The treatment of interstitial cystitis has many uncertainties, including which treatment is the most effective. Interstitial cystitis is a chronic inflammatory bladder disease that mostly affects women. It can present as recurrent non-bacterial cystitis or as chronic pelvic pain associated with frequency and urgency. It can take up to five years and five doctors to reach the correct diagnosis.5 Patients with interstitial cystitis are not a homogeneous population. Two distinct types of disease—classic and non-ulcer interstitial cystitis—have been described on the basis of pathological findings, and some treatments might work better for one type than for the other.4 Currently no treatment ladder exists. Oral treatments should be first line and intravesical therapies second line.

Interstitial cystitis can be a debilitating disease and has been described in the United States as a major health problem.5 The prevalence ranges from 5 per 100 000 women in Japan to 197 per 100 000 women and 41 per 100 000 men in the US.5,4 We have no prevalence estimates for the United Kingdom.

Because interstitial cystitis is a distinct pathologic entity, a biopsy can provide definitive diagnosis.5,6 However, criteria from the US National Institute of Diabetes and Digestive and Kidney Diseases, which required cystoscopy and bladder distension, need no longer be used.6 Instead, validated questionnaires like the O’Leary-Sant symptom index and the University of Wisconsin symptom index are now used to diagnose this condition and measure response to treatment.7,8

In addition, the International Continence Society now recommends the term interstitial cystitis/painful bladder syndrome to describe all cases of urinary pain that cannot be attributed to other causes, such as infection or urinary stones. Interstitial cystitis is used alone when describing cases that meet criteria of the US National Institute of Diabetes and Digestive and Kidney Diseases.

Patients with interstitial cystitis vary greatly in type and severity of symptoms, and the symptoms overlap with those of painful bladder syndrome and many other clinical entities. A recent systematic review of symptoms showed that interstitial cystitis and painful bladder syndrome share a similar cluster of symptoms, such as pelvic and bladder pain, urinary frequency, urgency, and nocturia.8,9 Hence a bladder biopsy is needed to confirm interstitial cystitis when a case of interstitial cystitis/painful bladder syndrome has been distinguished from recurrent urinary tract infections (by urine culture), overactive bladder, vulvodynia, chronic urethral syndrome, and endometriosis.

What is the evidence of uncertainty?

Interstitial cystitis currently has no standard treatment. One large study recorded 183 different treatments, and just under half of the women received a combination of two or more treatments.10

Randomised studies of drugs used for this condition have produced conflicting results. For example, a recent study of oral pentosan polysulfate sodium (Elmiron), a mucosal surface protectant, found that global improvement was similar to that for placebo after 24 weeks’ treatment,2 whereas a meta-analysis of four earlier studies showed that it was superior to placebo in relief of pain, urgency, and frequency, but not nocturia, after 12 weeks’ treatment.1 One study of 300 mg, 600 mg, and 900 mg of pentosan polysulfate sodium showed no difference in clinical response after 32 weeks of treatment.12 In another study, oral ciclosporin A, an immunosuppressant, was superior to oral pentosan polysulfate sodium in global symptom response after 24 weeks’ treatment.1 Uncertainty therefore exists regarding this commonly used oral treatment.

Results for oral L-arginine, a substrate for nitric oxide synthetase, are also conflicting. One study showed superior global improvement after 12 weeks compared with placebo,5 whereas another showed no superiority over placebo.6 Similarly, one study of intravesical BCG showed benefit7 and another showed no superiority over placebo.8

Amitriptyline, a tricyclic antidepressant, improved symptom scores more than placebo after 16 weeks’ treatment, although anticholinergic side effects were significantly worse.9

Current randomised evidence on intravesical resiniferatoxin,10 a vanilloid receptor agonist which desensitises C fibres that transmit pain; intravesical pentosan polysulfate sodium;11 and sequential oral antibiotics12 show no significant benefit over placebo in global symptom response after three months’ treatment.

