



The use of personalised patient information leaflets to improve patients' perceived understanding following open fractures

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Abstract

Open tibial fractures can have devastating long-term effects. In our centre, these patients are followed up in a multidisciplinary Orthoplastic Research Clinic. To improve patient comprehension of information, we have developed personalised information leaflets. This study determines patients' views on these. The leaflet was completed during clinic visits and its role explained. At their next appointment, patients were given anonymised feedback forms, adapted from previously published questionnaires, to complete on their views and use of the leaflet. During the study period, 48 new patients attended clinic; 40 completed questionnaires and were analysed. A majority of patients (39) self-reported improved understanding of their condition, and 11 patients used the information leaflet to improve communication with other healthcare professionals. A majority of patients (34) wished to receive the information leaflet on discharge. The majority of patients in this study felt the leaflet improved their knowledge of their injuries and management.

Keywords Open fracture · Tibia · Orthoplastic · Patient information leaflet · Health literacy

Introduction

Open tibial fractures can be devastating injuries and often result in a permanent change in the health status of a patient [1]. Early complications include acute compartment syndrome and infection, with later problems including non-union, osteomyelitis and, in some cases, amputation [2]. In addition to the physical consequences of these injuries, psychological problems are widespread with 42% of patients having a psychological disorder 2 years after injury [3]. The social costs are further amplified as, following the original injury, patients are known to have increased utilisation of healthcare resources [1]. The British Orthopaedic Association (BOA) and British Association of Plastic and Reconstructive and Aesthetic Surgeons (BAPRAS) have produced standards of care for these challenging injuries,

which recommend early combined orthopaedic and plastic surgery input [4].

This set of standards has led our unit to create a combined Orthoplastic Research Clinic (OPRC) to follow up these patients; this is a multidisciplinary clinic in which orthopaedic and plastic surgeons work alongside physiotherapists and occupational therapists (OTs). Benefits of this clinic include greater specialist input, the ability to collect data for research projects, and less clinic visits for patients with potential cost savings for the trust.

One problem that patients have reported in the OPRC is a feeling of being overloaded with information, and a subsequent struggle to recall details. Indeed, this is a well-recognised problem with studies showing 40–80% of information provided is forgotten immediately [5]. This problem is further exacerbated as around half the information remembered is incorrect [6].

It has been shown that written information aids patient recall more than purely spoken information [7], with the optimal approach being written material supplementing and reinforcing oral information [8]. One recent systematic review has shown patient information leaflets can improve patients' knowledge and satisfaction, whatever the clinical situation [9]. Furthermore, in the short term, this can

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contribute to improved adherence to treatment and lifestyle advice [9].

In view of the benefits of patient information leaflets, our team decided to design and begin distribution of leaflets for patients attending the OPRC. These were customised for each patient and, rather than containing generic information, highlighted key points raised in the consultation, as this approach is known to be more effective in leaflet design [9]. The purpose of this study was to assess the utilisation of these personalised patient information leaflets, with the primary outcome being the effect on patient self-reported understanding, which was assessed via a previously published questionnaire. Secondary outcomes concerned whether the leaflets were used to improve communication with other healthcare professionals, and the optimal time for distribution to patients.

Methods

Designing the leaflet

There were several important factors to consider when planning and preparing the leaflet. As the patients would be seen in the multidisciplinary OPRC, it was important we accounted for this in the leaflet layout; consequently, we included boxes to outline management considerations for orthopaedic and plastic surgeons, and also physiotherapists and OTs (Fig. 1). Evidence in the literature suggests that leaflets can be more effective if information is personalised [8, 9], and therefore, although we used the same generic template (Fig. 1) for leaflets, the clinical details would vary for each patient. The leaflet was updated at each visit, and therefore, patients would leave clinic with changes in their management and clinical progress clearly recorded. It was essential that the information provided related specifically to each patient's injury, exact treatment received and rehabilitation plan. Patients were informed from the outset of the risks of open tibial fracture, such as non-union and infection. Due to a combination of space restrictions, and the priority to personalise the leaflet, this general information was not included unless it was particularly pertinent to the individual patient, e.g. if a patient was being treated for osteomyelitis or non-union.

The NHS utilises large numbers of leaflets in a wide range of areas [10], but problems remain with their readability and usability [10], and a recent 'Please Write to Me' initiative, supported by the Academy of Medical Royal colleges, encourages the use of plain and simple English rather than complex medical jargon [11]. Two authors prepared our leaflet (RM and NCJ), and each was cross-checked to evaluate the language and terminology for clarity and content.

