



# Patient information leaflets for extracorporeal shock wave lithotripsy: questionnaire survey

A Askari • I Shergill

Department of Urology, Colchester Hospital University NHS Foundation Trust, Colchester C04 5JL, Essex, UK  
Correspondence to: A. Askari. Email: awaskari@hotmail.com

## DECLARATIONS

### Competing interests

None declared

### Funding

None

### Ethical Approval

Written informed consent was obtained from the patient or next of kin

### Guarantor

Iqbal Shergill

### Contributorship

The authors contributed equally to the work

### Acknowledgements

We thank NHS Trusts in the Greater London and East of England region for their support in providing their respective information leaflets

### Reviewer

Stewart Justman

## Summary

**Objectives** To compare the level of information provided in extracorporeal shock wave lithotripsy (ESWL) patient information leaflets in the London and East of England Deaneries

**Design** All trusts in the London and East of England Deanery who offer an ESWL service were contacted and leaflets were compared

**Setting** London and East of England Deanery

**Participants** Alan Askari, Iqbal Shergill

**Main outcome measures** Examination of key information that was communicated to ESWL patients via leaflets

**Results** 12 trusts responded across the two deaneries. There was significant variation in the amount of information provided in the leaflets with some leaflets not containing an adequate level of instruction or information to patients

**Conclusions** The authors propose that a national standardised information leaflet should be incorporated with the British Association of Urological Surgeons (BAUS) procedure specific information leaflet for ESWL procedures

## Introduction

According to the Department of Health, in order to provide the best level of healthcare, patients should not just be offered appropriate medical advice and procedures, but also be fully informed as to the condition or pathology they are affected by. Easy access to high quality and accurate medical information is paramount.<sup>1</sup> There is also a need for healthcare professionals to communicate effectively with patients. Studies have shown that a combination of both verbal and written information is more successful than purely verbal information in increasing patient

knowledge and satisfaction.<sup>2</sup> Extracorporeal shock wave lithotripsy (ESWL) is a common out-patient procedure performed in many trusts. Whilst it is a non-invasive procedure, it does carry some inherent risks. Whilst there are advice leaflets distributed by the British Association of Urological Surgeons (BAUS),<sup>3</sup> many trusts have their own variation of advice leaflets.

Many trusts across the country offer ESWL in the treatment of stones. A Cochrane Systematic Review in 2009 demonstrated that ESWL was as effective as Retrograde Intrarenal Surgery (RIRS) with the added benefit of shorter hospital stay.<sup>4</sup>

However, although ESWL is a non-invasive procedure, its risks are well documented in the literature<sup>5,6,7,8</sup> and although infrequent, very serious complications such as pancreatitis,<sup>9</sup> pulmonary contusions<sup>10</sup> and renal damage<sup>11</sup> have been reported. It is therefore important for patients to be as well informed as possible regarding their treatment. We evaluated the quality of patient information leaflets for ESWL in the London and East of England Deanery.

## Methods

A total of 32 trusts were contacted across London and East of England Deanery and ESWL leaflets were requested from each Urology unit. A significant proportion of these trusts did not offer ESWL on site, but rather referred their patients to tertiary

centres (particularly in the London region). Three trusts had ESWL leaflets designed by private companies and were unable to release these to us. In total, 12 trusts responded by sending their ESWL patient information leaflets.

Each leaflet was evaluated for a number of checklist items that were deemed to be important to include in any patient information leaflet (Table 1). In the absence of an established checklist for this purpose, several sources were used to derive this checklist. This included: The British Society of Gastroenterology [<http://www.bsg.org.uk>] guidelines<sup>11</sup> for items that should be included in any information sheet, originally developed for patients undergoing upper gastrointestinal endoscopic procedures; a similar study in the Urology literature investigating flexible cystoscopy information leaflets,<sup>12</sup> as well as procedure specific leaflets released by BAUS,<sup>3</sup> American Urological Association and European Association of Urology<sup>13</sup>

The items in the checklist included a variety of information points based on logistics (i.e. location and directions to facility site), explanation (including diagrams) of procedure, possible complications and contraindications to procedure, post-procedure advice and post-procedure care. Additionally, the leaflets were evaluated for diagrams to clarify the procedure and the anatomy, and sources of additional information, such as reference to published articles or patient support groups/internet websites.

## Results

Out of the 12 leaflets examined (Table 2), all (100%) had a clear description of the procedure as well as appropriate contact numbers for patients. However, none had directions to the location of the facility where the procedure was to be performed. The majority of the leaflets provided information about the preparation prior to the procedure (92%), analgesia (92%) and instructions for follow-up arrangements (75%).

