing aid' (unaided) and one for 'with my hearing aid' (aided). The measure of benefit is calculated by comparing performance in unaided and aided settings in four subscales: Ease of Communication (EC), Reverberation (RV), Background Noise (BN) and Aversiveness of Sounds (AV) (Cox & Alexander, 1995).

The APHAB was translated to Maltese with permission from the authors, following their translation guidelines. The Maltese translation of the questionnaire, titled *Profil Imqassar dwar il-Benefiċċju tal-Hearing Aids* (PIBHA), was piloted on five hearing-impaired adults between 20 and 60 years of age in order to pre-test its effectiveness with the local population. The first five subjects who accepted to participate in the clinical tests were involved in the pilot study. The PIBHA was used to obtain information on participants' age, perception of hearing aid benefit, hearing aid use and experience with hearing aids. Four participants in the main study volunteered to complete the questionnaire a second time after a one-month interval. A good test-retest reliability coefficient of 0.8 resulted. Figure 1 shows an excerpt of the PIBHA as employed in this study.

2.3 Non-word repetition tests

The Maltese Non-Words in Quiet (MNWQ) and the Maltese Non-Words in Noise (MNWN) are two non-word lists developed by Tabone (in preparation). The non-word

repetition test required the participants to repeat these non-word lists, providing information on aided speech perception in quiet and noisy conditions. During testing, the participants were seated in a sound-isolated chamber. The acoustic signal in the tests was presented through a loudspeaker placed at a distance of one metre in front of each participant at 0° azimuth. Presentation level was set at 65 dBA. Participants were exposed to the 24-item lists through speaker phones, with their hearing aids on, and were encouraged to repeat the non-words. In the MNWN, the subjects were asked to ignore the noisy background while repeating the words they heard. Constant noise background stimulus is not representative of everyday listening environments, and hence, multitalker babble at -5 dB was employed (Killion et al., 2004). The word lists were pre-recorded to ensure that the stimuli were presented at the same level to all participants. Prior to data collection, a pilot study was carried out on five adult normal hearing participants, in order to ascertain that all the words were well-perceived.

2.4 Real Ear Measurements (REMs)

Hearing aid performance was evaluated through Real Ear Measurements (REMs) using the Fonix 7000 Hearing Aid Test System. REMs were carried out according to the standard procedure outlined in the instruction manual. Specifically, the Real Ear Insertion Gain (REIG), which may be defined as the gain provided by the hearing aid (Pumford, 2001), was calculated. The insertion gain was measured at three levels: 50 dB (soft sounds), 65 dB (comfort testing) and 80 dB (tolerance testing). The fitting target was set on National Acoustics Labs, Non-Linear, version 1 (NAL-NL1), which is a prescriptive hearing aid fitting method for programming hearing aids in adults. REMs were always preceded by otoscopy.

2.5 Data Protection

Participants' contact details were not accessed unless they had previously agreed to participate in the clinical tests. Collected data was saved in a password-protected personal computer. Participants were also informed that once the study was completed, all personal information collected would be destroyed.

2.6 Data Scoring

In the PIBHA, unaided scores were subtracted from aided scores to determine total benefit for each category, namely EC, BN, RV and AV. Information about degree of hearing loss, daily hearing aid use and hearing aid experience was also analysed statistically.

Attempts at repeating the MNWQ and the MNWN were scored as either correct or incorrect on a whole word and phoneme basis. The number and percentage of correct responses was also calculated for words containing consonantal clusters as opposed to those having no

clusters. Additionally, responses were categorised according to the number of two-, three- and four-syllable words repeated correctly. Finally, correct responses were coded for high or low word likeness.

REMs were scored by calculating the difference between the target gain (NAL-NL1) and the actual hearing aid gain for the following frequencies: 250 Hz, 500 Hz, 1 kHz, 2 kHz and 4 kHz. Scores falling within 10 dB of the target gain were categorised as *Pass*, while those that did not were categorised as *Fail*, in line with other studies (Aazh & Moore, 2007). Additionally, they were also categorised by the discrepancy from target in 10 dB steps.

2.7 Data analysis

Descriptive statistics were used to compute the frequencies and means of scores obtained through self-report and non-word repetition. The dependent variables, namely the PIBHA benefit scores, the MNWQ, MNWN and the REM scores, were tested for normality using the Kolmogorov-Smirnov test, which yielded varying results. Normally distributed data was analysed using parametric tests, namely paired samples *t*-tests and independent samples *t*-tests, one-way Analysis of Variance (ANOVA), as well as Pearson's correlations. Analysis of non-normally distributed data employed four non-parametric tests: the Wilcoxon signed-rank test, the Wilcoxon Mann-Whitney test, the Kruskal-Wallis test and Spearman's rank correlations. Chi-squared tests were used to compare categorical variables.

3 Results

3.1 Profil Imqassar dwar il-Benefiċċju tal-Hearing Aids (PIBHA)

The mean scores for unaided conditions were higher than those for aided conditions (Figure 2). A paired-samples *t*-test and a Wilcoxon signed-rank test showed that the difference in mean scores was statistically significant across all categories of the PIBHA ($p < .001$). The participants perceived benefit on three categories, EC, BN and RV (Figure 3). All scores were normally distributed. The global scores comprising EC, BN and RV scores were also normally distributed ($p = .056$) and were used in subsequent statistical analyses.

A Pearson product-moment correlation coefficient analysis showed significant correlations between the PIBHA global and subscale scores. The PIBHA global scores had the strongest correlation with the RV ($r = .82$) and EC ($r = .82$) subscales. In addition, the internal consistency reliability values denoted by Cronbach's alpha were also fairly high, ranging from 0.78 to 0.82 across the four categories.

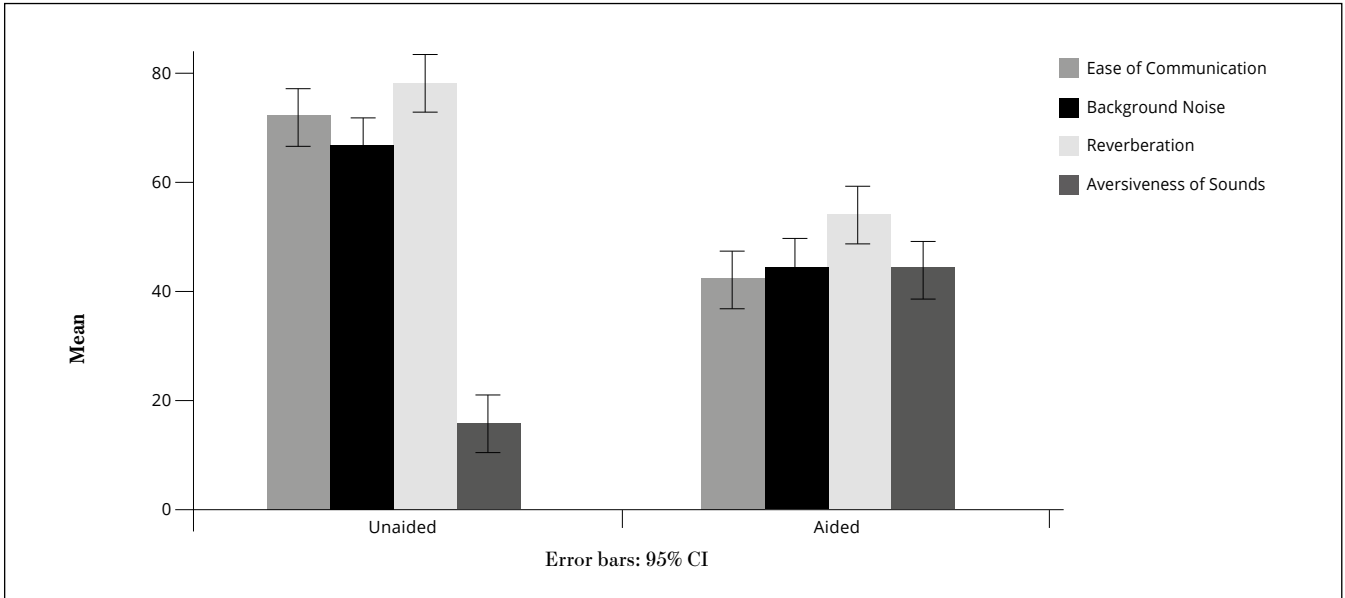


Figure 2. Mean unaided and aided scores on the four subscales of the PIBHA

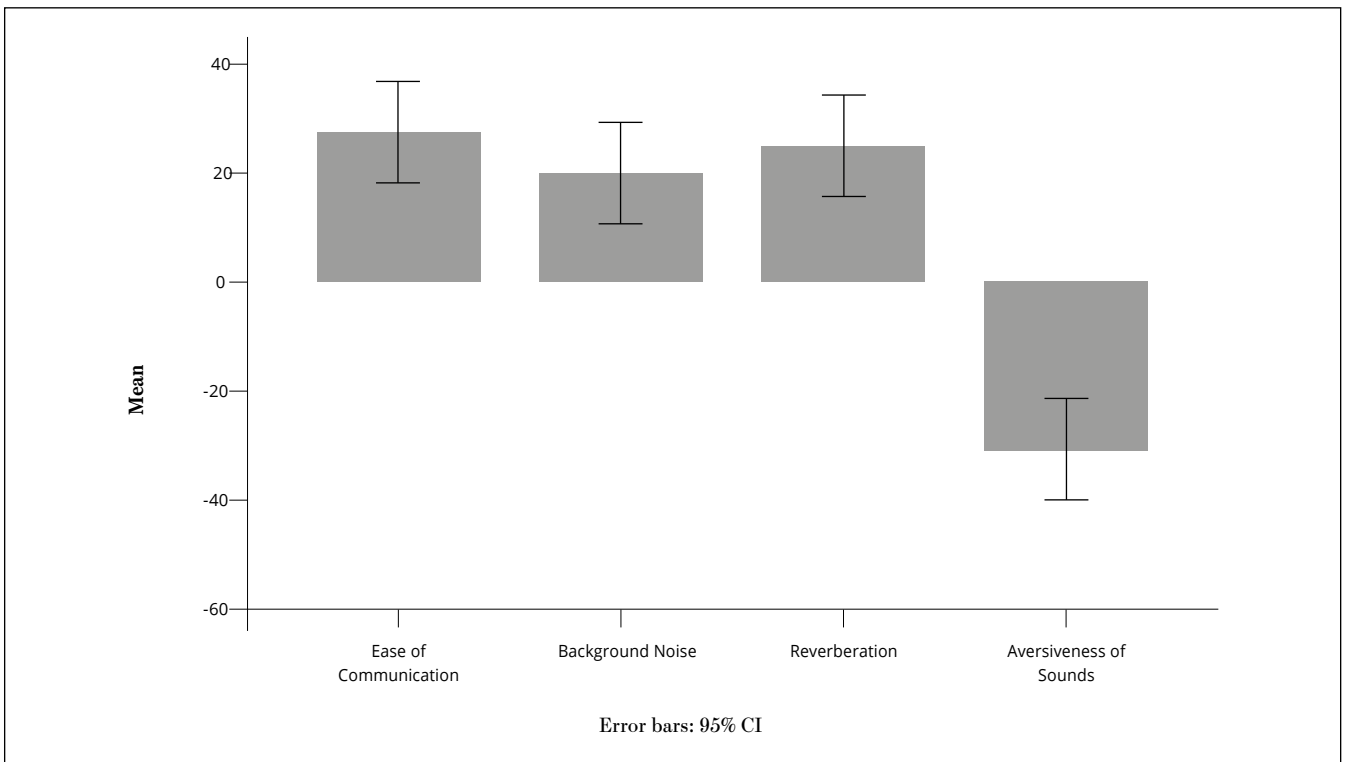


Figure 3. The mean benefit scores obtained on the four subscales of the PIBHA

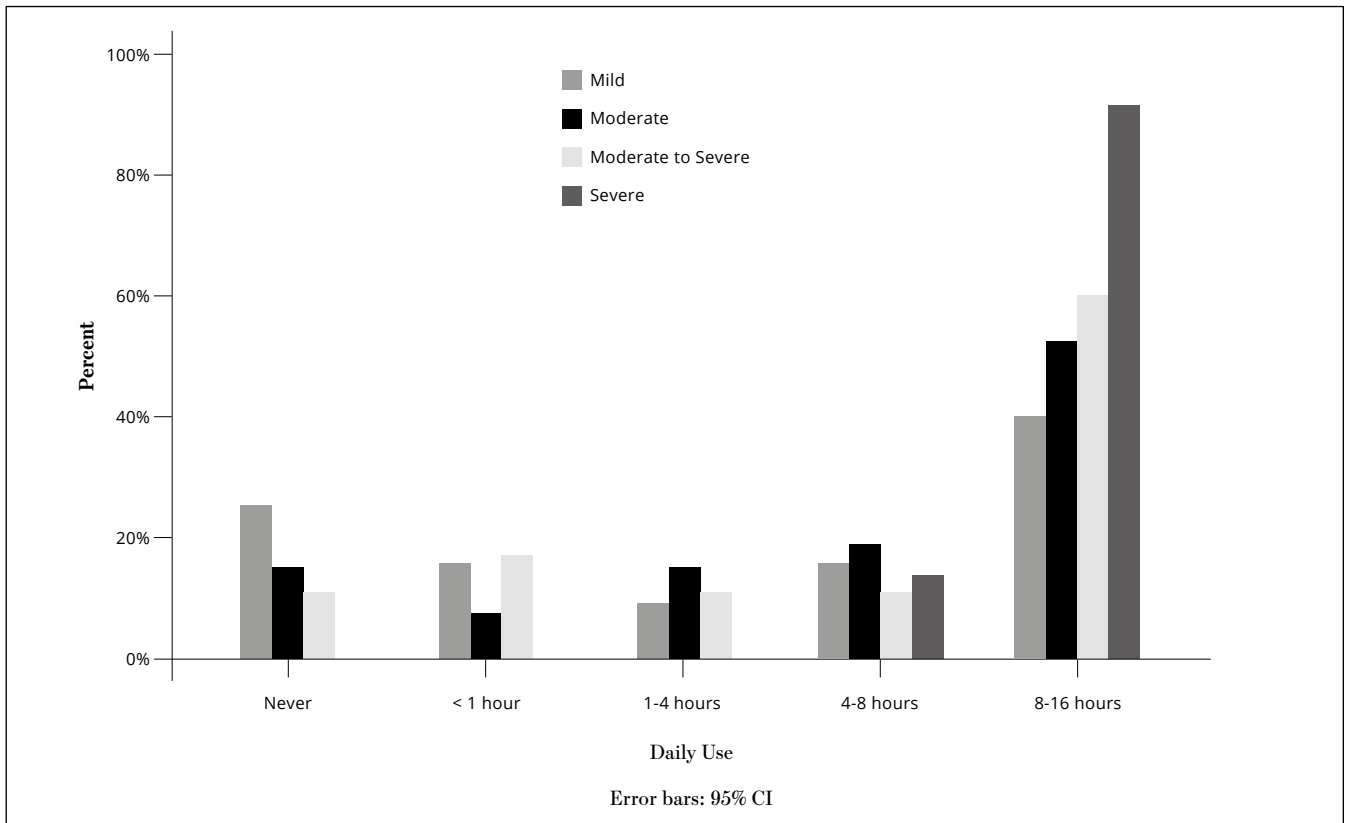


Figure 4. Hearing aid daily use in hours according to reported degree of hearing loss

