Data Article

Survey data on the quality of life of consumers fitted with osseointegrated fixation and bone-anchored limb prostheses provided by government organization

Laurent Frossard a, b, c, d, * , Luciann Ferrada e , Debra Berg e

a Griffith University, Gold Coast, QLD, Australia
b University of the Sunshine Coast, Maroochydore, QLD, Australia
c Queensland University of Technology, Brisbane, QLD, Australia
d YourResearchProject Pty Ltd, Brisbane, QLD, Australia
e Queensland Artificial Limb Service, Brisbane, QLD, Australia

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A B S T R A C T

The data in this paper are related to the research article entitled “Development of a government continuous quality improvement procedure for assessing the provision of bone anchored limb prosthesis: A process re-design descriptive study” (Frossard et al., Canadian Prosthetics & Orthotics Journal, 2018. 1(2). p. 1–14). This article contains quality of life data experienced by individuals before and after implantation of a press-fit or screw-type osseointegrated fixation when fitted with conventional socket-suspended and bone-anchored limb prosthesis, respectively. This specifically-designed survey was developed and administered by Queensland Artificial Limb Services (QALS), an Australian State government organization. It was an integrated part of QALS’ continuous quality improvement procedure for assessing the provision of bone-anchored prosthesis. A total of 12 out of the 65 consumers completed the survey, giving a return rate of 18%. This benchmark information can contribute to inform the design of (A) other patients’ experience surveys including those built-in governmental continuous quality improvement procedure as well as (B) clinical trials looking at the overall effects of surgical implantation of osseointegrated fixation on patients’ quality of life.

* Corresponding author. Griffith University, Gold Coast, QLD, Australia.
E-mail address: laurentfrossard@outlook.com (L. Frossard).

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Specifications Table

| Subject area                                      | Health service delivery                      |
|--------------------------------------------------|-----------------------------------------------|
| More specific subject area                       | Quality of life of individuals using lower limb prosthesis |
| Type of data                                      | Table, graph                                  |
| How data was acquired                            | Survey data                                   |
| Data format                                       | Raw and Analyzed                              |
| Experimental factors                             | A total of 65 consumers fitted with at least one osseointegrated fixation and bone-anchored limb prosthesis between 01/2011 and 06/2019 were asked to participate in this survey. A total of 12 consumers fitted with press-fit or screw-type osseointegration fixation between 07/2012 and 04/2019 responded to the survey, giving a return rate of 18%. |
| Experimental features                            | This specifically-designed survey was developed and administered by Queensland Artificial Limb Services (QALS), an Australian State government organization, as an integrated part of its continuous quality improvement procedure for assessing the provision of bone-anchored prosthesis. This 25-question survey was designed to assess change in quality of life experienced by QALS consumers before and after implantation of a press-fit or screw-type osseointegrated fixation when fitted with conventional socket-suspended and bone-anchored limb prostheses, respectively. The eligible consumers were asked to participate in this study over the phone by a QALS agent. Consumers could choose if they preferred receiving the survey by email or post. |
| Data source location                              | Brisbane, Queensland, Australia               |
| Data accessibility                                | Data is with this article. Transparency data including the actual survey associated with this article can be found in the online version at https://data.mendeley.com/datasets/bkbxxmrhfh/1 |
| Related research article                         | Frossard, L., Ferrada, L., Quincey, T., Burkett, B., and Berg, D., Development of a government continuous quality improvement procedure for assessing the provision of bone anchored limb prosthesis: A process re-design descriptive study. Canadian Prosthetics & Orthotics Journal, 2018. 1(2). p. 1–14 [1]. |

