Title:

An analysis of publicly available National Health Service information leaflets for patients following an upper arm break.

Abstract:

Background

Recovery following an upper arm break can be prolonged and cause loss of independence. Appropriate information provision to empower and enable active participation in rehabilitation is vital to achieve the best clinical outcomes.

Objectives

To identify and analyse, through the lens of health literacy, publicly available information leaflets produced for patients following upper arm breaks in the United Kingdom National Health Service (NHS) to understand their fitness for purpose.

Method

An electronic search of online search engines was undertaken using search terms to identify information leaflets for upper arm breaks. Relevant leaflets were retrieved and a thematic analysis was undertaken from a health literacy perspective. To complement this, each information leaflet was also formally assessed for readability.

Results

Thirty-five information leaflets were analysed. Two main themes were generated: 'Empowerment' and 'Language Use', with subthemes of promoting recovery, readability and risk of misinterpretation. The information presented in these leaflets was often complicated and sometimes contradictory. Less than half (46%) of the information leaflets were presented at a level that would be understood by the general population.

Conclusions

Current information leaflets made available for patients following upper arm breaks are not fit for purpose and are written in a way that the general population would not readily understand. There is an urgent need to understand the information needs of patients and present such information in an accessible way to optimise clinical outcomes following upper arm breaks.

Key words:

Patient information leaflet, upper arm break, proximal humerus fracture, readability

Highlights

- Information leaflets provided following an upper arm break are not fit for purpose
- Improved information provision is needed to optimise clinical outcomes

- Patient involvement in the development of appropriate information is needed

Introduction:

Breaks of the upper arm bone (proximal humeral fractures) are painful and debilitating injuries, accounting for 5-6% of all fractures in adults (Court-Brown & Caesar, 2006). Upper arm breaks are more common in women, with the typical mechanism of injury being a fall from a standing height (Mafi et al., 2014). The incidence increases with age, with the majority of fractures occurring in people aged 65 years and over (Palvanen et al., 2006). Upper arm breaks contribute to disability and loss of independence (Lee et al., 2002; Olerud et al., 2011; Slobogean et al., 2010) and are associated with significant patient mortality and increased utilisation of healthcare resources (Maravic et al., 2014). Recovery from upper arm breaks can be a long and often incomplete process that can be hindered by complications (Handoll et al., 2017), including a higher risk of re-hospitalisation or further fracture (Clinton et al., 2009). Upper arm breaks are either treated surgically or non-surgically.

Rehabilitation is the major component of non-surgical management. Key features of rehabilitation following upper arm breaks are promotion of home exercise and provision of information to assist in carrying out the exercises (Handoll et al., 2015). However, it has been shown that patients immediately forget 40-80% of verbal information provided to them by healthcare practitioners and that almost half of the information retained is incorrect (Haji, 2019; Kessels, 2003). Added to this, the shock and pain involved following a traumatic injury such as an upper arm break may lead to lower levels of information retention. However, research has shown that retention may be improved by up to 50% if text information is also provided (Haji, 2019; Kessels, 2003). This text information is commonly provided as written patient information leaflets.

There have been several studies focusing on the readability of a variety of information leaflets provided for medical procedures, and online physical activity education resources (Gargoum & O'Keeffe, 2014; Thomas & Cardinal, 2018; Williamson & Martin, 2010). These have been concerned with the complexity of words and sentences. Equally important are the comprehensibility (reader's comprehension of the text) and communicative effectiveness (patient's long-term responses to the text) of the information leaflet (Garner et al., 2012), which can lead to effective patient empowerment. Empowerment relates to the ability of a patient to use the information provided to enable them to make informed decisions regarding their health care and to take a proactive approach in their recovery following an injury such as an upper arm break. This empowerment is dependent on accurate and appropriate information being made available to the patient (Garattini & Padula, 2018). Health literacy is an important factor in the reading and understanding of information leaflets. Health literacy has been defined as an individual's ability to "obtain, process and understand basic health information and services needed to make basic health decisions" (Bostock & Steptoe, 2012, p1) and as such, it has significant impact on health outcomes. Much published patient information is of too high a reading ability for the

general public (Garner et al., 2012; Protheroe et al., 2015). If the information provided for patients is only accessible to those with higher health literacy, this may reduce the recovery ability of those with lower levels of health literacy.