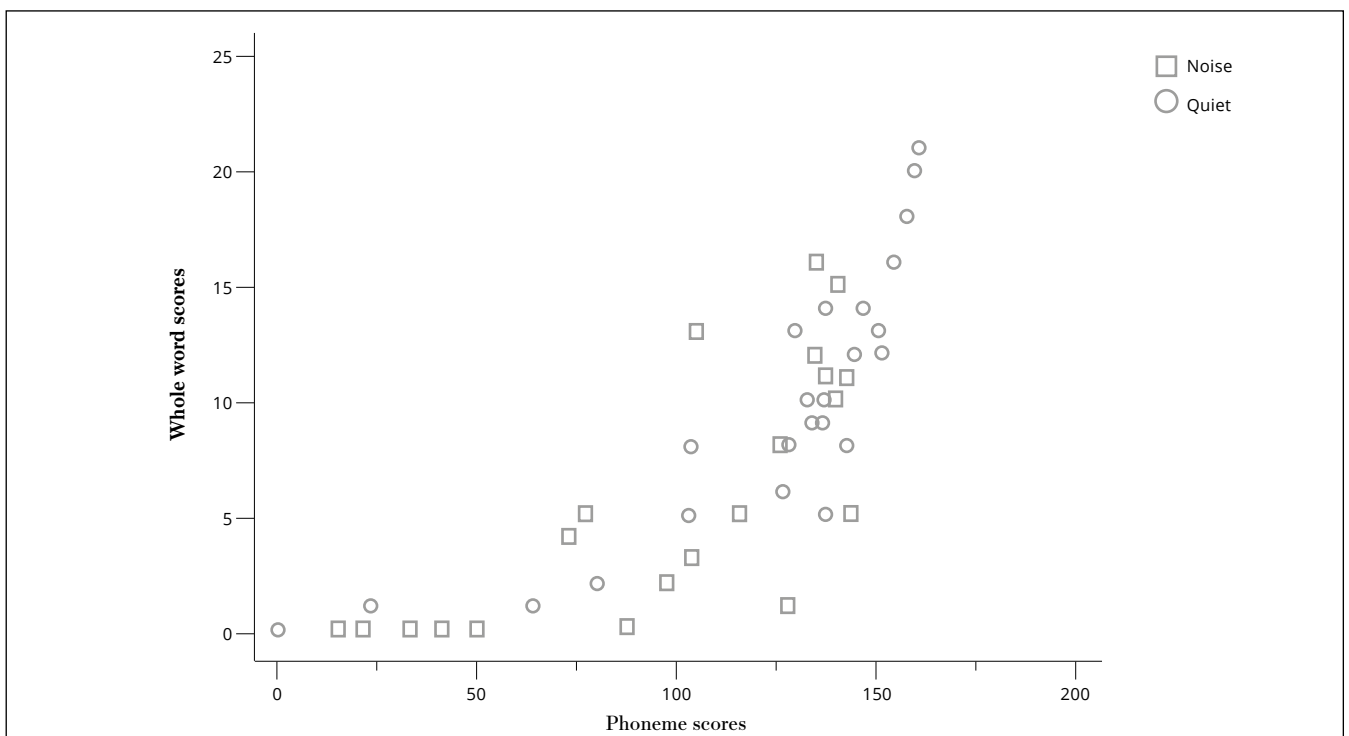


Figure 5. Individual participants' whole word and phoneme scores obtained in quiet and in noise

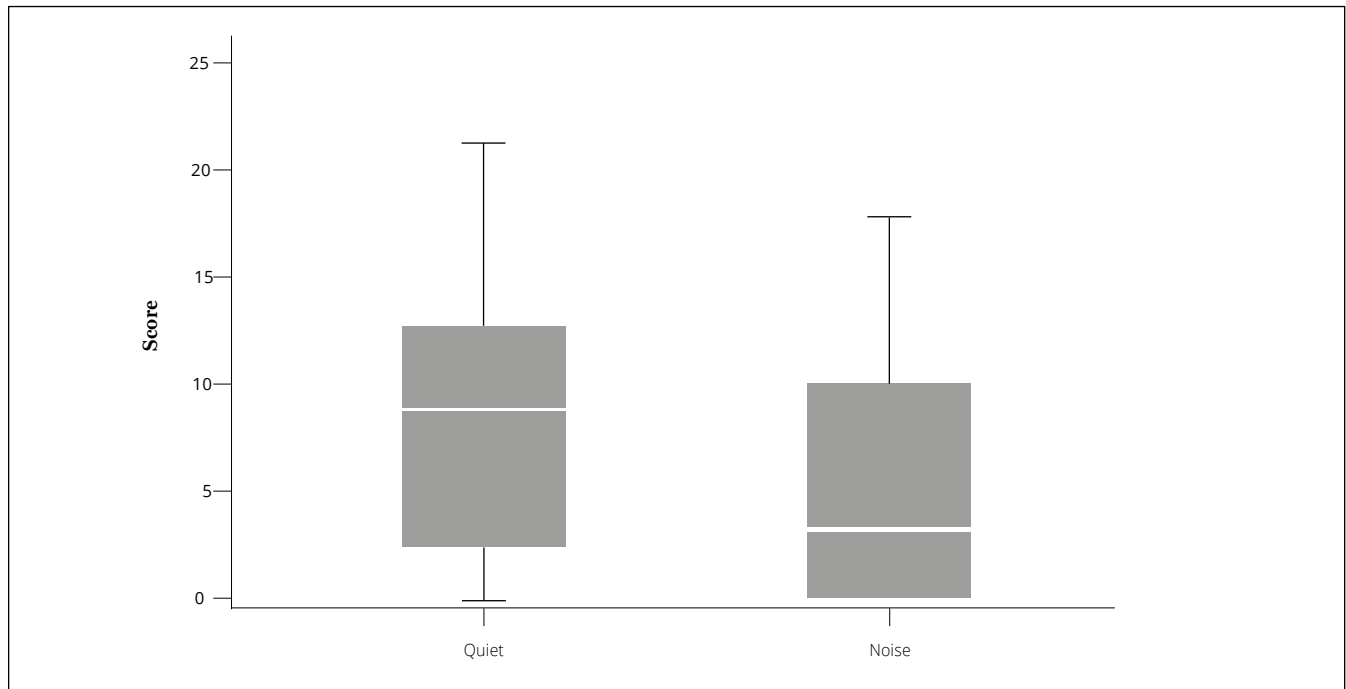


Figure 6. Distribution of scores in quiet and noisy settings when scoring with a whole word approach

3.1.1 Daily hearing aid use

More than half of the participants (57%) reported that they used their hearing aids for more than eight hours a day ($N = 56$). While 12% reported that they never used their hearing aids, the rest (31%) reported less consistent use of their hearing aids. The Wilcoxon-Mann Whitney test showed a statistically significant difference between daily hearing aid use scores of female and male participants ($p = .021$). In addition, there were more men (29%) who never used their hearing aids compared to women (7%). A Kruskal-Wallis test showed that increasing degree of loss was not related to an increase in daily hearing aid use ($p = .128$) (Figure 4). Users of digital hearing aids used their aids more than the users of analogue aids ($p = .019$, using the Wilcoxon Mann-Whitney test). Bilateral users made use of their hearing aids more than unilateral users. However, the Wilcoxon Mann-Whitney test showed that the difference was not statistically significant ($p = .098$).

3.1.2 Self-reported benefit on the Profil Imqassar dwar il-Benefiċċju tal-Hearing Aids (PIBHA)

A one-way between-subjects Analysis of Variance (ANOVA) test showed that there was no significant effect of mean daily hearing aid use on global scores on the PIBHA ($p = .840$). An independent samples t -test showed that there was no significant difference between the digital and analogue hearing aid user groups on self-reported benefit scores ($p = .252$). Similarly, an independent samples t -test showed that

hearing aid fitting was not related to daily hearing aid use ($p = .083$).

3.2 Non-word repetition results

3.2.1 Scoring method

Whole word scores for quiet conditions were normally distributed ($p = .200$) while scores obtained in noise showed a non-normal distribution ($p = .001$), just like phoneme-based scores in both quiet ($p < .001$) and noisy settings ($p = .034$). There was a strong, positive correlation between whole word and phoneme scores obtained on both quiet ($r = 0.932$, $N = 29$, $p < .001$) and noise tests ($r = 0.858$, $N = 29$, $p < .001$). The scatterplot in Figure 5 shows individual whole word and phoneme scores obtained in quiet and noisy settings.

3.2.2 Type of setting

The MNWQ elicited significantly higher scores ($M = 8.72$, $SD = 6.55$) than the MNWN ($M = 5.03$, $SD = 5.65$) on a whole word scoring approach ($p < .001$, using the paired samples t -test) (Figure 6). Phoneme-based scoring elicited similar scoring patterns: the MNWQ resulted in a higher score ($M = 107.14$, $SD = 58.25$) than the MNWN ($M = 80.34$, $SD = 56.69$) (Figure 7). A Wilcoxon signed-rank test showed the difference between phoneme-based and whole word mean scores to be statistically significant ($p < .001$).

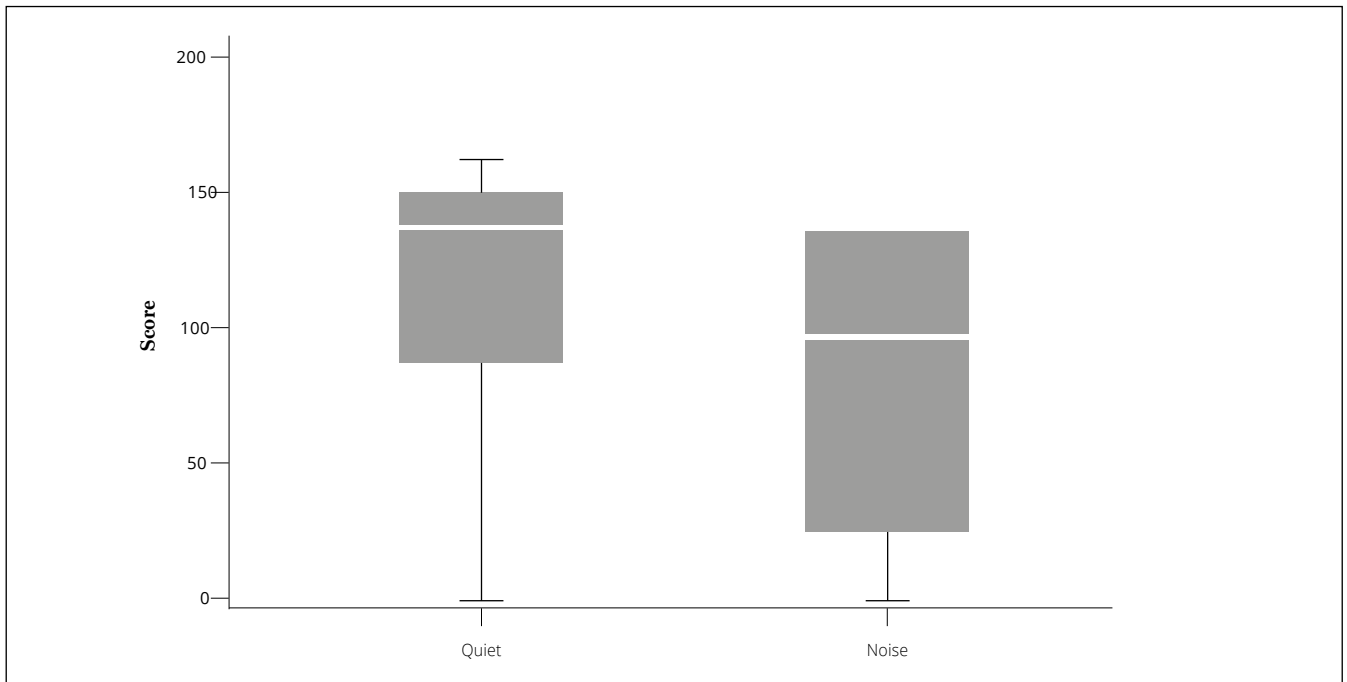


Figure 7. Distribution of scores in quiet and noisy settings when scoring with a phonemic approach