Older patients recall less information on average than younger patients [5], and this may be due to problems with unstructured information [5]. Therefore, we have explicitly categorised information in separate boxes (Fig. 1) [5] to confer structure and order to the written material.

We have used black Calibri text for each of the boxes with a font size of 11 on a white background to aid reading for all people [12]. We purposely limited each leaflet to one side of A4, which helped to prevent excessive, and potentially confusing, clinical details [12]. Emergency contact details were provided on each leaflet as a separate box, and patients were encouraged to contact these in the event of any concerns. Indeed, on several occasions patients did attend clinic earlier than planned after contacting us due to concerns, which facilitated prompt review and senior decision-making.

Recruiting patients for inclusion

In order to analyse the effectiveness of the leaflets, it was decided to survey patients following its introduction, using a modified version of a previously published questionnaire (Table 1) [13]. Prior to introducing the leaflet, ethical approval was granted from Swansea University Ethics Committee, and the local NHS trust (Abertawe Bro Morgannwg University (ABMU)) confirmed further approval was not required. Consequently, new patients (at their first or second appointment post-discharge) were approached on arrival in the clinic and the nature of the project explained. Inclusion criteria were: adult patients (> 16 years), recovering from open tibial fractures, which had required Orthoplastic management in Morriston Hospital. Patients were provided with a completed personalised leaflet to take away with them at the end of the clinic, regardless of their wishes to participate in the study. This approach ensured patients had access to the potential benefits of the information leaflet, but were not pressured to participate in the study. Patients were informed they could drop out of the study at any point for any reason.

Distribution of leaflets and questionnaires

The OPRC runs twice a month, and patients are normally seen post-operatively at 2, 6 and 12 weeks and then at 6, 9 and 12 months. On their first attendance in clinic, they were provided with a completed leaflet. These were completed partially before clinic (the two top boxes provide patient details and summarise the injury details), and the other four boxes were completed during clinic. Patients were encouraged to read the leaflet and show any family members if they felt necessary, and also use it to facilitate discussions with other members of the primary care team, e.g. GPs, district nurses.

At their next clinic appointment, patients participating in the study would be provided with questionnaires to

Fig. 1 Template used for the personalised patient information leaflet

<p>In-patient summary Orthopaedic Consultant..... Secretary contact no..... Plastic Surgery Consultant..... Secretary contact no..... Summary of injury..... Initial Orthopaedic management..... Definitive Orthopaedic management..... Plastic surgery management..... </p>	<p>Orthopaedic Research Clinic Morrison hospital Swansea, SA6 6NL</p>  <p>Name..... DOB..... Hospital no..... Date.....</p>
<p>Orthopaedic plan Current progress/problems..... Future plan.....</p>	<p>Plastic surgery plan Current progress/problems..... Future plan..... </p>
<p>Physiotherapy input Outpatient physiotherapy..... Weight bearing status..... Required exercises..... Special instructions..... Future plan..... </p>	<p>OT / dressings plan Dressings..... VAC dressing..... Dressing changes..... Splintage..... Duration..... Bathing..... Pressure garment..... Scar management..... To avoid on skin..... </p>
<p>Follow up: Orthopaedic.....Plastic surgery..... Physiotherapy.....Dressings.....</p>	
<p>Emergency contact numbers: Fracture clinic..01792 703852.....Dressing clinic/ Occupational therapy 01792 703886/ 703980 Physiotherapy department.. 01792 703124.....Research nurse..01792 703722..... Orthopaedic nurse practitioner (bleep 3845) via switchboard 01792 702222</p>	

anonymously complete. The questionnaires were distributed to patients prior to leaving clinic to reduce potential bias in feedback. Furthermore, questionnaires were deposited in a secure box to help preserve anonymity.