Previous research by Handoll et al. (2015) found that information provision regarding sling use to patients following an upper arm break is inadequate, with all centres in their trial lacking written information regarding sling use. Further research is required to establish whether or not the information that is provided to patients following an upper arm break is fit for purpose, which may lead to greater empowerment and improved outcomes for those who have sustained such an injury. The aim of this study is to identify and analyse, through the lens of health literacy, publicly available information leaflets produced for patients following upper arm breaks in the United Kingdom National Health Service (NHS) to understand their fitness for purpose.

Methods

During October 2021, an electronic search of Google, Bing, Yahoo, Duck Duck Go and Ecosia search engines was undertaken for publicly available information leaflets from websites of National Health Service (NHS) Trusts in the United Kingdom (UK). All searches were undertaken by the lead author (PM). Search terms related to upper arm breaks, proximal humerus fractures, NHS, physiotherapy and rehabilitation were used (see supplementary file).

Inclusion criteria

Information leaflets that included detail regarding rehabilitation following an upper arm break were retrieved. For example: the need for immobilisation, method of immobilisation, time to commencement of passive and active exercise, time to return to driving, and time to return to work.

Exclusion criteria

Information leaflets that did not provide any detail about rehabilitation following upper arm breaks were excluded from the study. Information leaflets not from UK NHS Trusts were also excluded. Searching continued until one full search page returned no relevant information leaflets.

Analysis:

Descriptive information was extracted e.g. NHS Trust, location, date of production, length of leaflet (see supplementary file).

The documents identified were analysed using the six stages of thematic analysis as described by Braun & Clarke (2006). Stage 1 involves the initial reading and familiarisation with the data which is followed by stage 2 – preliminary coding. A predominantly inductive approach was used to code the data to reflect the content of the data. However, there was some deductive analysis involved to ensure that the codes contributed to producing themes that were meaningful and relevant to the aim of this study. Braun & Clarke (2012) state that it is impossible to be purely inductive or purely deductive in the coding and analysis of data

in thematic analysis. Stage 3 involved searching for themes among the coded data. In stage 4, the themes were reviewed and refined through discussion and consensus was made between all authors. In stage 5 the themes were defined and named and stage 6 involved producing the report based on the final analysis of the fully worked-out themes. The main author (PM) undertook the initial analysis. The other authors (CL, GY and LC) reviewed a sample of the information leaflets and through critical discussion the main themes were agreed.

Microsoft Word 2010 was used to calculate readability scores using the Flesch Reading Ease and the Flesch-Kincaid Grade Level, which are two of the most common methods of assessing readability (Protheroe et al., 2015). These readability scores have excellent reproducibility, high correlations with other readability scores and have been used in many previous studies (Protheroe et al., 2015; Williamson & Martin, 2010). The information leaflets were copied and pasted into Microsoft Word 2021 and formatted to ensure paragraphs aligned with the original information leaflet. The recommended reading level for medical information is Flesch Kincaid Grade Level 6 and a Flesch Reading Ease score of 60 or more is considered well written and easy to follow (Williamson & Martin, 2010).

Results:

Thirty five information leaflets were found from 35 different NHS Trusts, 32 from England and 3 from Scotland. Twelve of the information leaflets did not report a date of production, while the other 23 ranged from 2010 to 2021, with 14 of those 23 being developed or reviewed since 2019. The volume of information provided in the information leaflets varied greatly, with the length ranging from 2 to 16 pages.

Two main themes were generated: 'Empowerment' and 'Language Use', with subthemes of promoting recovery, readability and risk of misinterpretation.

Table 1. Themes and subthemes generated from the data

Themes	Empowerment	Language use
Subthemes	Promoting recovery	Readability
		Risk of misinterpretation

The Flesch Reading Ease score of the information leaflets ranged from 49.2 to 82.3, with a mean of 68.1. The Flesch Kincaid Grade Level ranged from 4.7 to 10.8 with a mean of 7.1. On the Flesch-Kincaid Grade Level, only 16 (46%) information leaflets were within the recommended reading level of Grade 6 or below.

