Receiving A Diagnosis Of Mesothelioma (RADIO Meso): Improving the patient experience.

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National Lung Cancer Forum for Nurses Conference: Building hope in challenging times

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Background

- Communicating a diagnosis of mesothelioma is complex and highly skilled\(^1\).
- If done badly, ‘it can cause long lasting distress, confusion and resentment’\(^2,3\).
- There is a lack of evidence on how best to communicate a diagnosis of mesothelioma\(^4\).

Aim: To identify ways to improve the patient and family carer experience of receiving a diagnosis of mesothelioma by generating evidence based recommendations for practice.
Methods

- **Qualitative semi-structured interviews**
  - Patient and family carers (N=15)
  - Health care professionals (N=16)

- **Focus groups**
  - Patient and carers (N=27)
  - Mesothelioma Nurse Specialists (N=15)

  - Framework analysis\(^5\) to interpret the data and identify themes.

- **Consultation** on the draft recommendations
  - All participants
  - All BTOG members
  - All Mesothelioma UK members (electronic newsletter, website, Facebook, Twitter).
Recommendations: 10 top tips for communicating a diagnosis of mesothelioma

Launched at the International Mesothelioma Interest Group (iMIG) conference 2018, Canada.
Recommendation 1

Provide consistency and continuity in terms of who the patient sees and what is said.

- Diagnosis can be confirmed at a specific appointment or on a ward.
- Process of diagnosis.
- Follow up appointments.
- Role of the Clinical Nurse Specialist.
Recommendation 2

Involve the Clinical Nurse Specialist throughout, starting as early as possible in the diagnostic pathway.

- Anticipate communication needs.
- CNS can manage communication between MDT members and patient/family.
- Local systems need to be in place to ensure the CNS is informed as soon as a diagnosis is suspected.
Recommendation 3

Ensure that staff involved in communicating a diagnosis of mesothelioma have specialist knowledge and training.

“I’ve done the communications course, the advanced communication course. I did that in my previous role .... they still run them here periodically but they only allow you to go on it if you’ve never had communication training advanced. I feel that all...the refresher would probably be good”. (LCNS)
Recommendation 4

Be patient-centred when communicating a diagnosis. Take cues from the patient and family in balancing what information to give and when.

- Assessing what people know already.
- Taking cues from body language.
- Gauging people’s responses to information.
- Avoid the temptation to ‘go through everything’ if this is not appropriate.
- A relationship centred approach is important.
Recommendation 5

Ensure the patient feels they have been allocated sufficient time.

“I felt that there was a lot more that could have been done at that initial time .... you’re really left to go away and wait for an appointment. Certainly [I would have liked] a longer appointment”. (patient)

“They were very, very good. Time was no object, really, to them, if they could fit it in, and they’d answer all my questions”. (family carer)
Recommendation 6

Provide a quiet and private environment to facilitate communication.

“We were in this little tiny room and it was quite hot and the surgeon and the nurse left the room, as far as I recall, and we were left on our own looking at each other thinking what happens next” (patient)
Recommendation 7

Make the patient feel like the most important person in the room, and at the centre of the communication process.

If the patient feels that they are the most important person in the room, they are more likely to access on-going support and information to meet their needs across the diagnostic pathway.

‘Although it was devastating, it was actually told to us very well’ (patient)
Recommendation 8

Be direct and honest whilst maintaining hope where possible.

“She didn’t say ‘you’ve got this and that’s it’. She said ‘you’ve got this and this is the options, from radical surgery, there is chemotherapy ... So even though it was disastrous news in many respects, she gave us a list of things that, you know, like there was a plan around what would happen, as opposed to ‘you’ve got a terminal illness’ and that’s it. You know, there was a plan.” (family carer)
Recommendation 9

Use available expertise and resources. No single clinician should carry the responsibility of communicating a diagnosis on their own.

- Best practice is often from partnership working.

- Refer to practitioners and services as appropriate in order to use the expertise of others. For example, Asbestos Advisory Services/Groups and palliative care and counselling services.

- Use the resources available from specialist organisations to ensure up to date and good quality, accessible information and support. Examples include the information resources and telephone helpline developed and delivered by Mesothelioma UK.
Recommendation 10

Prepare and plan as a team before communicating a diagnosis of mesothelioma.

Patient:
1. Involve the CNS asap.
2. Check patient’s understanding – do not assume they understand.
3. Be aware of the family and social context.
4. If appropriate, ring the patient before the diagnostic clinic appointment.
5. Give a ‘warning shot’
6. Establish a clear plan with patient and family.

Team:
1. Discuss at MDT meeting and agree treatment options prior to confirming diagnosis with patient.
2. Have all the facts in front of you.
3. Source appropriate information resources to give to the patient.
4. Plan how to manage the communication of a diagnosis with colleague(s).
Recommendations: 10 top tips for communicating a diagnosis of mesothelioma

- Aspirational
- Actionable
- Apply to all episodes of breaking bad news.

Links below:
- https://www.sheffield.ac.uk/snm/research/radiomeso
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Thank you for listening.
References

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