No randomised studies exist for oral cimetidine in interstitial cystitis, although it has been shown to be
superior to placebo in patients with painful bladder disease.13

Bladder irrigation with dimethyl sulfoxide, an anti-inflammatory analgesic, was superior to placebo in subjective and objective measures after eight weeks’ treatment.14 This drug was also superior to intravesical BCG in a head to head drug trial.1 However, treatment with dimethyl sulfoxide is still uncertain. The evidence of benefit comes from two small trials of 53 subjects with a mean age of 48 years and a mean duration of symptoms of 5.5 years. These benefits cannot be generalised to all patients without larger trials or systematic reviews.

As a result of these uncertainties, the range of treatments offered to patients differs worldwide. For example, in the US, oral pentosan polysulfate sodium is used extensively, whereas dimethyl sulfoxide is more widely used in the Netherlands.w11 In the UK, the range of treatments is wide but drugs of “proven” efficacy were given to fewer than a third of patients.w12

Is ongoing research likely to provide relevant evidence? A phase III study of the efficacy and safety of amitriptyline in painful bladder syndrome is still recruiting in North America.15 The balance between benefits and adverse effects after 26 weeks’ treatment should become clearer. Another randomised study is evaluating the effectiveness of acupuncture in alleviating symptoms of interstitial cystitis/painful bladder syndrome, between 12 and 24 weeks of treatment.13

Although a Cochrane protocol for intravesical treatment of interstitial cystitis is available,w14 a separate systematic review of oral treatments is needed. This should examine the evidence of efficacy of oral treatments versus placebo, one oral treatment against another, oral treatment versus other modes of treatment such as dietary and lifestyle changes, and oral treatment combined with another form of treatment versus the other treatment alone.

What should we do in the light of the uncertainty? Patients and clinicians should understand the limitations of the evidence for current treatments and set realistic treatment goals. Before a diagnosis of interstitial cystitis is made, patients who report that their symptoms are triggered or exacerbated by certain foods or drinks might be advised to avoid them, although the evidence for avoidance was weakened by reporting bias.w13 Oral or intravesical treatments that produce modest benefit in some patients should be considered in sequence or combination, because no single treatment is likely to improve interstitial cystitis in all patients.

With this level of uncertainty, and until further evidence becomes available, a clinician faced with a patient with interstitial cystitis should consider offering six doses of intravesical dimethyl sulfoxide over three months. Apart from the transient garlic smell in some patients, and a report of eosinophilic cystitis,w16 the safety of dimethyl sulfoxide is established, and it is an effective early treatment for interstitial cystitis.w17-w19


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PRACTICE

PRACTICE POINTER

How to webcast lectures and conferences

Mark A Westwood,  Andrew S Flett,  Phil Riding,  James C Moon

This article describes how doctors with little previous experience have approached the recording and online broadcasting of talks and conferences.

Being unable to attend a key talk or conference can be frustrating. But it is now technically straightforward, with computer software, for anyone to record presentations as a movie for permanent access on the internet. Such recordings can act as an invaluable library and learning resource long after the event is over. They greatly increase the potential reach of a message, aiding medical education, research, and the originators—think YouTube for medicine—as well as potentially reducing the relative carbon footprint and cost of medical education.

The software required is widely available and cheap—even free—and the only additional kit needed is a digital dictaphone with a microphone. Distribution of the recorded talks on the internet is also cheap and increasingly simple, and may be supported by the local hospital or university’s information technology department. In this article, we share our experience of recording 10 conferences in our field—cardiovascular magnetic resonance—ranging from a single local lecture to a large international conference with 1000 delegates, and resulting in an online library of 100 lectures. Although technically straightforward, the process still requires thought and consideration, and a cautious approach for the initial rollout. This guide should point individuals and organisations considering web casting in the right direction to get started.

Webcasting

We prepare for webcasting (broadcasting on the internet) in four stages: planning, recording, producing, and uploading (figure). Webcasting has two forms: a live video feed broadcast in real time from the conference, or video on demand. Sometimes entire conferences are webcast live. The on demand approach is most beneficial, because it is easiest and creates a permanently available lecture.