Value of the Data

- The survey data presented here provided an initial appraisal of the change in quality of life following surgical implantation of osseointegrated fixation, enabling direct skeletal attachment of the prosthesis, experienced by consumers supported by an Australian State government [1]. This specifically-designed survey focused on multiple facets of quality of life deriving essentially from safety and efficacy of the procedure as well as overall satisfaction with prosthesis [2–4]. This survey allowed comparing the baseline quality of life before the treatment when fitted with socket-suspended prosthesis with quality of life after treatment when fitted with bone-anchored prosthesis. This benchmark information could be used in future comparative studies or meta-analyses involving other cohorts of individuals fitted with socket-suspended or bone-anchored prostheses, respectively [5–7].
- This new insight into the quality of life reported by consumers fitted with bone-anchored prosthesis provided by a governmental organization can contribute to inform the design of specific and more advanced quality of life surveys that could be administered by other government organizations supporting provision of bone-anchored prostheses. This information will be particularly valuable to those who have limited opportunities to administer standard generic health-related quality of life surveys (e.g., SF-36) as part of their continuous quality improvement of procedure [1].
- This quality of life data can also be valuable for researchers designing observational studies and clinical trials looking at the overall effects of particular interventions (e.g., design of osseointegrated fixation, effects of bone-anchored prosthesis components) on patients’ satisfaction and quality of life. For instance, the magnitude of the difference between quality of life experienced with socket-suspended and bone-anchored prosthesis can informed the sample size required to achieve sufficient statistical power during the analytical planning stage.
1. Data

Table 1 presented the three levels of focus, actual question and type of answer for each of the 25 questions focusing on quality of life of consumers fitted with socket-suspended and bone-anchored prosthesis provided by Queensland Artificial Limb Services (QALS) before and after implantation of osseointegrated fixation.

Table 2 presented the case-mix profiles including demographics, amputation, access to care and funder information for the QALS’ consumers fitted with bone-anchored prosthesis who were asked to participate in the study (N = 65) and responded (N = 12).

Figs. 1–7 provided the baseline outcomes for the seven questions related to the quality of life of QALS’ consumers provided with socket-suspended prosthesis before implantation of osseointegrated fixation focusing on efficacy (i.e., Q8, Q9, Q10, Q11), experience (i.e., Q12) and knowledge of the osseointegration treatment (i.e., Q2, Q3).

Figs. 8–24 provided the outcomes for the 17 questions related to the quality of life of QALS’ consumers provided with bone-anchored prosthesis after implantation of osseointegrated fixation.

Table 1

| Focus | Question                                                                 | Answer                                      |
|-------|--------------------------------------------------------------------------|---------------------------------------------|
| 1     | Quality of life with socket-suspended prosthesis before treatment         |                                             |
| 1.1   | Efficacy                                                                 |                                             |
| 1.1.1 | Function Q8 Before undergoing Osseointegration did you use a socket prosthesis? | Dichotomous (Yes or no)                     |
| 1.1.2 | Function Q9 How long did you use a socket prosthesis prior to having Osseointegration? | Open-ended (Enter number of years and months) |
| 1.1.3 | Function Q10 How many hours per day were you able to wear the socket prosthesis limb? | Open-ended (Enter number of hours)           |
| 1.1.4 | Function Q11 Were you able to perform normal activities with a socket prosthesis? | Dichotomous (Yes or no)                     |
| 1.2   | Experience                                                               |                                             |
| 1.2.1 | Satisfaction Q12 Please indicate on the line below your level of quality of life with a socket prosthesis | Likert-type scale (0: Not Satisfied, 10: Very Satisfied) |
| 1.3   | Knowledge                                                                |                                             |
| 1.3.1 | Motivation Q2 Why did you decide to have Osseointegration?                | Open-ended (Supply own answer)              |
| 1.3.2 | Information Q3 How did you hear about Osseointegration?                   | Open-ended (Supply own answer)              |
| 2     | Quality of life with bone-anchored prosthesis after treatment             |                                             |
| 2.1   | Surgery                                                                  |                                             |
| 2.1.1 | Onset Q1 When did you undergo the Osseointegration Surgery?               | Open-ended (Enter date)                     |
| 2.1.2 | Satisfaction Q7 Please indicate on the line below your initial level of satisfaction after your osseointegration surgery | Likert-type scale (0: Not Satisfied, 10: Very Satisfied) |
| 2.2   | Safety                                                                   |                                             |
| 2.2.1 | Infection Q4 Did you experience any infections around your abutment exit point post-surgery? | Dichotomous (Yes or no)                     |
| 2.2.2 | Infection Q5 If [your experienced infection around your abutment exit point post-surgery]— how long did you have infections for? | Open-ended (Enter number of days, weeks or months) |
| 2.2.3 | Infection Q13 Have you developed any infections or irritation since the initial surgery? | Dichotomous (Yes or no)                     |
| 2.3   | Efficacy                                                                 |                                             |
| 2.3.1 | Function Q6 How soon after the osseo surgery were you able to return to normal activities? | Open-ended (Enter number of days and weeks) |
| 2.3.2 | Function Q14 Are you able to mobilise on an Osseointegrated Prosthesis?   | Dichotomous (Yes or no)                     |
| 2.3.3 | Function Q15 How long have you been mobilising with a Osseointegration Prosthesis? | Open-ended (Enter number of years and months) |
| 2.3.4 | Function Q16 Does your Osseointegrated prosthesis function as it should?  | Dichotomous (Yes or no)                     |