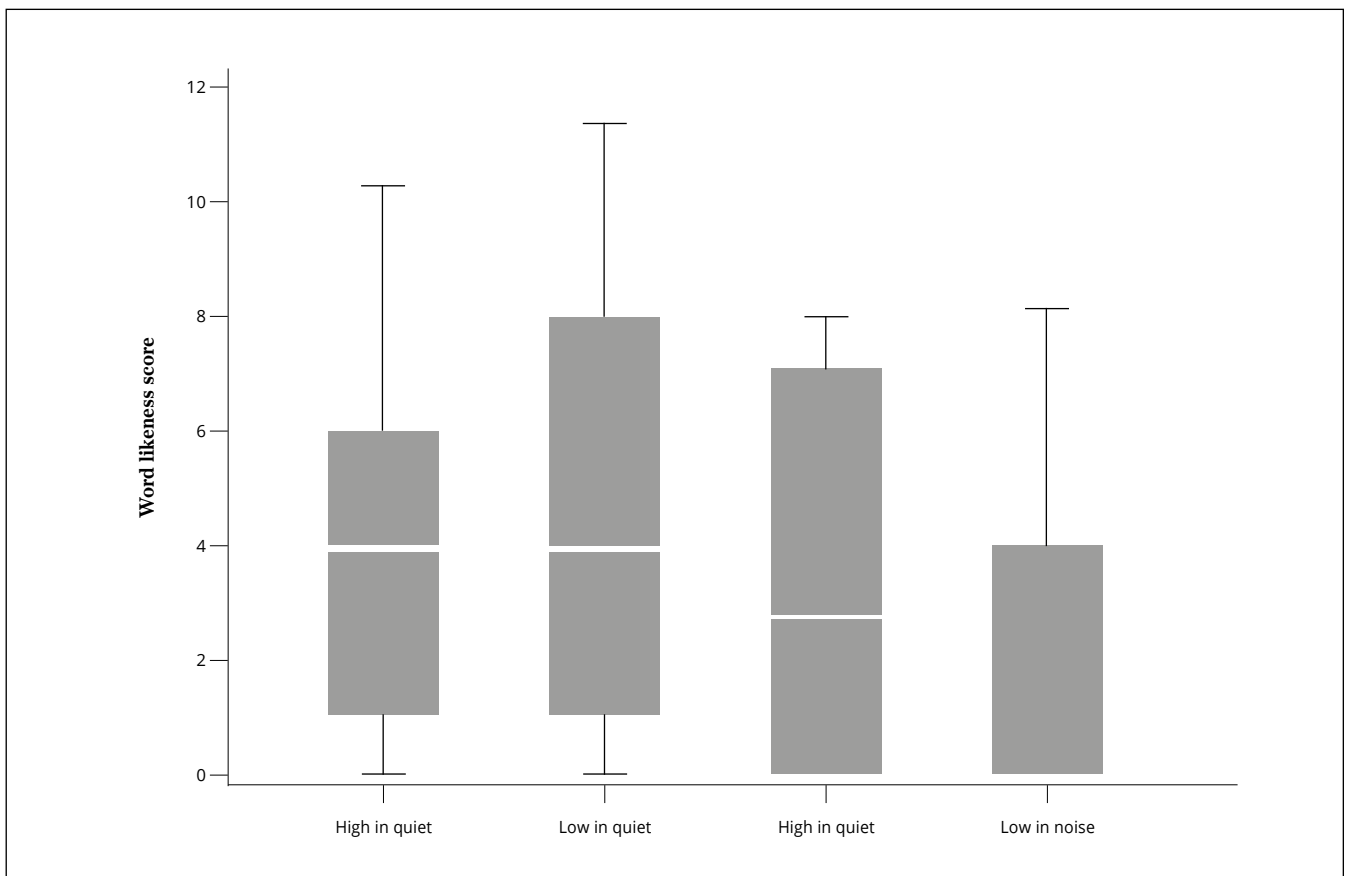


Figure 8. Dispersion of high and low word likeness scores in quiet and noisy settings

3.2.3 Word likeness, syllable length and consonant clusters

As seen in Figure 8, word likeness was associated with a higher number of correct responses only in the noisy condition ($p = .005$ using the Wilcoxon signed-rank test). The score for two-syllable non-words was higher than the scores obtained for three-syllable ($p = .005$, using the paired samples t -test) and four-syllable non-words ($p = .005$, using the Wilcoxon signed-rank test) in the quiet condition. Similarly, the Wilcoxon signed-rank test was also used to analyse the effect of syllable length on MNWN scores. The scores of two-syllable non-words were significantly different from those of three- ($p = .009$) and four-syllable non-words ($p = .008$). The Wilcoxon signed-rank test showed that there was no significant difference between the scores for three- and four-syllable non-words in both quiet ($p = .130$) and noisy conditions ($p = .617$). Words containing consonant clusters elicited a lower score ($M = 3.93$, $SD = 3.35$) than words without clusters ($M = 5.10$, $SD = 3.57$) in the MNWQ and similarly in the MNWN ($M = 2.07$, $SD = 2.63$ for words with clusters; $M = 4.61$, $SD = 3.51$ for words without clusters). The Wilcoxon signed-rank test showed that mean scores were significantly different in both quiet ($p = .001$) and noise ($p = .005$).

3.2.4 Hearing aid type and fitting

Users of digital hearing aids obtained a higher score ($M = 9.87$, $SD = 6.63$) than analogue users ($M = 7.50$, $SD = 6.48$) on the MNWQ when using a whole word scoring approach. Similarly, digital hearing aid users obtained a higher score ($M = 6.00$, $SD = 5.64$) than users of analogue hearing aids ($M = 4.00$, $SD = 5.69$) on the MNWN. An independent samples t -test confirmed that there was no significant difference between the two groups on non-word repetition mean scores in both quiet ($p = .340$) and noise ($p = .350$). Phoneme-based analysis scores similarly showed no statistically significant difference in both quiet ($p = .484$) and noisy ($p = .693$) settings, using the Wilcoxon signed-rank test.

Bilateral hearing aid users obtained a similar score ($M = 8.09$, $SD = 6.63$) to unilateral users ($M = 9.11$, $SD = 6.67$) on the MNWQ when using a whole word scoring approach. Similarly, bilateral hearing aid users' score on the MNWN ($M = 4.73$, $SD = 5.78$) was close to that of unilateral users ($M = 5.22$, $SD = 5.73$). An independent samples t -test showed no significant difference between the two groups on non-word repetition scores in both quiet ($p = .692$) and noise ($p = .824$). Phoneme-based scores were not significantly associated with hearing aid fitting in both quiet ($p = .636$) and noise ($p = .557$) on a Mann-Whitney test.

3.3 Real Ear Measurements (REMs)

Half the REMs did not meet prescribed targets by more than 10 dB. REMs at 50 dB met targets less frequently than 65 or 80 dB. However, no statistically significant difference was found between soft, medium and loud sounds at all frequencies using McNemar's test. As shown in Figure 9, up

to 30% of REMs were discrepant with their target by up to 20 dB and more than 10% were up to 30 dB off target.

Analogue hearing aid users failed to match the target more than digital hearing aid users (Figure 10). A Chi-squared test showed that the difference was statistically significant ($p < .001$). Further Chi-squared tests showed that a statistically significant difference was only found at the 50 dB level at the frequencies of 250 Hz ($\chi^2(1, N = 28) = 5.32$, $p = .021$), 500 Hz ($\chi^2(1, N = 28) = 5.32$, $p = .021$) and 4 kHz ($\chi^2(1, N = 28) = 9.40$, $p = .002$).

3.4 Correlations between outcome measures

REM scores showed no significant correlation with global scores on the PIBHA ($r = 0.364$, $N = 28$, $p = .057$). There was no statistically significant difference between daily hearing aid use and the REM categories of *Pass* and *Fail*. The correlations between non-word scores and PIBHA and REM scores respectively are tabulated in Tables 1 and 2.

Table 1. Correlations between non-word and PIBHA scores

		PIBHA	Correlation
Non-words (whole word approach)	Quiet	$r = 0.380$ $N = 29$ $p = .042$	Positive, weak
	Noise	$r = 0.263$ $N = 29$ $p = .168$	No correlation
Non-words (phonemic approach)	Quiet	$r = 0.428$ $N = 29$ $p = .021$	Positive, moderate
	Noise	$r = 0.243$ $N = 29$ $p = .205$	No correlation

Table 2. Correlations between non-word scores and REMs

		REMs	Correlation
Non-words (whole word approach)	Quiet	$r = 0.548$	Positive, moderate
	Noise	$r = 0.580$	Positive, moderate
Non-word (phonemic approach)	Quiet	$r = 0.703$	Positive, strong
	Noise	$r = 0.456$	Positive, moderate

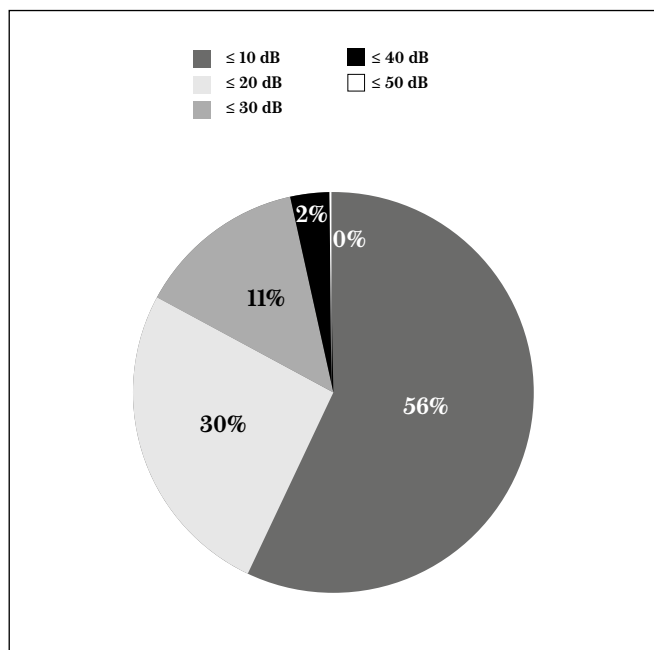


Figure 9. The percentage of REMs discrepant with target, expressed in categories of 10 dB

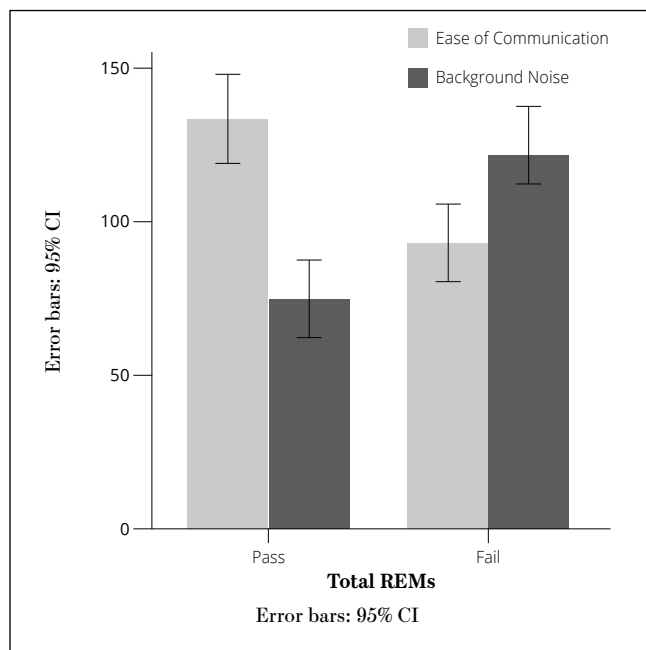


Figure 10. Pass and Fail outcomes in REMs across digital and analogue hearing aid users

4 Discussion

4.1 Outcomes of the Profil Imqassar dwar il-Benefiċċju tal-Hearing Aids (PIBHA)

In this study, 57% of the participants reported using their hearing aids for more than eight hours a day. Recent studies have shown a discrepancy in the frequency of self-reported hearing aid usage for more than eight hours a day, ranging from 15% ($N = 27$) (Roup & Noe, 2009) up to 61% ($N = 64$) (Williams, Johnson & Danhauer, 2009). Comparison of the frequency obtained for adult Maltese hearing aid users suggests that the latter fared quite well in the percentage of hours a hearing aid was used per day. In this study, 12% of the participants (mean age = 45 years) reported that they never used their hearing aids. This is in line with other findings reported in the literature (Hickson et al., 1999; Kochkin, 2010). As in other studies (Bertoli et al., 2009; Staehelin et al., 2011), male participants were four times more likely to never use their hearing aids when compared to females. In Staehelin et al.'s (2011) investigation, men indicated less benefit as a reason for non-usage. In the same study, women reported a higher prevalence of daily hearing aid use and a longer daily duration of use compared to men. This finding also corroborates the results of the present study. The reason for this effect was explored by Garstecki and Erler (1998), who found that females reported less denial and greater problem awareness related to hearing loss. This could explain why, in this study, women reported greater hearing aid use.