Results

From the 1st of September 2014 until 11 May 2015, all new patients attending the OPRC were approached about inclusion in the study. In total, 48 new patients attended the clinic with 44 consenting to be included. Of these 44 patients, 40

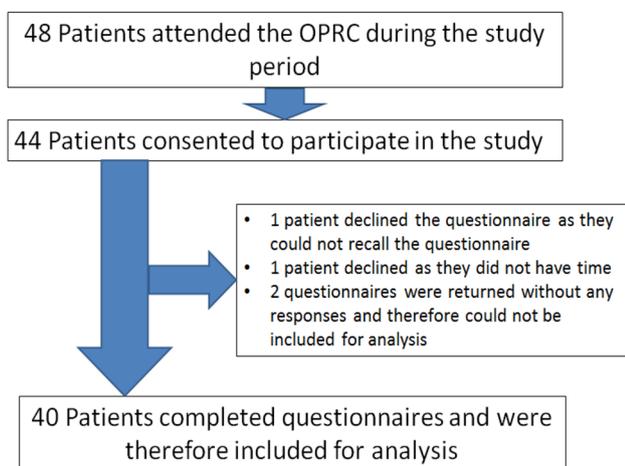
returned completed questionnaires following their next clinic visit (Fig. 2). The age range of patients who completed the questionnaire was 17–82, with a mean of 48, 10 (25%) of the patients being female. In most cases, patients were still in hospital at 2 weeks post-operation and therefore were first seen at 6 weeks in the OPRC. Feedback was then collected at the 3-month appointment.

When analysing the results for the questionnaire, three broad themes were addressed:-

- 1.1 Patient view on the leaflets and its utilisation (questions 1–5)

Table 1 Summary of questions used in questionnaire

Question	Options			
1. Did you read the letter?	Yes	No		
2. Did any member of your family and/or a friend read the letter?	Yes	No		
3. Have you discussed the letter with another healthcare professional, e.g. GP, practice nurse, district nurse, physiotherapist?	Yes	No		
4. If no for question 3, do you think it would be useful in future meetings with other healthcare professionals, e.g. GP, practice nurse, district nurse, physiotherapist?	Yes	No		
5. Would a letter of this nature have been useful prior to your discharge from hospital?	Yes	No		
6. Was the letter understood?	Yes, totally	Most of it	Some of it	None of it
7. Did the letter improve your understanding of your treatment plan to date and the future management?	Yes	No		
8. If you found the letter difficult to understand, do you think it was useful to have a copy of it anyway?	Yes	No		
9. How could the letter be improved?				

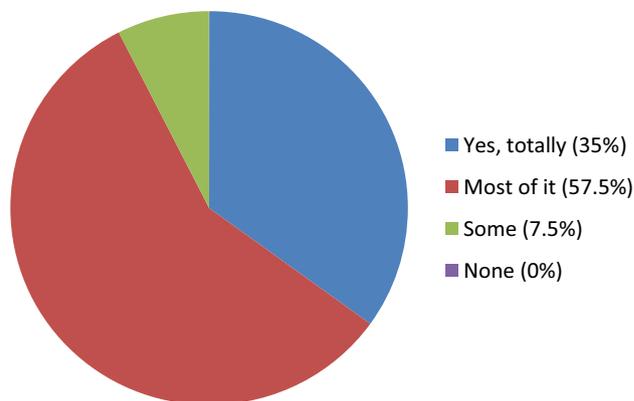
**Fig. 2** Flow diagram outlining the selection of patients for the study

Of the 40 patients who completed questionnaires, all had read the leaflet, with a majority (28) showing a friend or family member, and 11 had used the leaflet in discussion with another healthcare professional. Further questions on the 29 who had not used the leaflet with other healthcare professionals revealed 20 thought it would be useful. Most patients (34) felt the leaflet would be useful prior to hospital discharge.

1.2 Patient understanding of the leaflet and its content (questions 6–8)

Patients were given a list of options (question 6 in Table 1) to rank their understanding of the leaflets. A majority (37) commented they understood all or most of the leaflet (23 and 14 patients, respectively) (Fig. 3).

Overall, the majority of patients felt it improved their understanding (39), with only one thinking it made no difference,

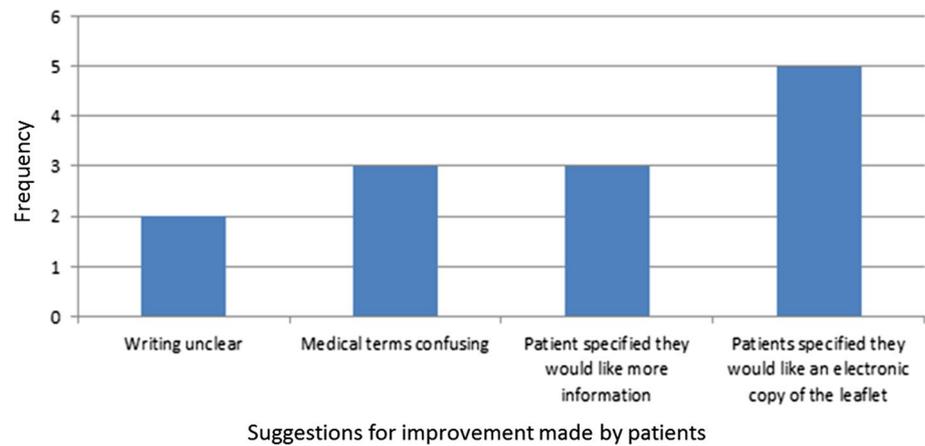
**Fig. 3** Level of patient understanding of leaflets (question 6 of the questionnaire)