Recording

What to record

“Screencapture” software unobtrusively records the speaker’s computer screen and speech. The audio and visual recordings are then combined into one file that can be webcast. We screencapture live PowerPoint presentations (including speaker’s mouse movements and embedded movies) and record the audio separately, using either the auditorium sound system or a digital dictaphone and microphone on the podium. For medical talks, video recording a talking head and locating it on the slides as a “picture-in-picture” does not seem worth while—a photo of the speaker in the online index suffices. We do not record informal sessions such as discussions (owing to lack of permission from participants), question and answer sessions, interactive case presentations, patient identifiable data, and new unpublished data.

Amateur versus professional recording

New technologies have made the recording process increasingly easy for amateurs. Professionals bring advantages, but can be expensive. At larger conferences, we have found that a hybrid approach works well: professionals record the audio and presentations, and a non-professional team produces and uploads the movies.

Capture software

Several screencapture software options are available, many of them free (for example, Wink http://www.debugmode.com/winkand Camstudio http://camstudio.org). Presentation programs such as PowerPoint (PC) and Keynote (Mac) include recording solutions as standard. However, when recording several sequential presentations, we recommend using screencapture software with a PowerPoint plug-in. In this case, the presentation is started from software embedded in PowerPoint with a screencapture toolbar. The slides and presentation run as usual, but simultaneously all

What we did

Initially, we (three medical doctors) worked together with the venue’s audiovisual team, who were paid to record the audio and run the presentation computers using Camtasia. A pre-conference workshop helped iron out problems. We recorded two rooms for three days, aiming to record 53 talks. We produced movies each evening, adding audio and optimising for webcasting. Three speakers declined permission, and five talks had to be re-created (one to embargo slides with new data, two where recording was omitted in error, and two for Mac presentations). Back-up audio was used for one talk. The total recording cost was about 1% of the total income from registration for the conference. Since then, we have recorded seven more conferences.
slides, movies, mouse movements, and audio are recorded as a movie for subsequent webcasting (table).

Many screencapture software companies offer hosting options (for example, screencast.com—prices range from free to $100 per year). This solution is worth considering if you are new to the process. Companies often seamlessly upload presentations from the software to the servers, and provide you with a URL (the link to the video) that you can place on your website. They can also offer technical support.

**Planning**

Proposal to record and practice

We wanted to record the Society for Cardiovascular Magnetic Resonance annual meetings as an educational resource. As a proof of principle, we recorded several in house meetings (using the free trial version of the software) before our first national meeting and used these recordings to create a proposal and budget to submit to the organising committee. We recorded a mixture of cutting edge scientific sessions and basic educational sessions, starting with a pre-conference session to iron out problems. Practice and local experience gave us the confidence that we could record at a large conference in an unfamiliar venue. We liaised with the society’s website team and decided to host the recordings directly on the website rather than uploading them to a specialist company.

**Speaker permissions**

It is easiest to seek permission to record and webcast from speakers prospectively at the time of invitation. Reassure speakers that only a movie of the slides is broadcast, rather than the actual slides themselves. We also add the conference logo in production as a watermark. Speakers can be asked to provide a short summary of the talk and a photo of themselves to aid online indexing.

Speakers should be asked to bring their presentations with the expectation of them being run from a central computer rather than from their own laptop. Find out if they are using Mac presentations, which will have to be converted to PowerPoint and run separately on an audience laptop (PowerPoint loads Mac Keynote presentations, but movies need to be converted from QuickTime).

**Webcasting—the process**

Slides including data from publications should be correctly referenced and are generally acceptable, if the recording is educational and not for profit. In a manner similar to an open access online journal, we leave copyright residing with the speaker. Patient identifiable information should not be presented—if such data are included, informed consent should be obtained exactly as it would be for publication.

For speakers with new data, speakers should not present more data than they would place in a conference abstract, otherwise final publication could be threatened by a claim of duplicate publication. If such concerns are raised, alternatives include not recording the talk, deleting slides (and audio) with novel data, or embargoing the whole talk for a period.