Degree of hearing loss was not associated with daily hearing aid use. This finding is in line with outcomes of Perez and Edmonds's (2012) systematic review. Digital hearing aid users were found to use their hearing aids more than analogue users in the current study, corroborating a finding reported by Magni, Freiberger and Tonn (2005). The latter authors also reported that 70% of digital hearing aid users used their hearing aids for more than eight hours a day. This is similar to the percentage identified in this study (67%). Daily hearing aid use was not affected by hearing aid fitting. This finding differs from the outcome reported by Bertoli, Bodmer and Probst (2010) for their study involving 6,027 participants. This discrepancy is probably due to the smaller sample in the population under investigation ($N = 56$). Further research is warranted to explore this dimension in more depth in the local population. Daily hearing aid use was not associated with reported benefit on the PIBHA, unlike several studies in the literature (Dillon, Birtles & Lovegrove, 1999; Olusanya, 2004; Roup & Noe, 2009). In spite of this, Perez and Edmonds (2012) emphasised that the relationship between hearing aid use and other outcome measures such as benefit is more complex than it seems. They reported that no single dimension was consistently shown to depend on hearing aid use. Perez and Edmonds (2012) argued that it may be more valuable to ask hearing aid users how much *more* time they spend on activities they like with the help of the hearing aid. This is more of a person-centred approach that looks at the true benefit of hearing aid use.

No significant difference was found between digital and analogue users on self-reported benefit scores. This is in line with the findings of Taylor, Paisley and Davis's (2001)

systematic review, which showed no significant differences in self-reported benefit and in speech recognition in quiet and noisy conditions between the two devices. Similarly, recent studies have reported no difference in benefit on the APHAB (Metselaar et al., 2009), or other self-report measures (Noble & Gatehouse, 2006), between unilateral and bilateral users. In this study, reported benefit on the PIBHA was also not associated with hearing aid fitting, thus corroborating previous studies' outcomes. One needs to keep in mind that other studies have found such a link (Boymans et al., 2009). This lack of homogeneity in results may imply that the type of fitting, just like daily hearing aid use, is only one of the factors that need to be taken into consideration when evaluating hearing aids, as outcome measures are indeed a multidimensional and complex entity. In fact, non-word scores obtained in this study were not affected by hearing aid fitting. There is a lack of research in the area, but a recent study by Henkins, Waldman and Kishon-Rabin (2007) showed that word recognition scores in quiet were comparable in unilateral and bilateral modes.

4.2 Non-word testing

Testing in noise addresses the most common complaint that persons with hearing loss report, which is listening in background noise. Indeed, higher scores for non-word repetition were obtained in the quiet setting in this study. This confirms that good non-word recognition in quiet does not indicate good non-word recognition in noise. Thus, in this aspect, both non-words and words are affected by the noise component (Wilson & McArdle, 2005). This can be explained by the fact that hearing aids improve perception in quiet largely due to the increased audibility (Wilson & McArdle, 2005). Speech in noise tests highlight the detrimental effect of the distortion component on everyday listening situations. Hearing in noise puts greater demands on the auditory and cognitive systems, which aim to interpret the limited and distorted auditory signal. This could explain the lower scores obtained by Maltese hearing aid users on the MNWN.

Word likeness was associated with a higher number of correct responses only in the noisy condition. This may be explained by the fact that noisy backgrounds lower the extrinsic redundancy of the speech signal even more (Cunningham, 2013). In noise, the phonological representations of non-words with high word likeness are supplemented by stored lexical knowledge that aids in the repetition of these non-words and helps in filling out missing information (Gathercole, 1995). In contrast, non-words having consonant clusters presented more difficulties than single segments in both quiet and noise. In addition, two-syllable non-words were more easily recalled than non-words having three and four syllables in quiet. In this respect, the findings corroborate those of other studies in the literature which report that syllable structure (Gallon, Harris & van der Lely, 2007) and length (Jones et al., 2010) have an effect on non-word repetition performance in normal

hearing children and adults. Studies on adult hearing aid users are lacking.

4.3 Real Ear Measurements (REMs)

Slightly more than half of the REMs ($N = 211$) did not meet prescribed targets by more than 10 dB in this study. This is very similar to other findings in the literature. Aazh & Moore (2007) reported that 64% of the fittings in their study did not meet the targets, a finding consistent with that of other studies (Aarts & Caffee, 2005; Hawkins & Cook, 2003; Mueller, 2005). The high percentage of unmatched hearing aids in this study and in the literature suggests a lack of use of REMs amongst hearing aid professionals at the time of fitting. Indeed, the discrepancy from target may be explained by the use of software-predicted values, or the lack of verification measures.

The findings of this study and of related studies bring up practical and ethical considerations for audiologists. In fact, Abrams et al. (2012) stress the importance of providing effective rehabilitation to hearing aid users that includes probe microphone verification measures in its fitting approach. The authors argue that REMs should be a routine and essential part of every hearing aid to be fitted. The failure to follow recommended best practices is viewed as a departure from standards of ethical competence by Palmer (2009). Notwithstanding philosophical arguments, Abrams et al. (2012) also mention the practical reasons to include REMs in the hearing aid fitting protocol; hearing aid owners who have received REM testing during the fitting procedure are reported to be more satisfied and perceive more hearing aid benefit (Kochkin, 2010).

4.4 Correlations between outcome measures

In this study, a finding similar to Mendel's (2007) was observed, in that benefit on the self-report measure was correlated with non-word scores in quiet. In noise, there was no correlation between the self-report and non-word scores. The latter finding is similar to the results of Cox & Alexander's (1992) study, which reported no correspondence between objective (speech test) and subjective (self-report) data in background noise conditions. In the current study, non-word scores were correlated with REMs. This means that well-matched REMs were associated with a higher score in non-word repetition testing. This adds more value to the fitting process and contributes to a more holistic and person-centred approach to auditory rehabilitation. These findings suggest that both measures could be part of the fitting process in the local population.

Unfortunately, REM scores did not show a correlation with the PIBHA scores in the population under study. This result conflicts with recent findings which report a significantly greater benefit on the APHAB when using REMs compared to no verification (Abrams et al., 2012). This may be explained by the fact that REMs may not necessarily reflect participants' functioning in everyday communication environments. Additionally, other characteristics of the

participants, such as personality and cognitive abilities, were not accounted for in the subjective self-report measure and could be key factors in self-reported benefit. Further research in this area is warranted, especially in the local population.

5 Conclusion

Overall, hearing aid outcome can be represented by a number of separate and unique dimensions. These include self-reported benefit, hearing aid usage, non-word speech repetition and REMs. All of these hearing aid outcomes have practical implications. Non-word repetition testing has been found to correlate with both subjective and objective measures. Further research on a larger scale would help to investigate whether non-word repetition scores can be considered as a predictor of self-report scores on the PIBHA and a pass in REMs. This is especially so in the Maltese Islands, where there is a lack of combined outcome measures being used in the fitting of hearing aids. As Curran and Galster (2013) argue, deciding which measure should be used to establish the best hearing aid fitting has remained a matter which is still imperfectly resolved. Over the years, amplification has changed and even clients have kept up with the technological advances. In this day and age, hearing aid users are more informed and demand to be involved in the decision-making process. As Hickson (2012) asserts, we have to accept the paradigm shift and move towards a more person-centred approach to audiological rehabilitation. This process should extend beyond the fitting of hearing aids and should be accompanied by counselling, user education and other audiological services.

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7 Conflicts of interest

The authors report no conflicts of interest.

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Research paper

LIVING WITH GUILLAIN-BARRÉ SYNDROME

Silvan Chetcuti, Victoria Sultana, Joanna Depares

Department of Nursing, Faculty of Health Sciences, University of Malta, Msida, Malta

Abstract. The potential long-term symptoms associated with Guillain-Barré syndrome (GBS) have been made evident in various studies. The purpose of the current investigation was to explore the meaning of living with GBS in a Maltese community setting following discharge from hospital. The study adopted a Heideggerian phenomenological approach. Four Maltese female participants were identified through purposive sampling, two to four years following their diagnosis. The women had all been treated in the Intensive Therapy Unit (ITU) of a Maltese general hospital at the acute stage of their illness. They were interviewed twice in their own environments. Data analysis led to the identification of three super-ordinate themes, namely Lost at Sea, Propelled into Change and The Aftermath. Participants spoke about the long-term symptoms related to GBS which left them feeling worn out most of the time. Subsequently, they were induced to delegate strenuous everyday roles to others, typically close family members. Participants highlighted a feeling of indebtedness towards their relatives, although at times they also felt ‘suffocated’ due to being over-protected. The women were very grateful for the professional care they received as hospital in-patients. However, when back in the community they felt that health care professionals failed to empathise with their needs. Participants described GBS as a “shot out of the blue” that totally transformed their lives. Although GBS changed their outlook on life, they never gave up hope of having a better future. However, in trying to re-integrate themselves in society, they were faced with various environmental obstacles and ‘human barriers’ that led them to social isolation. A key recommendation of the study is the need for an effective discharge planning programme intended to help these patients make a smooth transition as they return back to the community.

Keywords: Guillain-Barré syndrome, lived experience, phenomenology, hermeneutics, community, intensive care

Correspondence to Silvan Chetcuti
(silvanchetcuti@gmail.com)

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1 Introduction

Guillain-Barré syndrome (GBS) is an infective disorder of the nervous system involving the spinal roots, peripheral nerves and, occasionally, the cranial nerves (Bokhari & Zahid, 2010). In about two-thirds of affected patients, the presence of a preceding acute viral or bacterial illness is reported one to three weeks prior to onset (Atkinson et al., 2006). A definitive cause of GBS has still not been identified. The treatment options available, namely intravenous steroids, immunotherapy, plasma exchange and cerebrospinal fluid filtration, solely aim to decrease the duration and severity of the disease (Haldem & Zulkosky, 2005). While treatment may prove to be effective, it does not exclude the patient from requiring months or even years of rehabilitation (Haldem & Zulkosky, 2005). GBS affects around two persons in every 100,000 annually (Lugg, 2010; Sulston 2001), with literature even quoting figures of up to four persons per 100,000 annually (Akbarayam et al., 2011). In Malta, a total of 54 patients have been admitted to the state general hospital with GBS between 2012 and 2015 (S. Distefano 2016, personal communication, 6th June).

The suffering endured by patients diagnosed with GBS goes beyond the acute phase. Forsberg, Ahlstrom and Holmqvist (2008) report that during the acute stage of the illness, patients with GBS were already informed of possible long-term effects by their physicians. Fatigue has been cited as one of the most common and distressing long-term effects of GBS (Drory et al., 2012; Garssen, Koningsveld & Van Doorn., 2006). The physical symptoms also impact other aspects of life, particularly social activities. For example, following GBS, patients have had to temporarily suspend or end their job (Bersano et al., 2006; Bernsen et al., 2005).

The presence of psychological illness has also been associated with living with GBS, with Haldeman and Zulkosky (2005), Kogos et al. (2005) and Gregory (2003) reporting depression. Post-traumatic stress disorder, as well as living in constant fear of possible recurrence, has also emerged in the literature (Bernsen et al., 2002; Chemtob & Herriott, 1994). Additionally, Bernsen et al. (2002) reported patients to suffer from emotional instability, as well as concentration and/or memory disturbances.

While the research literature has described a number of long-term effects of GBS, there seems to be a lack of documentation related to individuals’ experiences of living

with GBS in the community. Here, the term ‘community’ implies independent living at home. The present study aimed to gain insight on what living with GBS in a Maltese community setting actually means to affected individuals.

2 Methods

2.1 Design

A qualitative design using the Heideggerian hermeneutic phenomenological approach was used. Hermeneutic phenomenology was considered as an ideal approach for this study as it addresses the intricacies of individual experiences (Robertson-Malt, 1999). Heideggerian phenomenology is based on the premise that an in-depth understanding of a person cannot take place unless the person’s world is also considered. Therefore, it adopts a ‘being-in-the-world’ approach to enquiry (Walters, 1995), with its fundamental aim being to gain an understanding of the meaning of Being.

2.2 Participants

A homogenous purposive sample of four Maltese female participants was recruited for the study. Pseudonyms were given: Mary, Grace, Joyce and Rita. Due to the fact that a purposive sampling method was adopted and participants meeting the inclusion criteria were limited, it was coincidental that all participants were female. All women were married with children. Mary and Joyce were employed whilst Joyce and Rita were full-time housewives. This sample size was considered as being appropriate as it allowed for an in-depth view into the participants’ experiences (Smith, Flowers & Larkin, 2010). The study’s inclusion criteria required the participants to be Maltese speakers who may have been making use of hospital out-patient services but were not being treated as in-patients. Other criteria were previous admission to the Intensive Therapy Unit of a general acute hospital and living in the community at the time of data collection. The participants were aged between 44 and 68 years and had been admitted to ITU with GBS between 2009 and 2011. Their involvement in the study took place two to four years following their diagnosis.

2.3 Procedure

Each participant was interviewed twice by the first author. All interviews were held in Maltese and took place in locations chosen by the participants. An intermediary period of six weeks between the first and second interview was used to listen and re-listen to the audio-recordings and transcribe them. Transcripts were also read over and re-read. Following this, a new set of questions for each participant was prepared to address issues that were felt to require clarification or further discussion. In fact, new concepts emerged from the second interview. All interviews were audio-recorded with the participants’ consent.

2.4 Ethical considerations

Ethical approval to carry out the study was granted by the University of Malta Research Ethics Committee. Potential participants were identified via the ITU patient database of a Maltese state general hospital by a proxy, who was a senior ITU nurse. The proxy passed on an information letter to the potential participants that provided details regarding the nature of the study and time requirements. The letter also stated that participants had the right to withdraw from the study at any point. Those persons who expressed their willingness to participate were then contacted by the first author and each individual was provided with an opportunity to clarify any queries. Those individuals who expressed their willingness to proceed were then asked to sign a consent form.

2.5 Data analysis

The interviews were transcribed and analysed by the first author using Van Manen’s (1990) approach. Accordingly, the first and second analytic stages included the reading and re-reading of the transcripts several times to allow immersion in the data. During the third stage, transcripts were re-read to identify emergent themes and distinguish them from the non-essential themes. A story for each participant was then written, in order to bring out the essential aspects of their experiences. This was followed by a joint review by all authors, together with agreement on a final set of themes. Following an in-depth analysis of the stories, three themes were created. These were then put together into one thematic statement, which eventually formed part of the study’s conclusion. Finally, participants’ stories were verified. Each participant was sent her story and was given one week to read and reflect on it, following which she was contacted by the first author for feedback.