Theme 1: Empowerment

Promoting recovery

Alleviation of stiffness and promoting recovery through exercise was the main aim of the majority of the information leaflets. Twenty-nine (83%) patient information leaflets (PIL) described exercises and 22 of these included either line drawings or photographs to

accompany the exercises described. The exercise guidance on the information leaflets ranged from no mention of exercises or a brief description of one exercise to a complex 4-stage rehabilitation plan of progressive exercises. The following quotes show the contrast in exercise advice from simple quotes to more detailed instructions.

> *"Pendulum exercises can be started immediately which means moving the arm in small circles when it hangs freely."* (PIL 18)

> *"Each stage of exercises is colour coded. Do not move onto the next stage until your physiotherapist has advised you to, or until the previous stage is feeling comfortable and easy. It is important that you do not push through pain that you would describe as being more than a 5/10. Any pain or discomfort after you have stopped exercising should settle down within 1 hour of you stopping the exercises. If your pain is still worse as a result of the exercises, you could be overdoing them, try moving your shoulder more gently and slowly and consider doing less repetitions [sic]."* (PIL 9)

However, many of the other information leaflets gave very little indication on how much effort to put into the exercises as pain and stiffness were commonly referred to as symptoms to expect. Some information leaflets advised to be guided by pain or not to force the movements.

> *"The following exercises can be done up to four times a day as pain allows. Stop if your pain gets worse."* (PIL 5)

A prognosis following an upper arm break was often provided in the information leaflets. Some information leaflets implied that greatly reduced range of movement and function is inevitable:

> *"The shoulder joint does not respond well to being injured and longstanding stiffness is almost inevitable. Following this type of injury you may never be able to fully lift the arm straight up in the air again."* (PIL 3)

Others stressed that perseverance can help improve health outcomes.

> *"It is also important to remember that you have had a fracture and that your arm will not return to normal immediately. Provided that you exercise and use the arm as much as possible it will improve with time and patience."* (PIL 4)

Most of the information leaflets (33/35, 94%) described the expected symptoms following an upper arm break such as pain, swelling, stiffness and weakness. Most information leaflets advised on what can be done to help alleviate these symptoms, for example, rest, immobilisation, movement, ice.

> *"Pain can be eased by simple analgesics prescribed by your GP or Consultant. The pain that you experience after a fracture may last for at least 6 weeks. Ice or heat may also help reduce your pain. Heat can be applied simply in a bath of hot water or by a hot water bottle/wheat pack wrapped in a towel. Ice may be applied by placing a bag of frozen peas in a damp towel. Either can be applied for 15-20 minutes up to 4 times a day."* (PIL 4)

Across the information leaflets reviewed, some contradictions in advice were evident as highlighted in the following quotes from two information leaflets:

> *"Do not place pillows under your elbow for support as this will encourage bone movement."* (PIL 14)

> *"A more comfortable way to support your arm without the sling is to rest your arm on a pillow/the arm of the sofa."* (PIL 9)

Theme 2: Language Use

Readability

In this study, many of the information leaflets were found to have a high degree of complexity, using language that would not be easily interpreted by the general public.

> *"You have sustained a minimally displaced fracture to your greater tuberosity of your shoulder."* (PIL 21)

Some information leaflets used plain English with medical terms in brackets after.

> *"You have sustained a fracture (break) to your Humerus (upper arm bone)."* (PIL 14)

There were instances of long complex sentences in the information leaflets.

> *"Evidence suggests excellent results have been achieved with short-term immobilisation and early exercise therapy with overall increased participation and activity levels and reduced impairment. Operative management appears to offer no better outcomes at two year follow-up compared to non-operative treatment for adults with displaced 2-part fractures of the proximal humerus."* (PIL 22)

The above extract has a Flesch Reading Ease score of 9.6 and a Flesch-Kincaid Grade level of 16.5, which corresponds to the reading level of a university graduate.

Risk of misinterpretation

A number of information leaflets had aspects of the writing that may risk being misinterpreted by the reader.

> *"Gradually start exercising by rotating your forearm in the sling. Be guided by the level of discomfort you feel."* (PIL 12)

In this case, the instruction to 'rotate your forearm' may be an unclear instruction and may not provoke the intended movement. Being guided by discomfort may result in over or under- activity compared to what is intended by the writer of the information leaflet. This may be interpreted as meaning that discomfort is acceptable or that no discomfort should be felt.