although, when asked further, thought it would still be useful to have the leaflet.

1.3 Suggestions for improvement (question 9)

This question was answered by 18 patients. Of these, six patients did not provide critical comments or clear suggestions for improvement (1 had “no suggestions”, 1 was “unsure”, and 4 commented the leaflet was already “good” or “clear”). Of the remaining 12 patients, 13 suggestions for improvement were made in total, with the most frequent being patients wanting an electronic copy of the leaflet (Fig. 4).

Fig. 4 Suggestions for ways to improve the leaflet by patients in the study



Discussion and conclusion

Discussion

Leaflets remain a very common way to provide written material to patients, and this pilot study has demonstrated that personalised patient information leaflets in an OPRC can improve how patients feel about their understanding of their condition, and treatment following open tibial fractures. In this case, the personalised information was updated at each visit and a fresh leaflet produced. Furthermore, these leaflets can also be useful in facilitating discussion with GPs and other members of the primary care team following discharge. Interestingly, the desire for more information on discharge was common, with many patients commenting they would prefer the leaflets on discharge from hospital.

Previous studies on their use to supplement clinic consultations suggest they are effective in improving patient recall of information with one study estimating 50% more information is retained [7]. Consequently, patient satisfaction and adherence to treatment can be improved [9]. This is particularly relevant in managing open tibial fractures, as patient adherence to smoking cessation, restricted weight-bearing instructions and participation in physiotherapy programmes can be crucial to the long-term outcome.

Additionally, increased awareness of conditions may help reduce patient anxiety, and better-informed patients may also exhibit altered health behaviour [8]: one study in primary care has demonstrated reduced re-consultation rates [14], with associated potential cost benefits. Interestingly, poorly worded patient information leaflets can actually increase GP consultations [15], hence the importance of plain and simple English.

Questions in our study revealed most patients showed it to their family or friends, with over a quarter also using it to aid discussion with other healthcare professionals. This was very reassuring as it showed patients took the leaflets seriously, and this fits with another study providing clinic

letters to cancer patients [16]. In this trial, 80% of patients shared their letter with other friends or family members [16], which compares with 70% in this study.

The finding that a majority of patients desired the leaflets on hospital discharge is very interesting and is likely to reflect the transition from hospital care to the community being a vulnerable time for patients [17]. Previous studies have estimated 19–23% of patients experience an adverse event in this time period and advised improving communication between inpatient and outpatient clinicians to reduce this [17]. Open tibial fracture patients in particular have increased unplanned healthcare utilisation in the first year following injury [1]. Interestingly, these rates are already significantly lower in those treated solely in orthopaedic centres [1], which may reflect higher-quality treatment, or clearer communication of management plans to patients.

Discharge summaries are the most common method of communication following hospital admission [17], but problems can occur. Unfortunately, there is often a marked time lag from writing them to their being received by GPs, with 75% of patients who attend primary care following discharge doing so before a discharge summary has been received by the GP [18]. This deficit in appropriate communication between hospital and primary based care may explain patients' wishes for greater written information on discharge.

Similarly, two patients commented on struggling to read handwriting as the contemporary plan recorded was handwritten into the boxes. This was an unfortunate necessity as no printing facilities were available during the pilot study. In future, it should be possible to update the leaflets in real time during consultations using electronic devices, e.g. a tablet. This would have the further benefit of allowing electronic copies to be made for patients, which was a suggestion made by several patients.

Despite the potential benefits of patient information leaflets, important challenges exist in their development and use, with readability and usability being widely reported

problems [10]. In our study, three patients commented on the use of medical terms being confusing, despite our efforts to minimise this by the two leaflet authors (RM and NCJ) proof-reading each other's leaflets. This suggests that fellow healthcare professionals may not be best placed to evaluate readability for patients. In future, we will consider the use of independent lay people or even literacy specialists in this process.