2.6 Credibility and trustworthiness of the study

The framework outlined by Yardley (2000) was applied to ensure trustworthiness of the current study. Yardley’s (2000) framework is based on four aspects: sensitivity to context, commitment and rigour, transparency and coherence, as well as impact and importance. Sensitivity to context was ensured by making the participants’ voices heard through accurate descriptions of their story. Stories are a good way to preserve the context and meaning of the experience (Johnson, 2000). The issues of commitment, rigour, transparency and coherence relate to the expectations of thoroughness in data collection, analysis and reporting in research (Yardley, 2000). These aspects were addressed by keeping a field journal as suggested by Wall et al. (2004) in order to provide a record of personal feelings, thoughts, ideas and biases, feedback and information gathered throughout data collection. Hence, the research process was described in detail and a rationale was given for all decisions and actions taken. The final criterion of impact and importance

was addressed by thoroughly documenting the meaning of the experience of living with GBS for the participants.

3 Results

Three super-ordinate themes emerged from data analysis. These were Lost at Sea, Propelled into Change and The Aftermath. Living with GBS was perceived by participants as a sudden loss. All the participants described how GBS made them feel at a loss, to the point where they felt the loss of their identities. This constituted the first super-ordinate theme, Lost at Sea. Propelled into Change describes the changes that participants experienced in their lives following the diagnosis of GBS, mainly the fact that they could not plan for the future, as well as the effect that these changes had on the family. The final super-ordinate theme, The Aftermath, highlights the impact of the illness on the participants' social relations. Each super-ordinate theme comprised sub-themes which are outlined in Table 1.

Findings are presented with verbatim extracts from participants' interview responses to illustrate each theme. The insertion of ellipses (.....) in the excerpts indicates removal of segments for editorial reasons. Brackets indicate information added for further clarification.

Super-ordinate themes	Sub-themes
Lost at Sea	Sudden onset Loss of identity Out in the cold
Propelled into Change	From a player to a spectator The after-effects of the storm Taking life day by day
The Aftermath	Social isolation Hoping for a better future

Table 1. Super-ordinate themes and sub-themes concerning the experience of living with GBS

3.1 Lost at Sea

3.1.1 Sudden onset

The women in this study spoke about their personal feelings after their diagnosis of GBS, and metaphorically described themselves as feeling "lost at sea". Joyce distressingly recounted:

"It is like I am lost at sea."

This feeling was also shared by Rita who, with a blank face, commented:

"Following GBS I feel like I am a lost person."

The feeling of loss attributed to GBS was exacerbated by the sudden, inexplicable onset of the illness. The onset of GBS disrupted the participants' entire life in an instant. Mary stated:

"It just happened overnight, like a shot from the blue. There were no signs or signals. It was not gradual... I was washing the dishes and I could not stand up properly.....until I had swollen up so much that I could not take off my clothes."

Furthermore, two years following onset, Rita described how she still could not believe what had happened or how the illness had struck her.

"I could not believe how bad and how sudden it was. One minute you are healthy and the next, that's history.... I was out at a restaurant with my husband and his colleagues..... The next morning, I tried to get out of bed and my legs felt dead."

3.1.2 Loss of identity

Loss of identity was perceived by the women as the result of their diminished ability to carry out one or more of their major roles, particularly those related to their occupation. The loss of roles was attributed to the physical and psychological residuals of the condition. Participants described how the loss of roles, or major alterations in them, made them feel no longer the same. For example, Joyce claimed:

"I had to stop working. I used to work a 12-hour shift and sometimes even 16. Certainly, I cannot do that now! When you have been working for 22 years, it is no joke suddenly finding yourself not working.... It is not just the money. It is your routine of getting up in the morning and meeting someone."

Rita and Grace never worked away from home and fulfilled the role of full-time housewives. Following GBS, they felt they could not fulfil this role the way they used to. For example, Grace said:

"I still feel that sense of disappointment, that I do not keep the house in good order as I used to... I am always at home. Before (GBS) I used to do everything myself; dusting, cleaning windows etc. but now I have to get help. What a big difference!"

3.1.3 Out in the cold

All participants further reported that their experience of feeling "lost at sea" was further exacerbated by the fact that they felt that their needs as individuals living with GBS in the community were not understood by health care professionals. Participants expressed their gratitude for the care they received in hospital. However, in the community they felt that, as opposed to in-patients in the acute phase of illness, these same health care professionals failed to understand them, or even listen to their concerns. This made them feel as if they were literally left out in the cold. For example, Joyce, with a sense of resentment in her voice, said:

“Whenever I went to hospital they (medical team) used to tell me that if I was walking I was fine. Then I stopped going. Do not get me wrong, I agree with them because I was practically dead, and the medical care I was given in hospital was excellent..... but in my case it left symptoms.”

Mary also expressed her disappointment at the fact that after being discharged back home, no one followed up her case.

“I never got any letters for a follow-up appointment, since I was out of hospital!”

Grace, on the other hand, acknowledged her regular appointments on out-patient basis, but she perceived such appointments as not having much significance. She stated:

“Today, for example, I had an out-patient appointment. I spent more time waiting rather than being seen by the medics. I would barely have the time to tell them how I am feeling.”

3.1.4 Propelled into change

Change is defined as a transition or transformation (Farlex Inc., 2016). Change was represented in participants’ attempts to move away from loss in the best way they could, although this was not always possible. Their changes in roles, relationships and abilities brought a sense of new direction.

3.1.5 From a player to a spectator

GBS brought about changes in the participants’ family dynamics and roles. All participants were responsible for housework, including those who were in full-time employment. In the present study, GBS brought limitations on participants in such a way that they were not even able to fulfil the role of a housewife any longer. Other family members, usually the husband or children, had to take on these roles, in addition to their other responsibilities. For example, Rita described how her daughter took over some of the housework duties which belonged to her prior to her illness.

“My children suffered too. That is how my daughter got sick. She had too much to do. She used to do everything, cook, clean the entire house for us.... The medical consultant told her she was taking on so much.”

Furthermore, Joyce said:

“My children’s life has changed due to my illness, even the fact that I still depend on them to do certain errands.”

Like Joyce, Grace depended on her daughter to go out.

“I now depend on my daughter to go anywhere.”

In order to decrease the burden on their family, the women reported that they tried to hide their pain and deal with its limitations by themselves. For example, Mary said:

“I try dealing with GBS myself. I have a son who is nineteen. I hide from him that I am in pain because I know he worries about me.”

Similarly, Grace also hid her worries from her daughter because she did not want to cause her extra burden over and above her work responsibilities.

“My daughter needs to go to work. I cannot depend on her for everything.”

All the women in this study expressed gratitude and appreciated the support they received from their families. Joyce fondly spoke about the support she received from her children.

“I am so grateful to my children. I cannot imagine how I would have coped without them!”

However, the same women revealed that, at times, they found this attention to be rather suffocating. For instance, Grace spoke about her regret on the fact that she had to refrain from carrying out certain household chores after her family insisted on this.

“My neighbours saw me sweeping the pavement in front of my house. They panicked and went to tell my brother about it. He was really cross at me! He was really worried that I would fall and hurt myself. Still, I used to feel good sweeping a little, as I used to feel that I can do the same work as before.”

Joyce also expressed her wish to get out of the house to do some paid work, even for a few hours a week. Like Grace, she tried to reclaim some of her ‘lost identity’. However, her children stopped her from doing this in good faith.

“Sometimes, I wish I could go and help someone, even for a few hours a week, like wash a few dishes... but my children won’t hear of it!”

3.1.6 The after-effects of the storm

All participants shared how they had to learn to live with the residuals of the condition, lamenting that GBS had left some form of permanent disability in their lives. Mary, for instance, recounted that:

“Recently a physiotherapist told me that my hand lacks strength and GBS has affected it.... There are days when I need to rub my right leg... or my arm as they feel stiff, especially at night when I come to roll over in bed.”

The residual symptoms were still experienced by the participants even two to three years after they had been living back in the community. For example, Grace, in an annoyed voice, said:

“If I spend a certain amount of time on my feet during the day, I get very tired.”

Similarly, Joyce felt fatigue which still caused several limitations in her life, even three years after diagnosis.

“When I left hospital I was still very tired and I am still so very tired. I cannot be on my feet for long. Two hours is the limit. After that my legs hurt a lot. It is like electric shocks.”

The ongoing residual effects of GBS also had an impact on the person’s body image, especially when incontinence and impaired bladder control were experienced. For example, Rita poignantly discussed how distressed she felt when making use of a diaper. Grace also said that she did not feel comfortable showing her legs in public. She lifted up her skirt and showed her legs, which were still emaciated due to muscle loss caused by immobility brought over by GBS. She further revealed that she always wore trousers outside, even during the hot summer months.

Another psychological aspect and after-effect that some of these women were dealing with on a daily basis was the ongoing fear that GBS may haunt them again, possibly with worse outcomes. With a worried expression, Mary said:

“I feel that GBS is always there, it is always asleep, and maybe it will re-emerge.”

Grace also lived with the same fear, but this was mainly exacerbated when she was having a bad day of excruciating pain.

“I have good moments and not so good moments... On a bad day, I am frightened that GBS will re-emerge.”

Furthermore, participants were still living with the memories of being patients in ITU. Rita spoke about how her stay in ITU still haunted her even in her dreams.

“Many times, two years later, I still dream I am still in ITU....I still get visions of a young child I remember dying over there.”

Mary had similar recollections, although in her case she preferred to avoid talking about these distressful memories.

3.1.7 Taking life day by day

The fact that GBS struck the participants suddenly made them realise the fragility of life and ultimately changed their outlook on it. They stopped making long-term plans and started taking life day by day, appreciating it more. Mary said:

“These days I accept the fact that I have a condition I need to live with. Before, I did not use to accept certain things. I used to say ‘But why me?’.... After the condition, this attitude taught me to live day by day, whatever happens.”

Taking life day by day also meant that these women became more thoughtful of the people around them. Rita acknowledged how she started to value her husband more.

“Today I appreciate much more how much he (husband) has done for me during my illness, and he still does. Following my illness, I started to appreciate him more in my life.”

3.2 The Aftermath

Re-integrating into society after this experience was, most of the time, not easy for the participants. Although these women took conscious actions to adapt to their new way of being, some still hoped that their residual symptoms may one day disappear.

3.2.1 Social isolation

The social isolation that the participants faced was evident through their poignant narratives of the numerous environmental obstacles and ‘human barriers’ that they encountered on a regular basis. Grace expressed this frustrated anger by saying:

“I need to spend a day in Gozo but I cannot do it. How can I go to Gozo and do my errands? For instance, I like to go to Ta’ Pinu Sanctuary, but there are steps there... I am scared I might trip.”

It was therefore evident that inaccessibility to certain places was isolating these persons, as they felt that, due to the obstacles, they would prefer to stay in the comfort of their homes, without facing more problems. This was further exacerbated by the fact that the women had to plan in advance where to go. As Joyce explained:

“You have to plan your life to do all you need to do. Although I walk, if I am walking and come across a high pavement, it is very difficult for me to go up.”

Indeed, what came to light when talking to these women was that, although they found the physical barriers distressing, they were more upset when they had to face ‘human barriers’. Some friends stopped talking to Rita during and following her illness, the reason being that they were unsure of how to console her without upsetting her. With tears in her eyes she said:

“What hurt me most was the fact that when I started to go out to the grocer’s shop to do my shopping, I used to realise that my friends were avoiding me.... I used to ask myself ‘But why they are not talking to me?’ By time I got to know... that they used to avoid me as she (friend) said I was so weak and frail and they were lost for words of what to tell me, and were afraid to speak to me.”

3.2.2 Hoping for a better future

Despite the fact that society did not make it easy for them to re-integrate, the participants still remained very positive in life as they hoped for a better future. With enthusiasm, Mary said:

“I always look forward to the future, and hope for a better future.”

Grace said that her hopes and expectations for a better future were kindled when she met other patients who managed to overcome similar hurdles.

“Sometimes I think I might be well again, at least well enough to do away with this (walking frame). When I used to go for therapy, it was encouraging to see the other patients. One of the patients used to tell me ‘You will be just fine. You will get better. I went through it myself.’”

4 Discussion

This study provides an in-depth exploration of adults living with GBS. Following GBS, participants started to feel “lost at sea”. The women in the study attributed the loss to the sudden inexplicable onset of the condition, this being a common phenomenon in GBS (Forsberg et al., 2008). It was in fact described as a “shot in the blue”. This sudden onset took away the normality of participants’ lives, leaving them to wonder what might have been the actual cause of the illness. As a result of this, it was discussed how the women started to hypothesise on what might have caused GBS, even comparing it to more commonly known illnesses such as cancer, in spite of the fact that the pathologies of the two illnesses are completely different. Heider (1958) viewed lay people as naive psychologists trying to make sense of the social world. Fiske and Taylor (1991) asserted that the social perceiver, that is, the lay individual, uses information to arrive at causal explanations for events, when individuals find themselves in difficult and uncertain situations. Furthermore, according to Clow (2001), the use of symbolic language helps affected people to derive meaning from their experience.

Participants in this study felt that they were not the same individuals they were prior to GBS onset, for different reasons. It was debated how, prior to their illness, work gave the women a chance to socialise. Furthermore, it made them feel they were ‘useful’ to society. These findings corroborate those obtained by Shaw et al. (2002), who looked at return to work behaviours of individuals following long-term disability leave. The participants in the latter study stated that work gave them an identity and a sense of attachment to what they did. Moreover, in the present study, being a housewife gave the women a sense of pride in being in charge of a family. Indeed, within the traditional Maltese nuclear family, the role of housewife is a crucial one.