As these information leaflets are all freely available online and may be found using a simple internet search, which is a common way for people to find information, having different

information leaflets with contradictory information may result in misinterpretation by the general public. An example of contraindications in the information leaflets was in relation to the use of a sling as the following quotes illustrate.

> *"Wearing your sling: Use your sling for 6 weeks, including in bed at night. You can take it off to wash, dress and do your exercises. Week 6-12: You can stop using the sling."* (PIL 32)

> *"You do not need to wear the sling – use for comfort only and begin moving your arm as soon as you are able. 0-3 weeks: Try to spend as much time as possible out of a sling."* (PIL 29)

Discussion:

This study investigated the content of 35 publicly available information leaflets that are provided to people following an upper arm break. The information presented in these leaflets was often complicated and sometimes contradictory. Due to this complexity and contradiction, most information leaflets developed for patients following upper arm breaks were regarded as not being fit for purpose.

Most information leaflets were complex in the language they used, with a mean Flesch Reading Ease score of 68.1 (range 49.2-82.3) and median Flesch-Kincaid Grade level 7.1 (range 4.7-10.8). This corresponds to a high level of literacy required which the general public may struggle to read. The Skills for Life Survey (2011) advises that information leaflets should be written at a Flesch-Kincaid Grade Level 6 or below to be accessible to most of the population. Only 16/35 (46%) of the information leaflets reviewed in this study met the recommendation of Flesch-Kincaid Grade Level 6. This means that 54% of the information leaflets are written at a level too complex for 15% of the population of the UK.

Many of the information leaflets included medical jargon which adds to their complexity and further limits their readability. For example, some information leaflets used the word fracture but did not explain this term Many people are aware of what a bone break is but a common misconception is that a break is not the same as a fracture and that a fracture is a more minor injury (Kampa et al., 2006). It is important to clarify aspects of jargon that may be included in information leaflets so that the reader will be able to appropriately understand as the writer intends. The Flesch Reading Ease and Flesch Kincaid Grade Levels are based on sentence length and the number of syllables in a word. They do not take into account how some long words may be more commonly understood than shorter words. A well understood word such as 'television' may have multiple syllables but a less understood word such as 'fracture' has fewer syllables. This may mean that shorter words that are less well understood may have a low readability score but may lead to confusion if the reader doesn't have the technical knowledge to understand these words.

It was apparent that there was no or very limited patient involvement in the development of any of the retrieved information leaflets. In all cases where it was reported, the authors were either specialist physiotherapists or orthopaedic doctors. Due to the information being written from the point of view of the healthcare professionals and not the patients, some information was not clear, for example in the explanations of exercises to perform. Some

information leaflets included diagrams to help with this, but this was not consistent and it is not clear whether this is helpful to patients. Herber et al. (2014) reported that patient groups should be included in all stages of the production of information leaflets to ensure clear communication and to reduce possible negative emotional arousal which may cause 'knee-jerk' reactions provoked by reading anxiety-inducing information.

The complexity of language and of sentence structure found in the information leaflets makes them difficult to read, especially for those of lower health literacy. This may lead to poorer health outcomes for people following an upper arm break. This is a significant problem given increasing social inequality. This corresponds to previous literature where information leaflets have been found to be complex in nature. Protheroe et al., (2015) in their study on information leaflets found that the leaflets provided in general practice were complex and that only 24.3% met the recommended reading-level criteria of Flesch-Kincaid Grade Level 6.

Previous studies have reported that patients may stop reading or discard the information leaflets, especially if they do not have adequate language skills (Herber et al., 2014). As communication is a two way process, the meaning of text may be interpreted in different ways depending on the readers' expectations, understanding, concerns and fears (Garner et al., 2012). Pleasant et al. (2016) have described a way in which the definition of health literacy should be adapted: that is considering the communication skills of the communicator (provider of information), not just the recipient of the information. This can be a challenge with written information as, by its nature, it is not adaptable. When a healthcare professional is speaking directly to a patient, the communication can be adapted as required. (Herber et al., 2014) in their study on patients' emotional reactions and behaviour towards medication leaflets found that one behaviour that was provoked by reading an information leaflet was to seek further information from healthcare professionals or other lay sources. It is possible (especially with the possible risk of misinterpretation with written information) to provide clearer information when direct conversation is utilised in conjunction with written information. Written information can be used to supplement spoken information and may not be a substitute for tailored information provided in consultations with health care providers (Hamrosi et al., 2014; Herber et al., 2014). However, with a written piece of information, the wording needs to be clearly understood by all recipients using short sentences and with any necessary medical terminology being explained adequately.