Complications such as risk of infection, haematuria, haematoma, steinstrasse, renal atrophy or damage were explained in varying frequency (33–92%), however, none of the leaflets examined explained that there is a risk of possible urinary retention, visceral injury (pulmonary contusion,

**Table 1**  
Important items/topics that should be included in patient advice leaflets.

Checklist Item
Directions to the location of ESWL
Contact numbers for queries or concerns before or after the procedure
Information about preparation prior to procedure
Information about regular medication
Anticoagulants
Diagrams to clarify the anatomy
Diagrams to clarify the procedure
Clear description of the procedure
Instructions for follow-up arrangements
Analgesia mentioned?
Sources of additional information
Risk of infection
Risk of haematuria
Risk of urinary retention
Haematoma (perinephric, subcapsular, intranephric)
Steinstrasse
Renal atrophy/damage
Hypertension
Diabetes (pancreatic damage)
Pulmonary contusion
Pancreatitis
Splenic haematoma
Hepatic dysfunction (LFTs abnormal)
Biliary colic
Check pacemaker
Pregnancy
Urine dipstick (infection is a contraindication)

**Table 2**  
**Results of leaflets surveyed**

<i>Checklist Item</i>	<i>Number of Trusts Leaflets</i>	<i>Percentage of Leaflets (n = 12)</i>
Directions to the location of ESWL	0	0%
Contact numbers for queries or concerns before or after the procedure	12	100%
Information about preparation prior to procedure	11	92%
Information about regular medication	7	58%
Anticoagulants	7	58%
Diagrams to clarify the anatomy	3	25%
Diagrams to clarify the procedure	6	50%
Clear description of the procedure	12	100%
Instructions for follow-up arrangements	9	75%
Analgesia mentioned?	11	92%
Sources of additional information	5	42%
Risk of infection	9	75%
Risk of haematuria	11	92%
Risk of urinary retention	0	0%
Haematoma (perinephric, subcapsular, intranephric)	9	75%
Steinstrasse	5	42%
Renal atrophy/damage	4	33%
Hypertension	1	8%
Diabetes (pancreatic damage)	0	0%
Pulmonary contusion	0	0%
Pancreatitis	0	0%
Splenic haematoma	0	0%
Hepatic dysfunction (LFTs abnormal)	0	0%
Biliary colic	0	0%
Check pacemaker	5	42%
Pregnancy	3	25%
Urine dipstick (infection is a contraindication)	1	8%

pancreatitis, splenic haematoma, hepatic injury), and hypertension post-procedure. Diagrams of anatomy and the procedure were provided in less than half of the leaflets (25–50%).

Certain leaflets did mention relative contraindications to ESWL such as pacemakers, pregnancy, positive urine dipstick for infection and pre-existing anticoagulants (8–58%). Sources of additional information (websites, publications etc.) were only mentioned in only 42% of the leaflets.

## Discussion

The aim of this study was to evaluate the quality of the information leaflets distributed to patients undergoing ESWL. The main finding is that the leaflets vary significantly in the quality of the

information they provide, with some leaflets providing only a minimal amount of information. Whilst some of the leaflets contain most of the information, not a single leaflet provided all the information highlighted in the checklist (Table 1).

None of the leaflets gave information as to where the procedure was being held and where to report to. Whilst this may have been discussed in clinic or on previous encounters with the patient, a brief explanation would be helpful, especially since many trusts referred patients to other hospitals to undergo the procedure. However, all leaflets did provide several contact information numbers and nearly half referred patients to other literature for more information and advice. There was also a good mention of preparation required prior to the procedure and what

the procedure actually involved. Analgesia was mentioned in all leaflets and this may be of some reassurance to patients. Very few leaflets gave advice on regular medications taken by the patient.

With regards to possible complications of the procedure itself, none of the leaflets mentioned all the common or uncommon side effects of the procedure. Haematuria (92%), haematoma (75%) and infection (75%) were widely reported as possible complications. Steinstrasse and renal damage, were mentioned in less than half of the leaflets (42% and 33% respectively). More serious, albeit rare complications such as pancreatitis, pulmonary contusion and splenic injury were not mentioned in any of the leaflets. Hypertension was mentioned in only one leaflet. This omission of rare but potentially life threatening injury has serious consequences, both in terms of patient wellbeing, patient choice and anxiety. There are also medico-legal ramifications in omitting these potential complications from advice leaflets, but importantly, it should be understood that unless it is made clear that complications, especially serious ones, are rare events, a list of them may actually result in more anxiety to patients.

There was also very little information available for pregnant women or patients with pacemakers undergoing ESWL with only 25% mentioning pregnancy and 42% mentioning cardiac pacemakers. Where mentioned, there was only a brief explanation of the contraindication to ESWL, but no suggestion of possible alternative therapies in these circumstances. Two leaflets did mention the possibility of alternative therapy options, in general terms, but did not go into detail to explain the different modalities or the efficacies of such treatment.