Furthermore, GBS made these individuals give up their leisurely activities, as was also evident among participants in Bernsen et al.’s (2002) study. Additionally, the participants perceived health care professionals as entities that further contributed to their loneliness, as they failed to understand their needs as individuals living in the community. They were sidelined by those health care professionals whom they had thought highly of when they were still in-patients. This insensitivity on behalf of health care professionals caused distress in participants’ lives.

Similar findings were reported by Forsberg et al. (2008). A different study carried out by Forsberg, Cuesta and Holmqvist (2006), which partly looked at satisfaction of 42 GBS patients in relation to health care services, concluded that patients were mostly dissatisfied with not being provided with adequate information with regard

to their rehabilitation. However, participants in Forsberg et al.’s (2006) study reported dissatisfaction with the information given throughout their care, including during the acute phase. In contrast, the women in the present study expressed satisfaction with the care given to them, including the information provided, while they were being cared for as in-patients.

The long-term effects of GBS were also the main reasons participants had to delegate their social roles to significant others. The women described guilt feelings of being a burden on the family. Bernsen et al. (2006) looked at the effects of GBS on close relatives during the first year of illness. Findings revealed that GBS had a psychosocial impact on relatives. Bernsen et al. (2006) highlighted the fact that, as relatives assumed new roles, they could not perform their own work properly due to psychological stress. However, in addition to what Bernsen et al. (2006) reported in their study, participants in the present study also expressed feelings of guilt. The latter feeling resulted from the fact that they felt like a burden on their children and family. In spite of all this, the women in the present study reported that the delegation of such roles brought family members closer together but also caused a feeling of ‘suffocation’.

Long-term effects which participants had to live with included fatigue and pain. Such long-term barriers hindered the women from regaining their independence in basic daily living activities. The presence of long-term fatigue related to GBS is also evident in the literature. Garssen, Koningsveld and Van Doorn (2006) looked at the issue of fatigue and reported that 60% of their participants reported severe fatigue two years following GBS. Furthermore, Garssen et al. (2006) concluded that fatigue was more common in female GBS patients who fell in the age bracket of 50 years and older, similar to the demographics of the participants in the present study.

Psychological long-term effects were also present in the women’s lives as they were still dealing with post-traumatic stress related to ITU admission even two or three years later. A study carried out by Russell (1999), which explored perceptions, memories and experiences of 298 patients in an intensive care unit, showed that participants were still battling with the traumatic experience of being admitted to intensive care even six months after their discharge. The disparity of experience between the present study and Russell’s (1999) is that distressing experiences for participants did not last for six months but for over two years, although no specific dynamics could be attributed to this outcome. The women also lived in constant fear of recurrence of GBS. Similar experiences of living in fear of GBS recurrence have also been reported in Chemtob and Herriott’s (1994) case study. The age difference between the young woman aged 24 years in the latter study and the women in the present study does not seem to have an effect on the experience. Therefore, the fact that the women in this study were older did not grant them the ability to deal better with feelings of worry and fear associated with the possibility of GBS re-emerging. Nonetheless, the women took conscious actions that helped them to move on. Participants started to choose alternative ways of filling their lives, such as strengthening their faith in

God. These women's experiences fit the ones presented in a review carried out by Koenig, Larson and Larson (2001), where the overall conclusion was that when people become physically ill, many rely heavily on religious beliefs to relieve stress and maintain hope.

This study also revealed how the women tried to re-integrate themselves back in society following their illness, and encountered considerable challenges due to several environmental barriers and societal attitudes. These barriers actually made them feel disabled and in turn kept them 'trapped' in their homes, where they felt more safe and protected. These experiences are echoed in detail in the Social Model of Disability, theorised by Oliver (1990). 'Human barriers' were also acknowledged by the participants, whereby friends or long-term employers started to avoid them or even failed to empathise with them. This is a common occurrence among people faced with serious illness (Buckman, 2012). It was also seen how the participants always hoped for a better future when their condition would improve, and the day when they would be totally free of GBS residuals. The importance of a GBS support group was also mentioned, particularly as sharing their concerns with people who went through a similar experience would have made them feel better.

4.1 Limitations

A potential limitation of the present study is the fact that a third brief interview was not carried out. This would have been beneficial, as it might have elicited more in-depth experiences. In fact, a heightened sense of trust in the interviewer was already felt by the second interview. Moreover, although all interviews were carried out in Maltese, interview transcripts were then translated to English. This might have led to the risk that, at times, the essence and meaning of a sentence or phrase might have been lost during the process of translation. To minimise this shortcoming, translations were carried out by an independent translator and it was agreed that when untranslatable words were present in the text, the original Maltese word was to be written in brackets next to the translation. This was done so that, as much as possible, the meaning would not change.

5 Conclusion

This study addressed the experiences of Maltese individuals living with GBS in the community. In conclusion, living with GBS was found to involve a continuous battle to reintegrate into society while trying to accept the resulting sudden losses, together with the tough and lifelong changes the condition brings. The study's findings generate a number of recommendations for practice. In order to help such individuals address challenges, they must continue to obtain necessary support following discharge from hospital. This support could be provided through further community services delivered by a multi-disciplinary team. Participants spoke emotionally about the environmental barriers they had to face while dealing with the illness. Diminishing

these would enable individuals with GBS to cope better psychologically and socially on a long-term basis. The various environmental restraints, such as the absence of ramps, need to be effectively addressed by the respective authorities. Addressing such barriers would enable these individuals to look forward to going out rather than having them dread the hurdles they have to face outside their homes.

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8 Conflicts of interest

The authors report no conflicts of interest.

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REFRAMING DEMENTIA CARE IN MALTESE HOSPITALS

Anthony Scerri,¹ Charles Scerri²

¹Department of Nursing, Faculty of Health Sciences, University of Malta, Msida, Malta

²Department of Pathology, Faculty of Medicine and Surgery, University of Malta, Msida, Malta

Abstract. This commentary addresses the urgent need to improve the care of patients with dementia and cognitive impairment in Maltese hospitals by proposing a number of dementia-friendly hospital-based initiatives. The authors discuss the rationale for developing these interventions in view of the increase in prevalence of persons with dementia in the Maltese Islands, some of whom may require hospital care at any time. Lessons learned from initiatives abroad are reviewed and an overview of the key objectives set out in the National Strategy for Dementia in the Maltese Islands is given. Finally, this article proposes a number of dementia-friendly initiatives that can be introduced in Maltese hospitals so as to induce the required change.

Keywords: dementia, Alzheimer's disease, hospital care

1 Introduction: A Rationale for Change

Dementia is a clinical syndrome caused by neurodegeneration, with Alzheimer's disease as well as vascular, Lewy-body and frontotemporal dementias being the most common underlying pathologies. It is characterised by progressive deterioration in cognitive ability and capacity for independent living. It is a health and social care priority for many high-income countries. At any time, a quarter of the patients in acute hospitals are persons with dementia or cognitive impairment (Royal College of Psychiatrists, UK, 2011). Persons with dementia may require the need for referral and admission to an acute hospital due to different comorbid conditions. Moreover, due to the demographic changes of the Maltese population and global population ageing, the number of persons with dementia is most likely to increase over the coming years. It is estimated that there are currently around 6,071 individuals with dementia in the Maltese Islands, with the number expected to rise to 12,955 (equivalent to 3.26% of the total population) by the year 2050 (Scerri & Scerri, 2012).

Correspondence to Anthony Scerri
(anthony.t.scerri@um.edu.mt)

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In parallel with population ageing, the number of older individuals aged 65+ in hospital wards is expected to increase. For example, according to unpublished data collected by the first author from the Clinical Performance Management Unit of Mater Dei Hospital, Malta (MDH), approximately 20 % of all MDH admissions in 2012 were over the age of 75 years. Consequently, using a rough estimate based on the EUROCODE age range prevalence rates (Alzheimer Europe, 2009), around 3,600 individuals with dementia were admitted to MDH during the year 2012, which is equivalent to around 3.8 % of the total yearly admissions.

2 The International Situation

International studies show that dementia patients may account for as much as 42% of patients aged over 70 years in general hospitals (Lyketsos et al., 2000). However, there is ample evidence that the quality of care of patients with dementia in hospital settings is far from optimal (Zekry et al., 2008) and can be very challenging (Clissett et al., 2013). The Royal College of Psychiatrists, UK (2011, 2013) carried out two national audits of dementia care in general hospitals in the UK and identified "disappointing results" in the first audit. The second national audit found that positive initiatives had been taken since the first audit, although much more had to be done. Positive initiatives included the development of Dementia Champions, the collection of a life history (personal information) of persons with dementia when in hospital and reduction in the use of anti-psychotic medications. Nevertheless, a number of negative findings were also noted, such as a dearth of proper assessment for delirium risk and cognitive function, as well as a general lack of staff awareness of how best to care for these patients, indicating a huge need for better staff training and support. Moreover, discharge plans often failed to record important details about ongoing health needs and only 36% of hospitals had a fully developed care pathway. Finally, hospital boards were still not sufficiently engaged in scrutinising dementia care by measuring readmission rates, delayed discharge, falls and relative complaints. These findings, together with the recommendations of the National Strategy for Dementia in the Maltese Islands 2015-2023 (Scerri, 2015), were used to identify a set of proposals for Maltese hospitals. A brief overview of the National Strategy for Dementia in the Maltese Islands (Scerri, 2015) will be given first.

3 The National Strategy for Dementia in the Maltese Islands (2015-2023)

This recently launched strategy highlights six key objectives, a brief summary of which is given here.

3.1 Increasing awareness and understanding of dementia

One fundamental aspect of this strategy is that of increasing awareness and understanding of dementia among the general public and health care professionals, in order to reduce stigma and misconceptions about the condition. Information campaigns that will seek to provide information about dementia and measures that aid its prevention will be launched, highlighting the importance of timely diagnosis and services that are available in the community and elsewhere. The strategy also aims to provide adequate knowledge on dementia to non-professional sectors of the population, including service providers who come into direct contact with individuals with dementia.

3.2 Timely diagnosis and intervention

Early symptom recognition and interventions through appropriate referral pathways, together with the necessary pharmacological and psychosocial support, offer the best possible management and care for individuals with dementia. This strategy also encourages the development of advanced care directives.

3.3 Workforce development

Good quality care will be ensured through the provision of training and educational programmes for staff working with individuals with dementia, giving particular importance to challenging behaviour and palliative care. Caregivers and family members who are responsible for the daily care of individuals with dementia will also be provided with adequate training. This would help them offer the best quality care and cope with new challenges.

3.4 Improving dementia management and care

A holistic approach to service provision for individuals with dementia, their caregivers and family members will be adopted. Apart from providing all pharmacotherapeutic options to Alzheimer's disease patients, individuals receiving a diagnosis of dementia will have care plans developed by a multidisciplinary team specialised in dementia management and care. These will address activities that maximise independent living, adapt and develop skills, and minimise the need for support. This, together with a rehabilitation service for those with other comorbidities, will seek to better equip the patient to return to the community. The strategy also aims to strengthen community care for individuals with

dementia and their families so that services are closer to the people who need them. The individual with dementia, as well as the caregiver and family members, need to be viewed as a single unit requiring appropriate care and support. The proposed creation of a Dementia Intervention Team will serve as a single point of referral for individuals with dementia and their caregivers, and will help in providing the most appropriate support according to the family's needs. Provision of different forms of respite services and the availability of outreach support are being seen as central in achieving quality care in the community. This strategy also aims to create extra dementia units in community care homes. Regular monitoring of homes in order to ensure high standards of care and the gradual incorporation of dementia-friendly measures are also addressed.

3.5 Ethical approach to dementia management and care

This strategy aims to promote an ethical approach to dementia management and care by providing individuals with dementia and their caregivers with the necessary psychological support needed in making important decisions regarding their health and welfare.

3.6 Research

Information regarding the epidemiology of dementia in the Maltese Islands, patterns of detection and diagnosis, and delivery of care are needed for proper planning and allocation of health and social care resources and for outcome evaluation. Since delivery of care is context-specific, the strategy aims to promote and support epidemiological research in the field of dementia in different local care settings. Other research initiatives in the dementia field, through collaboration with other research entities, will be strongly encouraged.

4 Reframing Dementia Care in Hospitals: Some Proposed Initiatives

Based on the objectives highlighted in the National Strategy for Dementia in the Maltese Islands and together with key partners such as the Administration of all local hospitals, the Secretariat for Rights of People with Disability and Active Ageing, the Psychiatric and the Neurological Departments at MDH, the Department of Geriatric Medicine at the Department of Health, the Geriatric Medicine Society of Malta, the University of Malta and the Malta Dementia Society, a working team can be set up with the ultimate aim of improving the quality of care of persons with dementia admitted to Maltese hospitals and their relatives/informal carers, by making these hospitals more dementia-friendly.

Table 1 highlights some of the possible initiatives that can be adopted to reach this aim and the rationale for developing them.