(continued on next page)
**Table 1 (continued)**

| Focus | Question | Answer |
|-------|----------|--------|
| 2.3.5 Function | Q19 How many hours per day are you able to wear the Osseointegrated Prosthesis? | Open-ended (Enter number of hours) |
| 2.3.6 Function | Q20 Would you like to be able to wear it more? | Dichotomous (Yes or no) |

**Experience**

| 2.4.1 Satisfaction | Q17 Are you satisfied with the componentry fitted to your Osseointegrated prosthesis? | Dichotomous (Yes or no) |
| 2.4.2 Satisfaction | Q18 Overall, were you happy with your Osseointegration prosthesis? | Dichotomous (Yes or no) |
| 2.4.3 Limitation | Q21 If [you like to be able to wear it more], what stops you from wearing it as much as you would like to? | Open-ended (Supply own answer) |
| 2.4.4 Satisfaction | Q22 Does your Osseointegration Prosthesis support your life style needs? | Dichotomous (Yes or no) |
| 2.4.5 Limitation | Q23 If [our Osseointegration Prosthesis support your life style does not support your lifestyle] – please state why | Open-ended (Supply own answer) |
| 2.4.6 Satisfaction | Q24 Please indicate on the line below your level of quality of life with Osseointegration | Likert-type scale (0: Not Satisfied, 10: Very Satisfied) |

**3 General comments**

| 3.1 Comment | Q25 Any additional comments | Open-ended (Supply own answer) |

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**Table 2**

Case-mix profiles including demographics, amputation, access to care and funder information for the Queensland Artificial Limb Services (QALS) consumers fitted with press-fit (N = 64) or screw-type (N = 1) osseointegrated fixation and bone-anchored prosthesis between 01/2011 and 06/2019 who were asked to participate in the study (N = 65) and responded (N = 12 including incomplete record for one respondent). PSP: Prosthetic Service Provider, DVA: Rehabilitation Appliance Program of the Department of Veteran Affairs, NDIS: National Disability Insurance Scheme.