Less than half of the leaflets employed photographs or diagrams to explain the anatomy or the procedure involved. When provided however, all diagrams were labelled and clear. Some leaflets provided anatomical diagrams demonstrating the site of calculi, but did not provide diagrams/photos of the ESWL machine. Diagrams can be a useful way of understanding the anatomy of the pathology and give the patient a good idea of what to expect during the procedure, potentially reducing anxiety and uncertainty. In all cases the diagrams adhered to Department of Health guidelines i.e. illustrations should be simple to understand, clearly written and any label should not be overwritten.<sup>14</sup>

Whilst all leaflets supplied alternate sources of information for the patients, only two leaflets referenced the source(s) of information used to compile the publication.

The results from this survey suggest that there is a great degree of variability in the information contained in ESWL patient advice leaflets within the London and Eastern Deanery, with some leaflets giving minimal information. There may be even greater variability if this survey was to be extended to encompass a wider geographic area or even nationally. We recommend that a standardized national leaflet that incorporates current clinical evidence and BAUS, AUA and EAU recommendations would be beneficial in supplying patients with appropriate information and possibly helping to allay anxiety and uncertainty during ESWL treatment. Such a leaflet should be standardized nationally and subject to audit.

## References

- 1 Department of Health. Better information, better choices, better health: Putting information at the centre of health. See [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4098576](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4098576) (last accessed 20 March 2012).
- 2 Johnson A, Sandford J, Tyndall J. Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database of Systematic Reviews* 2003;**S1:4**
- 3 British Association of Urological Surgeons. Shockwave Lithotripsy for Stones - Procedure Specific Information. See <http://www.baus.org.uk/Resources/BAUS/Documents/PDF%20Documents/Patient%20information/ESWL.pdf> (last accessed 30 March 2012).
- 4 Srisubat A, Potisat S, Lojanapiwat B, et al. Shock wave lithotripsy (ESWL) versus percutaneous nephrolithotomy (PCNL) or retrograde intrarenal surgery (RIRS) for kidney stones. *Cochrane Database of Systematic Reviews* 2009;**S1:4**.
- 5 Madbouly K, Sheir KZ, Elsobky E, et al. Risk factors for the formation of a steinstrasse after extracorporeal shock wave lithotripsy: a statistical model. *Journal of Urology* 2002;**167:3**
- 6 Segura JW, Preminger GM, Assimos DG, et al. Nephrolithiasis Clinical Guidelines Panel summary report on the management of staghorn calculi. The American Urological Association Nephrolithiasis Clinical Guidelines Panel. *Journal of Urology* 1994;**151:6**
- 7 Fujita K, Mizuno T, Ushiyama T, et al. Factors for pyelonephritis after extracorporeal shock wave lithotripsy. *International Journal of Urology*, 2000;**7:6**
- 8 Evans AP, Willis LR. ESWL: Complications. In: Smith A, Badlani G, Bagley D, eds. *Smith's Textbook of Endourology*. Hamilton, Ontario: Wiley-Blackwell Publishers, 2007, 598–610.
- 9 Hassan I, Zietlow SP. Acute pancreatitis after extracorporeal shock wave lithotripsy for a renal calculus. *Urology* 2002;**60:6**

- 10 Samkaoui MA, Ziadi A, Harifi G, *et al.* Severe pulmonary contusion after extracorporeal shock wave lithotripsy: *Annales Françaises d'Anesthésie et de Réanimation* 2009;28:3
- 11 British Society of Gastroenterology. Guidelines for Informed Consent for Endoscopic Procedures. See [http://www.bsg.org.uk/attachments/217\\_consent.pdf](http://www.bsg.org.uk/attachments/217_consent.pdf) (last accessed 25 March 2012)
- 12 Shah J, Sill S. Evaluation of information leaflets for flexible cystoscopy. *Clinical Governance: An International Journal* 2007;12:38–41.
- 13 American Urological Association and European Association of Urology. Guideline for the Management of Ureteric Calculi. See <http://www.auanet.org/content/clinical-practice-guidelines/clinical-guidelines/main-reports/uretc07/appendices.pdf> (last accessed 20 March 2012)
- 14 National Health Service. NHS Brand Guidelines. See <http://www.nhsidentity.nhs.uk/tools-and-resources/patient-information/templates> (last accessed 23 January 2012).

© 2012 Royal Society of Medicine Press

This is an open-access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by-nc/2.0/>), which permits non-commercial use, distribution and reproduction in any medium, provided the original work is properly cited.