Table 1. Possible initiatives that can be adopted and the rationale for developing them

Key objectives as highlighted by the National Strategy for Dementia in the Maltese Islands	Initiatives	Rationale
Increasing awareness and understanding of dementia	Develop a dementia information unit in hospitals that provides information to the general public and acts as a point of contact for persons with dementia and their informal carers requiring use of this service.	Increasing awareness reduces stigma associated with the condition and fosters an inclusive and dementia-friendly society.
Timely diagnosis and intervention	<p>Encourage cognitive testing using standardised instruments to increase case finding, especially in older persons with suspected cognitive impairment.</p> <p>Encourage interdisciplinary collaboration and immediate referral to clinical specialists such as neurologists, psychiatrists and geriatricians when a patient presents with suspected cognitive impairment.</p> <p>Decrease waiting times for appointments with specialists for individuals with suspected cognitive impairment through the recruitment of additional specialists.</p>	Evidence shows that the majority of persons with dementia are never diagnosed. The benefits of timely diagnosis include identification of treatable physical and psychiatric causes, treatment of comorbid conditions, initiation of psychosocial support, and instigation of pharmacological symptomatic treatments (Prince, Bryce & Ferri, 2011).
Workforce development	<p>Develop training programmes for all hospital staff.</p> <p>Encourage interdisciplinary and inter-departmental collaboration in the development of these training programmes.</p> <p>Introduce person-centred dementia care training in induction programmes for newly recruited staff and continuous professional development programmes for skills updating.</p>	<p>Local studies indicate that health care professionals lack the necessary knowledge about dementia (Caruan-Pulpan & Scerri, 2014; Scerri & Scerri, 2013) and there is an information gap on dementia amongst the general public (Scerri, 2010).</p> <p>In 2010, the Rehabilitation Hospital Karin Grech, Malta (RHKG), in collaboration with MDH and the Malta Dementia Society, organised a number of information sessions in MDH which were well-attended. Since then, however, no further training initiatives have been implemented, especially with newly recruited staff.</p> <p>Feedback from a public questionnaire indicated that only 36% of respondents considered health care professionals as having the necessary skills in dementia management and care (Scerri, 2015).</p>
Improving dementia management and care	<p>Reduce the use of anti-psychotic medications and physical restraints by:</p> <ul style="list-style-type: none"> - encouraging the use of non-pharmacological interventions and increase staff 'resilience' through staff training and development, interdisciplinary collaboration and better use of voluntary services; - providing appropriate activity to encourage social engagement, maintenance of function and recovery through the use of interdisciplinary teams; - developing hospital protocols on when and how to use anti-psychotic medications and physical restraints in persons with dementia; - developing care plans that are based on individuals, their biographies, preferences and an understanding of their abilities. This may require the collection of personal life history information. <p>Involve family members in care planning and encourage staff to recognise their own needs by, for example, providing flexible visiting times so that family carers can be involved directly in care where desired.</p> <p>Reduce readmissions and length of stay of long-term care dementia patients in acute hospital wards through better collaboration between MDH and the Memory Clinic or Geriatric Clinics and Wards at RHKG.</p>	<p>Anti-psychotic medications and physical restraints are still being used to manage challenging behaviour in dementia patients in hospitals, although there is evidence that these increase the risk of death (Gill et al., 2007).</p> <p>Working in partnership with family carers and friends is not only important for delivering the right care but can also be helpful for staff. Families often hold valuable information that can help staff obtain an accurate assessment, provide care which meets the needs of the individual, as well as facilitate effective discharge planning.</p> <p>Public questionnaire feedback showed that only 21% of individuals received an initial dementia diagnosis at MDH. Moreover, although the Memory Clinic has been running for more than a decade, only 42% of respondents comprising individuals with dementia, caregivers and relatives, reported using this service (Scerri, 2015).</p>

Table 1 (cont). Possible initiatives that can be adopted and the rationale for developing them

Key objectives as highlighted by the National Strategy for Dementia in the Maltese Islands	Initiatives	Rationale
Improving dementia management and care (cont.)	Enhance a smoother transition from the Emergency Department to hospital wards or transfers from one hospital to another and improve discharge planning processes through the development of clear care pathways.	It may be difficult for dementia patients to understand the various changes in setting following admission to hospital.
Ethical approach to dementia management and care	Monitor any complaints of abuse in relation to patients with dementia and take immediate action. Provide health care professionals with access to appropriate training programmes in dementia disclosure, respect for personhood and wellbeing. A 'partners in care' approach would also be encouraged.	Individuals with dementia may be subjected to a greater risk of physical abuse than individuals without cognitive impairment (Cooper et al., 2009).
Research	Consider funding dementia research in Maltese hospitals. Research areas that may be considered include but are not limited to: <ul style="list-style-type: none"> • prevalence of persons with cognitive impairment admitted to these hospitals; • effectiveness of dementia training strategies for staff working in these hospitals; • perspectives of dementia patients and their family caregivers in relation to their hospital experience; • use of Dementia Care Mapping (DCM) to evaluate the quality of care/life of persons with dementia in hospitals 	Research on dementia in Maltese hospitals is currently lacking and requires more funding. DCM has been used in research studies to measure the quality of care/life in hospital settings (Goldberg et al., 2013).

5 Current Evidence on the Effectiveness of Similar Initiatives

The initiatives proposed in Table 1 are similar to the National Institute of Clinical Excellence, UK (NICE) Quality Standards (2010) that encourage the development of “a liaison service that specialises in the diagnosis and management of dementia and older people’s mental health” (p. 25) for patients with suspected or known dementia using acute and general hospital in-patient services. Although still in its infancy, evidence of the potential impact of such services is emerging. In a recent randomised controlled trial, Goldberg et al. (2013) compared patients in a medical and mental health unit (MMHU) with those in standard care wards in a general hospital. The primary outcomes consisted of the number of days spent at home in the 90 days following randomisation, while the secondary outcomes consisted of patients’ and family carers’ experiences with hospital care. Although there was no significant difference in the number of days spent at home between the specialist unit and standard care groups, patients in the specialist unit spent significantly more time with a positive mood or engagement and experienced more staff interactions that met emotional and psychological needs. Moreover, family carers’ satisfaction with care was significantly more pronounced for patients in the specialist unit group. The study concluded that patient

experience and carer satisfaction might be more appropriate outcomes in such a population. A secondary analysis of the same trial (Goldberg et al., 2014) showed that the main reason for these outcomes was the type of care provided in the MMHU, which was distinctively different from that in the standard care wards. This was probably due to the introduction of additional staff such as nurses specialised in mental health and activity organisers. However, this study concluded that implementing best practice and person-centred dementia care in hospital settings remains challenging and may require additional expenses.

The initiatives for Maltese hospitals proposed in Table 1 are also based on the Royal College of Nursing, UK (RCN) guidelines (see Thompson & Heath, 2013) that propose five principles for improving dementia care in hospital settings, namely staff, partnership, assessment, individualised care and dementia-friendly environments. In order to put these guidelines into practice, a RCN project that included nine National Health Service, UK (NHS) general hospitals was commissioned (Brooker et al., 2014), with the aim of improving the experience of care for people with dementia and their carers in these hospitals. The evaluation report concluded that a structured development programme for staff was a catalyst to achieve positive outcomes. Many of the hospitals participating in the programme developed and implemented training for their staff that increased

staff knowledge and confidence, while also bringing about observable changes in practice. Patient outcomes such as better documentation systems, more patient engagement and a reduction in complaints related to dementia care were evident. This project concluded that better networking among hospitals can help to spread good practice, while similar initiatives should be tailored to the needs of staff working in each hospital.

6 Conclusion: Setting Priorities

Current developments in other countries provide preliminary evidence that initiatives similar to those proposed in this commentary (see Table 1) have potential to improve the experience of patients with dementia and their carers in Maltese hospital settings. Moreover, the proposals presented here are comprehensive and target different key objectives of the National Strategy for Dementia in the Maltese Islands. It is understandable that all these initiatives cannot be implemented immediately. As a result, it is suggested that priority areas are identified in consultation with the major stakeholders, so that these initiatives are implemented over a defined period of time. In this respect, short-, medium- and long-term goals can be developed, as shown in Table 2. Together, these proposals should pave the way for Maltese hospitals to become truly dementia-friendly.

Table 2. Short-, medium- and long-term goals that can be developed to reach key objectives highlighted by the National Strategy for Dementia in the Maltese Islands

Key objectives as highlighted by the National Strategy for Dementia in the Maltese Islands	Short-Term	Medium-Term	Long-Term
Increasing awareness and understanding of dementia			+
Timely diagnosis and intervention		+	+
Workforce development	+	+	+
Improving dementia management and care	+	+	+
Ethical approach to dementia management and care	+	+	+
Research		+	+

7 Funding

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8 Conflicts of Interest

The authors report no conflicts of interest.

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SEAFOOD FROM NORWAY – FOOD SAFETY

Grete Lorentzen, Sten I. Siikavuopio, Ragnhild D. Whitaker

Nofima AS, P.O. Box 6122, N-9291, Tromsø, Norway

Abstract. Since Norway is a major supplier of seafood worldwide, monitoring the food safety of Norwegian fish products is a priority. This commentary gives a brief overview of the food safety of seafood from Norwegian waters. Several preventative measures during harvest/catch, processing and distribution have been established and are implemented regularly. Furthermore, comprehensive monitoring programmes to detect and quantify undesirable substances, such as heavy metals and polychlorinated biphenyls (PCBs), in Norwegian seafood are carried out. Substances with health benefits, such as omega-3 fatty acids, are also analysed. In general, evidence shows the level of undesirable substances in seafood from Norway to be low. In fact, in the majority of samples analysed, levels of undesirable substances were reported to be below the maximum limit set by the European Union (EU). This leads to the conclusion that consumption of seafood originating from Norway involves a low risk of negative health effects and that consumers can have confidence in the products they purchase.

Keywords: seafood, food safety, Norway, Norwegian practice

1 Introduction

The fisheries and aquaculture industry is one of Norway's most important industries with respect to value and volume. In fact, Norway is the world's second largest exporter of seafood and the European Union (EU) is its most important market (Ministry of Trade, Industry and Fisheries, Norway (MTIF), 2016). About 90% of Norwegian seafood is exported to more than 140 countries worldwide, representing a consumption of approximately 31 million meals daily. In 2015, Norway exported 5.21 billion euros worth of Atlantic salmon and trout, making the aquaculture industry one of the foremost export industries of the country (Norwegian Seafood Council, 2016). This industry represents a vital settlement along the long Norwegian coastline. Among the

farmed species, salmon and trout are the key species, but others such as Atlantic cod, Atlantic halibut and Arctic charr are also farmed (Le Francois, Jobling, Carter & Blier, 2010; Sæther, Siikavuopio & Jobling, 2016). In 2015, the weight of Atlantic cod, Atlantic halibut and Arctic charr was 205,935, 15,145 and 52,919 tonnes respectively (Statistics Norway, 2016). From time to time, food safety issues related to seafood are in focus. This can be a result of consumers' experience of seafood meals, or thorough analyses of seafood products. However, such a focus can also be a result of conflicts between countries. In 2011, three Norwegian producers of Atlantic salmon were banned from the Russian market on accusations of the pathogen *Listeria monocytogenes* (*L. monocytogenes*) being present in their products. This was followed up by additional sampling of the salmon by authorities from both countries, resulting in cancellation of the ban (Norwegian Food Safety Authority (NFSA), 2011).

Regardless of the reasons for questioning food safety, buyers of seafood must have confidence in the products they purchase and consume. In Norway, organisations dedicated to seafood safety have created a meticulous surveillance programme that also considers the feed ingredients used in farming. This programme includes both wild caught and farmed fish. The role of such organisations with respect to food safety will be described in this commentary.

Risks associated with the consumption of seafood include the ingestion of microbes (i.e. pathogens), toxins (i.e. algal toxins) and chemical contaminants (i.e. lead, mercury, cadmium or polychlorinated biphenyls (PCBs)). However, consumption of seafood also represents health benefits with respect to nutritional value, with the nutrients best known being omega-3 fatty acids, vitamin D and minerals (i.e. iodide and selenium). The beneficial effects of omega-3 fatty acids on cardiac organs have been extensively studied and they continue to show promising effects in the prevention of cardiovascular disease (Soumia, Sandeep & Jubbin, 2013). The benefits associated with omega-3 are enjoyed through consumption of fatty fish species like Atlantic salmon, trout and herring. It is important to emphasise that most of the risks and benefits described here are not limited to seafood only, but are more prominent in seafood compared to other food products. The aim of this paper is to give a brief presentation of food safety aspects of seafood originating from Norway.

Correspondence to Grete Lorentzen
(Grete.Lorentzen@Nofima.no)

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2 Controlling Food Safety in Norway

The NFSA is Norway's official national supervision and monitoring body for food safety, health and welfare of fish. It implements measures with respect to food safety on behalf of Norway's MTIF. MTIF is the secretariat to the Minister of Fisheries that exercises its administrative authority through adoption and implementation of legislation and regulations. Norway's National Institute of Nutrition and Seafood Research (NIFES) controls seafood with respect to undesirable substances such as veterinary drugs and environmental toxins. Beneficial substances such as omega-3 fatty acids and vitamin D are also analysed by the NIFES. The results of all analyses are available in published reports and internet sites (e.g. www.NIFES.no). The NIFES controls seafood safety on behalf of the NFSA.

In addition to these organisations, the Norwegian Scientific Committee for Food Safety (VKM) carries out independent risk assessments for the NFSA. Topics addressed include environmental risk assessments of genetically modified organisms (GMOs), foreign species and micro-organisms. Incidences of foodborne illnesses are reported to the Norwegian Institute of Public Health (NIPH) on a regular basis. Results are available on the NIPH's homepages (www.MSIS.no). In the EU, the Rapid Alert System for Food and Feed (RASFF) enables information about food safety to be shared among its members, namely EU-28 national food safety authorities, Commission and the European Food Safety Authority (EFSA), including the food safety authorities of Liechtenstein, Iceland, Switzerland and Norway. In the case of food safety issues, information exchanged through this system can lead to recall of products from the market.