| | Overall population (N = 65) | Respondent population (N = 11) |
|---|---|---|
| **Demographics** | | |
| Male | 50 (77%) | 10 (91%) |
| Female | 15 (23%) | 1 (9%) |
| Age (years) | 65 (100%) 52 ± 13 | 11 (100%) 57 ± 12 |
| Height (m) | 58 (89%) 1.75 ± 0.10 | 10 (91%) 1.75 ± 0.08 |
| Mass (kg) | 62 (95%) 82.86 ± 17.29 | 11 (100%) 79.82 ± 17.92 |
| **Amputation** | | |
| **Timeline** | | |
| Time since first amputation (years) | 65 (100%) 20 ± 15 | 11 (100%) 17 ± 13 |
| Time since first surgery for BAP (years) | 64 (98%) 3 ± 1 | 11 (100%) 3 ± 1 |
| **Cause** | | |
| Trauma | 44 (68%) | 6 (55%) |
| Vascular insufficiency | 9 (14%) | 0 (0%) |
| Malignant neoplasm | 6 (9%) | 4 (36%) |
| **Level of amputation** | | |
| Transfemoral | 53 (82%) | 9 (82%) |
| Transtibial | 9 (14%) | 2 (18%) |
| Through Knee | 3 (5%) | 0 (0%) |
| Hip disarticulation | 1 (2%) | 0 (0%) |
| **Number of amputations** | | |
| Unilateral | 58 (89%) | 9 (82%) |
| Bilateral | 5 (8%) | 1 (9%) |
| Quadrilateral | 2 (3%) | 1 (9%) |
| **Access to prosthetic care** | | |
| Distance-Residence to PSP (km) | 60 (92%) 145 ± 212 | 11 (100%) 162 ± 248 |
| Distance-Residence to QALS (km) | 62 (95%) 364 ± 499 | 11 (100%) 369 ± 506 |
| **Funder** | | |
| QALS | 38 (58%) | 9 (82%) |
| DVA | 8 (12%) | 1 (9%) |
| NDIS | 12 (18%) | 1 (9%) |
Fig. 1. Outcomes of Q8 focusing on the capacity to use socket-suspended prosthesis before surgical implantation of the osseointegrated fixation (Q8: Before undergoing Osseointegration did you use a socket prosthesis?, Response rate: 100%).

Fig. 2. Outcomes of Q9 focusing on the duration of usage of socket-suspended prosthesis before surgical implantation of the osseointegrated fixation (Q9: How long did you use a socket prosthesis prior to having Osseointegration?, Response rate: 83%, Mean: 14.90 ± 13.25 years).

Fig. 3. Outcomes of Q10 focusing on the daily ability to wear socket-suspended prosthesis before surgical implantation of the osseointegrated fixation (Q10: How many hours per day were you able to wear the socket prosthetic limb?, Response rate: 67%, Mean: 5.84 ± 6.01 hours).
focusing on surgery (i.e., Q1, Q7), safety and harms (i.e., Q4, Q5, Q13), efficacy and benefits (i.e., Q6, Q14, Q15, Q16, Q19, Q20) and overall experience (i.e., Q17, Q18, Q21, Q22, Q23, Q24).

Fig. 25 showed the general comments provided by consumers (i.e., Q25).

2. Design of survey

The initial survey focusing on quality of life of consumers with socket-suspended prosthesis or bone-anchored prosthesis provided by Queensland Artificial Limb Services included 25 questions, as described in Table 1.
Fig. 6. Outcomes of Q2 focusing on the motivations for choosing surgical implantation of the osseointegrated fixation (Q2: Why did you decide to have Osseointegration?, Response rate: 100%).

Fig. 7. Outcomes of Q3 focusing on the source of information found about surgical procedure for implantation of the osseointegrated fixation (Q3: How did you hear about Osseointegration?, Response rate: 100%).

Fig. 8. Outcomes of Q1 focusing on the time since the surgical implantation of the osseointegrated fixation (Q1: When did you undergo the Osseointegration Surgery?, Response rate: 100%, Mean: 3.37 ± 2.12 years).
Fig. 9. Outcomes of Q7 focusing on the percentage of participants in each level of satisfaction after surgical implantation of the osseointegrated fixation ranging between 0 (not satisfied) and 10 (very satisfied) (Q7: Please indicate on the line below your initial level of satisfaction after your osseointegration surgery, Response rate: 100%, Mean: 9.54 ± 0.72).

Fig. 10. Outcomes of Q4 focusing on the infection experienced after the surgical implantation of the osseointegrated fixation (Q4: Did you experience any infections around your abutment exit point post-surgery?, Response rate: 100%).