**Onsite initial setup**

Communicate with the conference centre’s audiovisual team in advance. Although the software is reliable, you may decide not to put it on the venue’s computer, to avoid being blamed if talks go wrong. As an alternative, we often put a team member in the audience with a copy of the speaker’s PowerPoint presentation on a laptop, screencapturing by cloning the speaker’s slide-advances and mouse movements. This method is robust and cannot affect the main presentation, but is more labour intensive than recording from the venue’s computer.

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**Screencast software with PowerPoint plug-ins**

<table>
<thead>
<tr>
<th>Software</th>
<th>Pros</th>
<th>Cons</th>
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<tbody>
<tr>
<td>TechSmith Camtasia—www.techsmith.com</td>
<td>Market leaders, reliable, the most production options, fully functioning 30 day downloadable trial*</td>
<td>$299, slow learning curve</td>
</tr>
<tr>
<td>ViewletCam—www.qarbon.com</td>
<td>Good user interface, 30 day trial version available</td>
<td>$179, limited set of features</td>
</tr>
<tr>
<td>BB Flashback—www.bbsoftware.com</td>
<td>Good editing features</td>
<td>$225, limited output and compression options</td>
</tr>
<tr>
<td>Adobe Captivate—www.adobe.com</td>
<td>Easy to use, powerful features, highly rated, exceptionally slick interface and production</td>
<td>$699</td>
</tr>
</tbody>
</table>

*The software we used.
We prefer to add the audio track during production. If necessary, using the speaker’s slides and room audio, you can re-create talks afterwards (perhaps using blank slides where new data were presented) by re-running the presentation, changing slides in sync with the audio. Even if the venue’s audiovisual team are recording the audio, a backup option is worth while in case of technical faults or missed recordings. A USB handheld digital recorder with 256 megabytes or more of memory and a lapel condenser microphone (we use Olympus WS-311M digital voice recorders with ME15 tieclip microphones, total cost less than £80) can record a whole day’s talks: place on the podium, turn on at the beginning of the day, lock the buttons (to prevent accidental stoppage), and collect at the end of the day. Batteries should be changed every day, whether they are running low or not.

Conference day
If possible, get used to the venue by recording a pre-conference workshop or satellite symposium. A low profile team of two people per room is ideal. Distribute pre-arranged planning documents and file names and get details of last minute changes in speakers. Try to identify potential computer problems in advance. Generally, be wary of using the very latest software. Ensure computers are set up for recording—check the software is loaded, screen resolution is not too high (1024 x 768), and PC hardware acceleration is low (using display properties, settings, advanced, troubleshoot; in Windows XP, not Vista). Check that antivirus software is working and up to date.

Producing
Audio can be added to the visual recording during production, although if you have recorded the audio with the screencapture software, this step may not be necessary. Production also allows optimisation of files for the internet so that streaming is fast and smooth. We aim for a file size of 1 megabyte per minute of talk. For speakers using many embedded movies (for example, at imaging conferences), we produce at a resolution of 320 x 240 pixels; but use higher resolution (800 x 600) for other talks. Options for optimisation of bandwidth—the amount of data being transmitted and received by the host to the viewer—include reducing mono-audio quality (don’t set this too low if clarity is an issue, for example with speakers using a second language), colour quality (16 bit instead of 32 bit), and frame rate (for example to 5 frames per second). We add other optional features, including a table of contents and a watermark or copyright statement, at this stage.

Uploading
The produced talks need to be stored somewhere that they can be accessed easily and quickly. This service is provided by web hosts (probably the same company that hosts your website, or you may use a specific web host for this purpose). Uploading—the process of sending your files to the host—is straightforward, particularly if you are using the screencapture software company for web hosting, as the software often has tools to make uploading seamless. Basically, talks are saved on to the web server and a specific link to each is placed on your website, allowing them to be opened. We email speakers and invite them to review their talks before general release. Once the talks are available on the website, we add a paragraph of introduction from the conference organiser (and acknowledgment to the recording team). We then delete any of the presenters’ original PowerPoint files from our computers.