3 Wild Fish

Baseline studies of relevant contaminants in wild fish are carried out on a regular basis. Wild fish includes mackerel, Norwegian spring-spawning herring, North Sea herring, Greenland halibut, Atlantic cod and saithe. Based on the results obtained, a follow-up plan is drawn up for each species to ensure that any changes in levels of undesirable substances are discovered. The sampling plan is adjusted according to previous results, volume and position of harvesting. In the case of saithe, analyses of undesirable substances are carried out for fish harvested in the North Sea, the Norwegian Sea and the Barents Sea. Table 1 shows the levels of arsenic, mercury, cadmium and lead, in muscle and liver respectively, for saithe from the North Sea as reported by Nilsen et al. (2013). Fillets of saithe were found to have low levels of undesirable substances, while the level of cadmium in the liver was above the maximum level specified by current EU legislation (Commission Regulation (EC) No. 1881/2006). As seen in Table 1, there are no maximum levels established by the EU for arsenic in seafood. Saithe caught in the Norwegian Sea and the North Sea had higher levels of undesirable substances compared to saithe caught in the Barents Sea.

4 Crustaceans

Analyses indicate that foods with the highest levels of cadmium contamination are shellfish and the kidneys of animals such as pigs (Bendell, 2010; Järup et al., 1998). In Norway, the level of cadmium in edible crab, *Cancer pagurus*, has recently been monitored along the coast of northern Norway (Frantzen, Duinker & Måge, 2015). According to Commission Regulation (EC) No. 1881/2006 of the EU, the maximum limit of cadmium in samples of crustacean is 0.5 mg/kg wet weight (ww). Frantzen et al. (2015) reported the level of cadmium in the meat from edible crab to vary in the range of 0.13 to 1.50 mg/kg meat. This study revealed that the average level of cadmium exceeded the maximum limit in 11 out of 20 samples.

Snow crab (*Chionoecetes opilio*) and king crab (*Paralithodes camtschaticus*) are high-priced commercial species that are mainly consumed in high-end markets in Korea, Japan and the United States of America (Anderson, Martinez-Garmendia & King, 2003; Lorentzen et al., 2014; Lorentzen et al., 2016). In our research, meat from snow crab and king crab has been analysed with respect to undesirable substances (Table 2). The snow crabs were collected from the Loophole in the Barents Sea in April 2015, while the king crabs were caught in the Varanger fjord in Northern Norway during November 2012. Before the sampling and killing, the snow crabs were starved for four weeks, while the king crabs were killed immediately after harvest. Snow crab meat includes protein, water, ash (including carbohydrates) and oil, with a distribution of 18.3, 79.6, 1.6 and < 0.5% respectively, while the corresponding values for king crab meat are 18.0, 78.3, 3.2 and < 0.5%. For both species, the level of cadmium and mercury in the meat was below the maximum limit (EU Commission Regulation (EC) No. 1881/2006). Since inorganic arsenic is more toxic than organic arsenic (Raber et al., 2012), levels of both organic and inorganic arsenic were determined and found to be below the set maximum levels. At present, no maximum limit is set by the EU for total arsenic, inorganic arsenic and manganese. However, based on the results from this study, it is concluded that meat from snow and king crab is safe to eat.

In a study by Julshamn et al. (2015), claw and leg meat of king crab was analysed for dioxins, furans, non-ortho and mono-ortho PCBs, non-dioxin-like PCBs, polybrominated diphenyl ethers, arsenic, cadmium, mercury and lead. From April to November 2012, the king crabs were collected from different areas of the Barents Sea, including the Varanger fjord. The concentrations of persistent organic pollutants and metals in the king crab meat were low and below the maximum limits laid down by the EU, leading Julshamn et al. (2015) to conclude that red king crab is safe to eat.

5 Farmed Fish

Food safety of farmed fish has received increasing attention in recent years, especially with respect to environmental contaminants. The fish is farmed in net cages that are sited in sheltered bays along the Norwegian coastline. In the case

of Atlantic salmon, it takes about 15-18 months for the fish to obtain a weight of approximately 4-5 kg from smolt stage.

Farmed fish are monitored frequently with respect to undesirable substances (Council Directive 96/23/EC). For every 100 tonnes of farmed fish produced, at least one fish is analysed. The NFSA performs sampling from the slaughterhouses and processing facilities on a regular basis. All these samples are analysed by the NIFES. In the last years, about 12,000 farmed fish have been analysed annually. Table 3 shows levels of undesirable substances such as arsenic, cadmium, mercury, lead and tributyltin in fillets of farmed fish, namely Atlantic salmon, rainbow trout and Atlantic cod, as reported by Hannisdal et al. (2015). Tributyltin includes a class of organic compounds and was used as an ingredient in anti-fouling paint applied to the hulls of boats.

The general trend for most contaminants analysed shows that the levels of undesirable substances in farmed salmon are declining significantly, reflecting the shift from fish-based to more vegetable-based raw materials in the feed. For example, the levels of dioxins have decreased from 1.4 ng TEQ/kg ww to 0.5 ng from 2002 to 2013, where TEQ refers to toxic equivalents of mixtures of polychlorinated dibenzodioxins (PCDDs), polychlorinated dibenzofurans (PCDFs) and PCBs and is used for risk characterisation. The present World Health Organisation (WHO) scheme is represented as TEQ/WHO. Since 2005, when the metals were included in the monitoring programme, the level of

mercury and arsenic declined from 0.037 to 0.014 mg/kg ww and from 2.00 to 0.55 mg/kg ww respectively.

Occasionally, drugs are used in fish farming. The use of antibiotics in Norwegian fish farming is low and less than 1.0 mg/kg farmed fish. About 0.5 to 1.0% of farmed fish has been treated with antibiotics (Utne Skåre et al., 2015). Norwegian legislation concerning residues of drugs in fish is similar to EU legislation. Fish treated with drugs are held in quarantine (withdrawal time) to make sure that the levels of residuals are below maximum limits. The fish farmer and the veterinarian are responsible for keeping the withdrawal time, the latter depending on drugs applied, size of the fish and water temperature. If drugs are used, this is reported to the NFSA.

From time to time, a parasitic nematode, *Anisakis*, is present in wild caught fish. *Anisakis* species are infective to humans as they can cause anisakiasis. Fish products that are intended to be consumed raw are kept at -24 °C for a minimum of 24 hours to kill the parasite. To our knowledge, *Anisakis* has not been detected in farmed salmon. The most apparent explanation of this is that the fish feeds on dry feed, which is unlikely to contain parasites. Based on these facts, the NFSA considers it safe to consume raw farmed salmon, as in sushi and sashimi, without any freezing in advance.

The prevalence of the pathogen *L. monocytogenes* in raw and ready-to-eat seafood and fish products, especially in smoked fish, can be up to 25% (Farber, 1991). Salmon is one of

Table 1. Concentrations (mg/kg ww) of arsenic, mercury, cadmium and lead in muscle and liver of saithe from the North Sea; mean, standard deviation (SD), median, minimum and maximum values and number of fish with concentrations below the limit of quantification (LOQ) are given (Copyright ©2013 Nilsen et al.; reproduced with permission)

Element (mg/kg ww)	Mean ¹	SD ¹	Median	Min	Max	#< LOQ	EU limit
Arsenic in muscle (N = 664)	2.9	2.1	2.5	0.37	15	0	--
Arsenic in liver (N = 636)	6.5	4.6	5.6	0.86	41	0	
Mercury in muscle (N = 664)	0.066	0.037	0.057	0.015	0.35	0	0.5
Mercury in liver (N = 636)	0.020	0.019	0.015	< 0.003	0.19	22	
Cadmium in muscle (N = 664)	0.0016	0.0011	0.0010	< 0.001	0.010	271	0.05
Cadmium in liver (N = 636)	0.32	0.24	0.28	< 0.004	1.8	1	
Lead in muscle (N = 664)			< 0.006	< 0.006	0.075	637	0.3
Lead in liver (N = 636)			< 0.02	< 0.02	0.40	590	

¹Mean and standard deviation (SD) were not determined in cases where more than half the number of fish had concentrations below the LOQ.

Table 2. Concentrations of undesirable substances in meat from snow crab and red king crab. The samples were obtained from legs from 10 crabs

Element	Snow crab meat	King crab meat	EU limit
Arsenic (mg/kg ww)	112.00	8.29	--
Cadmium (mg/kg ww)	0.0140	0.0035	0.50
Mercury (mg/kg ww)	0.1190	0.0539	0.50
Manganese (mg/kg ww)	0.195	0.221	--
Zinc (mg/kg ww)	31.00	22.00	--
Sum PCB (TEQ)/WHO ¹	< 0.24	NA ²	
Sum PCDD/PCDF (TEQ/WHO)	< 0.36	NA	

¹Includes PCB 77, PCB 81, PCB 105, PCB 114, PCB 118, PCB 123, PCB 126, PCB 156, PCB 157, PCB 157, PCB 167, PCB 169 and PCB 189 ²NA = not analysed

Table 3. Concentrations of arsenic, mercury, cadmium, lead and tributyltin in fillets of farmed fish; no mean or median is given if more than 50% of the results are below the limit of quantification (LOQ) (Copyright ©2015 Hannisdal et al.; reproduced with permission)

Element		Atlantic Salmon	Rainbow trout	Atlantic Cod	Atlantic halibut	LOQ	EU limit
Arsenic (mg/kg ww)	N	105	8	2	1		
	Median	0.58	0.62	0.62			
	Max	2.1	1.0	0.63	1.6	0.003	
Cadmium (mg/kg ww)	N	105	8	2	1		
	Max	0.002	LOQ	LOQ	LOQ	0.001-0.003	0.050
Mercury (mg/kg ww)	N	105	8	2	1		
	Median	0.019	0.018	0.042			
	Max	0.059	0.035	0.043	0.069	0.002	0.50
Lead(mg/kg ww)	N	105	8	2	1		
	Max	0.026	LOQ	LOQ	LOQ	0.005-0.01	0.30
Tributyltin (µg/kg ww)	N	59	4	2	0		
	Max	0.60	LOQ			0.3-0.5	

Table 4. Concentrations of PCB-28, PCB-52, PCB-101, PCB-138, PCB-153 and PCB-180 and sum PCB6 in fish feed, fishmeal and fish oil for 2014; values are given as µg/kg sample with mean value and range¹

	PCB-28 (µg/kg)	PCB-52 (µg /kg)	PCB-101 (µg /kg)	PCB-138 (µg /kg)	PCB-153 (µg /kg)	PCB-180 (µg /kg)	Sum PCB6 (µg /kg)
Fish feed (N = 73)	0.3	0.5	1.0	1.5	2.5	0.7	6.5
Min-Max	0.1-0.7	0.1-0.4	0.1-3.0	0.2-5.0	0.3-8.0	0.1-2.3	0.8-20.4
Fishmeal (N =10)	0.3	0.5	1.1	2.0	2.8	0.7	7.4
Min-Max	< 0.04-0.6	< 0.04-1.0	0.1-1.8	0.1-5.0	0.1-6.0	< 0.04-1.4	0.3-15.2
Fish oil (N = 7)	2.5	4.6	9.5	12.7	21.6	6.5	56.0
Min-Max	< 0.2-5.0	< 0.2-10.0	0.6-21.0	1.0-28.0	1.5-48.0	0.8-14.0	3.8-120.0

¹Data reported in Sanden et al. (2015)

several potential sources of the pathogen. The presence of *L. monocytogenes* was investigated in three Norwegian companies processing salmon (Lunestad, Truong & Lindstedt, 2013). In this study, 15 types of *L. monocytogenes* were detected. Among these, nine strains belonged to a genetic variant similar to that found in patients with listeriosis. To our knowledge, no cases of listeriosis have been linked to the consumption of salmon. The limited numbers of listeriosis cases reported might be due to levels below the infective dose of 100 colony-forming units (CFU)/g (or ml), which is insufficient to cause illness in most healthy consumers. This assumption is supported by the fact that this pathogen has been isolated from 1-6% of faecal samples from healthy people (Ooi & Lorber, 2005; Rocourt & Cossart, 1997).

6 Fish Feed

Food safety issues of farmed fish have been predominantly related to fish feed. Thus, considerable resources have been allocated to monitor fish feed frequently. In 2014, a total of 126 samples were analysed with respect to PCBs, including 78 feeds, 10 fishmeals, 10 plant proteins, 12 plant oils and seven fish oils (see findings reported by Sanden et al. (2015) in Table 4). The NFSA is notified in the case of non-compliant results. With the exception of one non-compliant complete feed containing the pesticide hexachlorobenzene (HCB), results showed that all samples of feed and feed ingredients were compliant with regard to the maximum levels of heavy metals and organic contaminants. One of the feed samples exceeded the maximum limit with respect to cobalt, copper, manganese, iodine and zinc, while several of the feed samples exceeded the maximum limit with respect to vitamin D3 and selenium.

7 Conclusion

Overall, consumption of seafood from Norway involves low risk of negative health effects. This may be due to a thorough knowledge of food safety risks, a comprehensive monitoring programme for seafood safety and a strict regime of fish farming in Norway.

Utne Skåre et al. (2015) have carried out a comprehensive assessment of the available scientific literature on the positive health effects of seafood consumption, the contribution of fish to the intake of beneficial substances, as well as exposure to hazardous contaminants in Norway. They concluded that the benefits clearly outweigh the negligible risk presented by current levels of contaminants and other known undesirable substances in seafood.

It is foreseen that more information about the effects of climate change in terms of food safety issues will be required. Such information should address the effects of an elevated sea temperature and increased acidification. In addition, climate change might also generate extreme weather, which is expected to have consequences for biodiversity, the aquaculture industry, maritime transport and infrastructure. If climate change or any other conditions are found to affect

seafood safety, the NFSA and NIFES will take this into account and adjust the monitoring programme accordingly.

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9 Conflicts of Interest

The authors report no conflicts of interest.

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