Fig. 11. Outcomes of Q5 focusing on the duration of infection after surgical implantation of the osseointegrated fixation (Q5: If you experienced infection around our abutment exit point post-surgery—how long did you have infections for?, Response rate: 50%, Mean: 4.68 ± 5.48 months).
3. Population

The Queensland Artificial Limb Services asked 65 consumers with osseointegrated fixation and bone-anchored prosthesis to complete the survey as presented in Table 2.

4. Quality of life with socket-suspended prosthesis before treatment

The baseline outcomes for the seven questions related to the quality of life of QALS’ consumers provided with socket-suspended prosthesis before implantation of osseointegrated fixation focusing on efficacy (i.e., Q8, Q9, Q10, Q11), experience (i.e., Q12) and knowledge of the osseointegration treatment (i.e., Q2, Q3) are presented in Figs. 1–7.

5. Quality of life with bone-anchored prosthesis after treatment

The outcomes for the questions related to the quality of life of QALS’ consumers provided with bone-anchored prosthesis after implantation of osseointegrated fixation focusing on surgery (i.e., Q1,
Q7), safety and harms (i.e., Q4, Q5, Q13), efficacy and benefits (i.e., Q6, Q14, Q15, Q16, Q19, Q20) and overall experience (i.e., Q17, Q18, Q21, Q22, Q23, Q24) are presented in Figs. 8–24.

6. General comments

The general comments provided by consumers (i.e., Q25) are summarized in Fig. 25.

6.1. Experimental design, materials, and methods

6.1.1. Participants

This study involved all of 65 QALS’ consumers fitted with at least one bone-anchored prosthesis after implantation of press-fit (N = 64) or screw-type (N = 1) osseointegration fixation between 01/2011 and 06/2019. This cohort represented circa 16% and 7% of existing population estimated at 400
in Australia and 950 worldwide, respectively [1]. A total of 12 out of 65 consumers fitted with bone-anchored prosthesis between 07/2012 and 04/2019 responded to the survey, giving a return rate of 18%. The individual question’s response rate corresponded to the number of responses for a given question over 12 respondents.

6.1.2. Survey

This specifically-designed survey data on the quality of life was administered by Queensland Artificial Limb Services (QALS), an Australian State government organization, as an integrated part of its continuous quality improvement procedure for assessing the provision of bone-anchored prosthesis [1,8–10]. This survey was designed to assess change in quality of life experienced by QALS’s consumers before and after implantation of a press-fit or screw-type osseointegrated fixation when fitted with conventional socket-suspended and bone-anchored limb prosthesis, respectively [3,4,11].

First, participants were required to indicate their name, address, date of birth and email. Then, participants answered 25 questions organized around the three following sections:

Fig. 16. Outcomes of Q16 focusing on the functionality of bone-anchored prosthesis since surgical implantation of the osseointegrated fixation (Q16: Does your Osseointegrated prosthesis function as it should?, Response rate: 92%).

Fig. 17. Outcomes of Q19 focusing on the daily ability to wear bone-anchored prosthesis since surgical implantation of the osseointegrated fixation (Q19-How many hours per day are you able to wear the Osseointegrated Prosthesis? Response rate: 75%, Mean: 17.89 ± 5.10 hours).
7 (28%) questions about “Osseointegration Surgery Details” (i.e., Q1 – 7),
5 (20%) questions about “Pre-Osseointegration Surgery” (i.e., Q8 – 12),
13 (52%) questions about “Post-Surgery Osseointegration” (i.e., Q13 – 25).

The 65 eligible consumers were asked to participate in this study over the phone by a QALS’ agent. Consumers could choose if they preferred receiving the survey by email or by post with pre-paid return envelope.

6.1.3. Data mapping
Analysis of the survey data consisted in extracting information for:
7 (28%) questions providing baseline outcomes that related to the quality of life of QALS' consumers fitted with socket-suspended prosthesis before implantation of osseointegrated fixation including:
- 4 (16%) questions focusing on efficacy, particularly the level of function (i.e., Q8, Q9, Q10, Q11),
- 1 (4%) question focusing on experience, particularly the level of satisfaction (i.e., Q12),
- 3 (12%) questions focusing on knowledge of the osseointegration treatment (i.e., Q2, Q3), particularly the motivation for considering the procedure and the sources of information considered where promotional information included TV and social media.