If you have recorded a large conference for the first time, let web traffic grow gradually by not immediately advertising the recordings, to avoid large spikes of demand, which could slow your website down if it is hosted on a shared rather than dedicated server. If all goes well the implications may be large, so be prepared to change and rescale future plans and consider making the previous year’s talks available to non-members.

Contributors: The authors—all UK based cardiologists without remarkable pre-existing internet skills—have successfully captured, produced, and uploaded about 100 key presentations from local and international conferences including the 2008 annual Society of Cardiovascular Magnetic Resonance conference in Los Angeles and EuroCMR 2008 in Lisbon. These recordings are now freely available online for members of the society at www.scmr.org. JCM is guarantor. JCM and MAW took part in the conception, design, drafting, and final approval of the manuscript, ASF and PR took part in design, drafting, and final approval. Conflicting interests: None declared. Provenance and peer review: Not commissioned, externally peer reviewed.
**LESSON OF THE WEEK**

**Life saving treatment for a “palliative care” patient**

Jane Gibbins, Gaye Senior Smith, Karen Forbes

A “palliative care” label should not prevent life saving treatment for an illness with reversible cause

The word palliative is used in different ways in different contexts. Lack of clarity about its meaning can lead to confusion about the role of palliative care teams and the appropriateness of active management in a patient’s care.

**Case report**

A 60 year old woman was diagnosed with a rare haemangioendothelioma of the lung with liver, bone, and lung metastases in April 2004. She was referred to the outpatient clinic run by our specialist hospital palliative care team in December 2006 by her respiratory physician. Although she was extremely independent, she had severe right upper quadrant pain, which was consistent with liver capsular distension secondary to liver metastases. She had tried non-steroidal anti-inflammatory drugs and steroids with no effect. Her pain responded to opioids. Her morphine was increased, and pain was controlled by 550 mg modified release morphine twice daily, with no opioid side effects.

She remained stable with no changes in her medication. In June 2007 she was admitted to hospital with a two week history of severe diarrhoea (10 to 15 times a day) and vomiting. On examination her Glasgow coma score was 12/15, and both her arms and legs were twitching. She was confused, hallucinating, and dehydrated and had a temperature of 36.6°C. She was tachycardic (pulse 130 beats per minute) with a blood pressure of 117/86 mm Hg.

The working diagnosis was acute renal failure secondary to prolonged diarrhoea and vomiting (and possible sepsis) leading to accumulation of morphine metabolites, which are renally excreted. Investigations confirmed a creatinine of 281 umol/l, urea 28.1 mmol/l, potassium 6.2 mmol/l, haemoglobin 111 g/l, albumin 18 g/l, C reactive protein 112 mg/l and raised white cell count 39.6×10⁹ with a severe neutrophilia. She was screened for infection and treated with intravenous hydration. Broad spectrum intravenous antibiotics were started for a possible urinary tract infection and her morphine dose was reduced to a third of the usual dose she had every 24 hours.

The next day, the patient became increasingly agitated and the specialist hospital palliative care team was asked to review her for symptom control. The medical team was managing her actively on the ward but felt that high dependency or intensive care unit support was not appropriate because she was a “palliative care patient.” At this stage a “do not attempt resuscitation” order in the event of a cardiac arrest was agreed.

The patient had severe myoclonic jerks and was frightened and agitated secondary to visual hallucinations, consistent with opioid toxicity. After discussion with the medical team, oral morphine was stopped and substituted by fentanyl given subcutaneously for pain as needed because it lacks renally excreted metabolites, with haloperidol for hallucinations and agitation.

Despite rehydration the patient’s urine output remained poor and her renal function deteriorated further (creatinine 474 umol/l, urea 37.5 mmol/l). Her white cell count and inflammatory markers had, however, fallen (C reactive protein 37 mg/l). This woman’s acute renal failure was due to benign reversible causes, and although she had lung and liver metastases, she had a slowly progressive tumour and had been well until this admission. We therefore discussed the role of haemofiltration to remove morphine metabolites.

The patient was transferred to the intensive care unit and received haemofiltration. Five days later, her renal function had returned to normal and she was transferred to a medical ward. After a short period of rehabilitation, she was discharged home. She remains well.