Another important consideration when introducing patient information leaflets is poor health literacy (defined as the ability to obtain, process and understand basic health information, to make better decisions [19]). This has been described as a 'silent epidemic' by the Institute of Medicine, with approximately half of Americans lacking the competency to make informed decisions on their health [20]. It is quite feasible this figure is similar in many Western countries, and other authors fear may be even higher for musculoskeletal health [20]. For example, one questionnaire-based study showed that 69% of patients with musculoskeletal complaints lacked adequate musculoskeletal health literacy [21]. Awareness of this is crucial in producing information leaflets for orthopaedic patients, with one recent study showing most online patient education material on the American Academy of Orthopaedic Surgeons (AAOS) website exceeds the average patient reading age [22]; consequently, the efficacy of well-intentioned health leaflets may be seriously diminished. This was evidenced in one study which showed that despite information provision, nearly half of orthopaedic trauma patients could not identify their weight-bearing status [23].

A further challenge for our patient cohort arises because adult tibial diaphyseal fractures are more common in areas of social deprivation [24], and educational attainment, on average, is lower in these areas. In order to help overcome this challenge, it was essential that each leaflet was personalised for each patient and used appropriate language and terms. Our study population was White British, which reflected the local demographics, with all patients speaking English as a first language. Awareness of language barriers is a crucial consideration when designing patient information leaflets in populations where English may not be well spoken. In fact, one focus group study suggested patients with poor command of the native language, in which leaflets were written, were actually more likely to seek additionally support [15].

There are several possible limitations to this study that should be considered when interpreting the results. The sample size of 40 is relatively limited, and future studies could use a larger cohort of patients and compare patients' understanding with and without the leaflet. The nature of questions was predominantly binary, i.e. yes or no responses, which aided analysis of responses, but did not allow exploration of patient views or ideas. A qualitative study design

would be useful to evaluate in more detail the effects of the information leaflets on patient feelings and any underlying reasons.

One study on illiteracy in healthcare settings showed around 40% of patients with low literacy rates felt ashamed, and did not disclose their problems to others [25]. This could be a problem in our study, as some patients may have been too embarrassed to admit they did not understand the leaflet and therefore answered questions inaccurately. However, we decided not to objectively test health literacy, as this carries a risk of stigmatising people who score poorly [26]. Patients with low health literacy often dislike being tested [26] and may even avoid healthcare settings to escape testing [27]. This would be counterproductive as it may reduce study participation and even compromise care if patients shun clinic follow-up. To further reduce any stigma associated with poor literacy or comprehension, we emphasised the questionnaires were anonymous, with use of the deposit box providing further reassurance.

Screening patients for health literacy requires significant time and resources [26], and national and international organisations have suggested using universal precautions for managing patients with low health literacy by providing clear communication to all patients [28].

Although our results suggest patients regarded their understanding of their injuries improved as a result of the information leaflets, we were unable to objectively quantify this. Testing patient understanding pre- and post-questionnaire would be useful to measure effects, although this would be very labour intensive, given each patient's injury and management varied, and therefore, any test papers would need to be personalised.

Conclusion

Overall, this study, given the limited sample size, strongly suggests that the use of personalised information leaflets in an OPRC improves patients' perceived understanding of their injury and management plan. Additionally, the information leaflets can be used as a bridge to aid communication between patients and other healthcare professionals in primary care. This seems to be particularly important to patients, as many would prefer more information on discharge.

Practice implications

Development and distribution of personalised patient information leaflets in the OPRC is a relatively simple and low-cost intervention to improve patient understanding and awareness of injuries. Furthermore, through improving patient comprehension of the management plan, other

benefits can follow such as improved adherence with treatment [9] and more appropriate healthcare behaviour [8].

Many areas of clinical practice are utilising a multidisciplinary approach to manage complex patients, with examples in oncology and diabetic foot clinics. The production and distribution of patient specific information leaflets could be a useful tool to inform and educate patients on their conditions, with some thought possibly given to final draft readings by lay persons or even literacy/language specialists. This raised awareness can help patients to have a more active and engaged role in their health care and therefore to improve the quality of care and outcomes.

In the future, it is hoped these leaflets will be provided to open tibial fracture patients on discharge, possibly following earlier active discussion regarding the information, which should ensure the language and terms used are understood and clear to the patient.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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