17 (68%) questions assessing the quality of life of QALS' consumers fitted with bone-anchored prosthesis after implantation of osseointegrated fixation including:
- 2 (8%) questions focusing on surgery (i.e., Q1, Q7), particularly the time of the surgery and the level of satisfaction with the procedure,
2 (8%) questions focusing on safety or harms (i.e., Q5, Q13, Q4), particularly the occurrence of infection [12,13],

- 7 (28%) questions providing baseline outcomes that related to the quality of life of QALS’ consumers fitted with socket-suspended prosthesis before implantation of osseointegrated fixation including:
  - 4 (16%) questions focusing on efficacy, particularly the level of function (i.e., Q8, Q9, Q10, Q11),
  - 1 (4%) question focusing on experience, particularly the level of satisfaction (i.e., Q12),
  - 3 (12%) questions focusing on knowledge of the osseointegration treatment (i.e., Q2, Q3), particularly the motivation for considering the procedure and the sources of information considered where promotional information included TV and social media.

- 17 (68%) questions assessing the quality of life of QALS’ consumers fitted with bone-anchored prosthesis after implantation of osseointegrated fixation including:
2 (8%) questions focusing on surgery (i.e., Q1, Q7), particularly the time of the surgery and the level of satisfaction with the procedure.

2 (8%) questions focusing on safety or harms (i.e., Q13, Q4, Q5), particularly the occurrence of infection [12,13].

6 (24%) questions focusing on efficacy or benefits (i.e., Q6, Q14, Q15, Q16, Q19, Q20), particularly the level of function [14,15].

6 (24%) questions focusing on overall experience (i.e., Q17, Q18, Q21, Q22, Q23, Q24), particularly the limitations and level of satisfaction.

1 (4%) general comments provided by consumers focusing on limitation of their observation time as well recommendations, benefits and shortcomings of the treatment (i.e., Q25).

Answers to the 10 (40%) dichotomous questions (i.e., Yes or no) were expressed in percentage of individual responses (i.e., Q4, Q8, Q11, Q13, Q14, Q16, Q17, Q18, Q20, Q22).

Answers to the 3 (12%) Likert-type scale questions were expressed as percentage of participants in each of the 10 levels between 0 for “not satisfied” and 10 for “very satisfied” (i.e., Q7, Q12, Q24).

Answers to the 12 (48%) open-ended questions were coded accordingly to the recurrence of themes in the replies (i.e., Q1, Q2, Q3, Q5, Q6, Q9, Q10, Q15, Q19, Q21, Q23, Q25).
6 (24%) questions focusing on overall experience (i.e., Q21, Q23, Q17, Q18, Q22, Q24), particularly the limitations and level of satisfaction.

- 1 (4%) general comments provided by consumers focusing on limitation of their observation time as well recommendations, benefits and shortcomings of the treatment (i.e., Q25).

Answers to the 10 (40%) dichotomous questions (i.e., Yes or no) were expressed in percentage of individual responses (i.e., Q4, Q8, Q11, Q13, Q14, Q16, Q17, Q18, Q20, Q22).

Answers to the 3 (12%) Likert-type scale questions were expressed as percentage of participants in each of the 10 levels between 0 for “not satisfied” and 10 for “very satisfied” (i.e., Q7, Q12, Q24).

Answers to the 12 (48%) open-ended questions were coded accordingly to the recurrence of themes in the replies (i.e., Q1, Q2, Q3, Q5, Q6, Q9, Q10, Q15, Q19, Q21, Q23, Q25).

7. Data analysis

Only aggregated data was presented in this study. Exploration of more detailed analysis revealed that proportionate and disproportionate stratification sampling were unattainable given the diversity of case-mix and the small number of respondents.

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Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dib.2019.104536.

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