**Discussion**

**WHO definition of palliative care**

The most recent World Health Organization definition describes palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems; physical, psychological and spiritual.” No reference to life expectancy is made—the definition encompasses the care of patients with a spectrum of illnesses and prognoses.

**Use of the word palliative**

The word palliative has different meanings within the phrases “palliative treatment” and “palliative care.” Many patients and healthcare professionals still associate palliative care with care in the last few days or weeks of life only. As the WHO definition indicates,
this is not the case. A woman with advanced breast cancer could have a prognosis of more than a decade while being treated with palliative intent; patients in their last days of life should receive good palliative care; treatment options for both would be different. The term palliative care does not mean care given only to patients who will die soon.

The palliative care label
In this patient, the label of palliative care was double edged. Because of its association with care at the end of life, it suggested that initial treatment should not be escalated beyond management in the ward. It did, however, prompt a request for the hospital palliative care team to review the patient, which led to the (perhaps unexpected) suggestion that more aggressive, life prolonging treatment was appropriate. Patients with a palliative care label develop medical emergencies, such as sepsicaemia after chemotherapy, hypercalcaemia, or spinal cord compression. Dedicated, skilled clinicians may question the worth of treating in these situations, or they may continue inappropriately with active management, perhaps finding it difficult to accept that the patient might be dying. Decision making around whether such emergencies should or should not be treated is challenging for all healthcare professionals. It demands clarity about the patient’s prognosis and treatment aims so that a balance between the possible burdens of aggressive active treatment and the benefits of maintained or improved quality of life, or prolonged survival, can be sought.

Patients with advanced non-malignant disease, such as heart failure, chronic obstructive pulmonary disease, or end stage renal failure can also be given a palliative care label. As with our patient, however, active intervention may be appropriate for quality or length of life, or both. Open discussions with patients and their families are needed to explore their understanding and expectations and to allow advance care planning because patients’ preferences may differ from those of their healthcare professionals.

Perceptions of palliative care; the evidence
Hospital colleagues’ understanding of the roles and responsibilities of specialist palliative care teams is poor, and which specialties will refer to a hospital palliative care team can vary. A recent qualitative study of doctors and nurses working in acute trusts showed that few recognised the role of palliative care teams in managing the symptoms and other needs of patients with chronic illnesses other than cancer, and most perceived palliative care as a means of limiting life sustaining treatment or allowing death.

Conclusion
Despite advanced metastatic cancer and a palliative care label, this patient benefited from management in intensive care to reverse acute renal failure that had resulted in an acute deterioration due to opioid toxicity. This case shows that healthcare professionals must be clear about the prognosis and treatment aims for all patients, particularly patients who are receiving palliative care, to avoid “therapeutic nihilism” for those who have a reasonable prognosis even though they have an incurable disease. Undergraduate medical education in palliative care should mean that tomorrow’s doctors have a clearer understanding about what palliative care does and doesn’t mean.

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Trial registration: advice to authors
In accordance with the International Committee of Medical Journals Editors (ICMJE) uniform requirements for manuscripts submitted to biomedical journals, the BMJ will not consider reports of clinical trials unless they were registered prospectively before recruitment of any participants. This applies to trials that started after 1 July 2003; for older trials, retrospective registration will be acceptable, but only if completed before submission of the manuscript to the journal.

Eligible trials have been defined by ICMJE since 1 July 2008 as “where human participants are prospectively assigned to one or more health-related interventions [including health services and behavioural interventions] to evaluate the effects on health outcomes”; before that, they were defined more narrowly as trials “where human participants are prospectively assigned to investigate the cause and effect relationship between a medical intervention and health outcome.”

The BMJ’s criteria for a suitable public trial registry are: free to access, searchable, and identifies trials with a unique number; registration is free or has minimal cost; registered information is validated; registered entry includes details to identify the trial and investigator and includes the status of the trial; and the research question, methodology, intervention, funding, and sponsorship must all be disclosed at registration.

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