The words that are used with people in distressing and vulnerable situations can have a significant effect on their recovery and clinical outcome (Stewart & Loftus, 2018). Words have the ability to change the way a person thinks and may influence their behaviour, attitudes and beliefs (Darlow et al., 2013). Words can encourage a positive outlook which in turn may lead to a more positive recovery and outcome (Stewart & Loftus, 2018) but low recovery expectations have been shown to be strongly linked to poor outcome (Benedetti et al., 2007). The nocebo effect is the phenomenon whereby the expectation of a negative outcome may lead to a worsening of symptoms (Benedetti et al., 2007). This nocebo effect with pessimistic language may lead to resignation in thinking that function will not improve following an upper arm break such as the pessimistic views on outcome as described in some of the information leaflets reviewed. Other information leaflets, with a less pessimistic

outlook, may encourage longer term progress as optimism can reduce the negative influence of pain catastrophizing (Coronado et al., 2017).

It is vital to ensure that information leaflets contain sufficient, understandable and reliable information in order to effectively enhance patient care through informed participation and self-determined action (Hirschberg et al., 2013). It is clear that the upper arm break information leaflets in this review do not consider the needs and wants of patients who have sustained these types of injuries. The addition of patient involvement in the production of information leaflets could help to optimise the amount of information provided in order to engage the majority of patients. The benefits of including the lived experience of patients in all stages of the production of the information leaflets has been advocated (Herber et al., 2014; Kennedy et al., 2017).

Strengths and Limitations

Only publicly available information leaflets were included in the study. It is possible that NHS Trusts who publicly present their processes in information leaflets might be different from those who do not. Hence, the described information leaflets might not fully reflect the entire NHS. Out of 152 UK NHS Trusts, only 35 had publicly available information leaflets for patients with an upper arm break. Of the 35 information leaflets found, 12 did not report date of production and only 14 were produced or reviewed within the last two years. Given the lack of production date for 12 of the information leaflets, it is unclear how old they are and to what degree they reflect contemporary practice in the respective NHS Trusts. None of the information leaflets that were publicly available originated in Wales or Northern Ireland, which also does not provide a broad generalisation to current practice within the NHS as a whole. Furthermore, such a review of information leaflets is necessarily limited by the breadth and depth of information reported in the information leaflets and it was apparent that such information was variable.

Although information leaflets are a major source of information for patients, there is also the important aspect of direct information exchange between healthcare professional and patient in face to face discussions within consultations. It is unlikely that patients will rely solely on information leaflets for their information.

Due to the nature of the thematic analysis by the 6 stage method of Braun & Clarke, (2006), it is recognised that the author's perceptions, beliefs and experiences may influence the analysis and interpretation of data. Patient involvement in the analysis stage may have resulted in different themes. As a physiotherapist with an interest in written communication between health care professionals and patients, the author may have a bias towards some aspects of the information leaflets. In order to mitigate this, generated themes were critically reviewed and discussed with the research team and consensus was made between the authors.

Conclusion

Information leaflets are an important part of information provision for patients. This study has shown that there is a great variability in information provided to patients following an upper arm break. It has also highlighted the issue of high complexity and possible risk of

misinterpretation in information leaflets for upper arm breaks. The language used in an information leaflet may either positively or negatively impact patient outcomes. The complexity of the language used and its impact on patient empowerment may have a detrimental effect on patients' recovery following an upper arm break. Patient participation is necessary to ensure that appropriate information is provided to patients following an upper arm break. Despite current evidence that patient participation is beneficial in the compilation of information leaflets, there is no evidence to show that patient perspective has been included in the writing of the information leaflets analysed in this study. Further study, including patients' involvement, is required in order to achieve the optimal information provision to patients who have sustained an upper arm break, which is understandable and meets their requirements.

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