Person-centred communication & cancer care

Peter Martin
Professor of Clinical Communication & End of Life Care
Overview: why, deconstruction, policy & practice

Peter Martin

Diverse ways to teach healthcare communication

Meg Chiswell

A broader view of person-centred healthcare; beyond just communication skills

Matthew Links

Beyond just the patient; involving the family

Ilona Juraskova
Context

Why is the time right?
Clinical Communications

The Clinical Communications program works within key areas of clinical communication known to influence quality and safety outcomes throughout the patient journey.

The program currently focuses on two main streams of work:

- Clinical Handover, and
- Patient-Clinician Communication

Clinical Communications plays a vital role in several aspects of quality and safety in healthcare. This work is integrated into other Commission programs, such as, Open Disclosure, Electronic Discharge Summaries, Accreditation, Shared Decision Making and Health Literacy.

Clinical Communications will continue to evolve in future years. The Commission is committed to addressing other high risk areas of communication as the need arises.

Popular publications

- ONSIE Guide to Clinical Handover Improvement
- Clinical Handover and Patient Safety – Literature Review Report
Discussion

Consensus statement on an updated core communication curriculum for UK undergraduate medical education

Lorraine M. Noble*, Wesley Scott-Smith†, Bernadette O’Neill‡, Helen Salisbury§, On behalf of the UK Council of Clinical Communication in Undergraduate Medical Education

*UCL Medical School, University College London, London, UK
†Division of Medical Education, Brighton & Sussex Medical School, Brighton, UK
‡School of Medical Education, King’s College London, London, UK
§Deakin University Department of Primary Care Health Sciences, University of Oxford, Oxford, UK
PROF DEVELOPMENT
MINIMISING UNWANTED VARIATION
Deconstructing what we see
WHAT OUTCOMES ARE IMPACTED BY HEALTHCARE COMMUNICATION?
OUTLINE OF OUTCOMES DIRECTLY RELATED TO HC

- Shared Decision Making
  - Why do repeated studies show that Drs consume less health resources
- Communicating Risk
- Diagnostic Accuracy
- Person-Centred Healthcare
- Patient & Carer Experience
- Adjustment to illness
  - Psychological burden in response to illness
- Aiding recall
  - Audio recordings of consultations
- Adherence to treatment
  - Think of the waste in regards to our precious health $
- Lifestyle modification
  - Lifestyle related chronic illness and concepts of motivational interviewing
    - In general our skills are poor for such a key skill
  - Actual disease outcomes
WHICH KEY SKILLS IMPROVE TIME EFFICIENCY?
TIME EFFICIENCY

**Building rapport**

Spotting and responding to cues (verbal and non-verbal)

Early shared / negotiated agenda setting

---

**Relationship, Communication, and Efficiency in the Medical Encounter**

Creating a Clinical Model From a Literature Review

Larry B. Maukoch, MEd; David C. Dugdale, MD; Sherry Dodson, MLS; Ronald Epstein, MD

**Results:** Three domains emerged that may enhance communication efficiency: rapport building, up-front agenda setting, and acknowledging social or emotional clues.

**Conclusions:** Building on these findings, we offer a model blending the quality-enhancing and time management features of selected communication and relationship skills. There is a need for additional research about communication skills that enhance quality and efficiency.

*Arch Intern Med.* 2008;168(13):1387-1395
Eliciting the Patient’s Agenda—Secondary Analysis of Recorded Clinical Encounters

Naykky Singh Ospina, MD, MSc1,2, Kari A. Phillips, MD3, Rene Rodriguez-Gutierrez, MD, MSc2,4,5, Ana Castaneda-Guardeñas, MD6, Michael R. Gionfriddo, Pharm D, PhD7, Megan E. Branda, MSc8,9, and Victor M. Montori, MD MSc2

**KEY RESULTS:** Clinicians elicited the patient’s agenda in 40 of 112 (36%) encounters. Agendas were elicited more often in primary care (30/61 encounters, 49%) than in specialty care (10/51 encounters, 20%); p = .058. Shared decision-making tools did not affect the likelihood of eliciting the patient’s agenda (34 vs. 37% in encounters with and without these tools; p = .09). In 27 of the 40 (67%) encounters in which clinicians elicited patient concerns, the clinician interrupted the patient after a median of 11 seconds (interquartile range 7–22; range 3 to 234 s). Uninterrupted patients took a median of 6 s (interquartile range 3–19; range 2 to 108 s) to state their concern.

**CONCLUSIONS:** Clinicians seldom elicit the patient’s agenda; when they do, they interrupt patients sooner than previously reported. Physicians in specialty care elicited the patient’s agenda less often compared to physicians in primary care. Failure to elicit the patient’s agenda reduces the chance that clinicians will orient the priorities of a clinical encounter toward specific aspects that matter to each patient.
What

Intervention Outline
Core vs. Flexible
Figure: GoM and VAleus documentation over time in a tertiary ICU

Values and GoM documented for ICU patients with an LLI

- ICU training
- ICU program
- Target >80%
- e-GOM form
- Hospital baseline

Graph showing the percentage of LLI patients over time with GoM and Values, with data points indicating trends and improvements.
Your Thoughts Matter

Full 8 day training process to become Faculty/facilitators. Recommended threshold of 25 staff.

Participate in full day workshop.

Consumer/patient input – driving the training focus and context of the evidence-based workshops
Thank you from us:
peter.martin@deakin.edu.au

**OCPH**
CENTRE FOR ORGANISATIONAL CHANGE IN PERSON-CENTRED HEALTHCARE

www.ocph.deakin.edu.au
Education and training approaches to support effective person-centred communication.

Megan Chiswell, Cancer Council Victoria

megan.chiswell@cancervic.org.au
Twitter: @meg_chiswell
Communication...

- Participation in healthy lifestyle behaviours
- Engagement in screening, and follow-up
- Deal with diagnosis, life threatening illness
- Make decisions about treatment
- Participation in clinical trials
- Transition to survivorship
- End of life care
Objectives of communication....

In teaching communication…..

Core clinical skills…..

• Effective **listening** and open history taking
• Picking up and responding to **cues**
• Discovering the patient’s **ideas** and **concerns**
• Effective **non-verbal communication**
• Demonstrating **empathy**
• Lack of inappropriate **jargon**
• **Giving** and **gathering** information
• Empowering patients to ask **questions**

Considering…

Structure:  
*where am I and what do I want to achieve?*

Specific skills:  
*how do I get there?*

Phrasing or behaviour:  
*how can I incorporate these skills into my own style and personality?*
Learning for behavior change

- Effective feedback
  - Observation of behaviours (video)
  - Repeat practise
  - Improving communication skills
  - Small group or individual learning
  - Reflection (repeat)
Frameworks

- McWhinney et al. (1984)
- Health professionals must elicit (content task) both
  - Biomedical history
  - Patient experience of their illness
- Content, process, clinical reasoning
- Where is my focus?
THE ENHANCED CALGARY-CAMBRIDGE GUIDE TO THE MEDICAL INTERVIEW

Academic Medicine 78(8):802-809

THE BASIC FRAMEWORK

- Initiating the Session
- Gathering information
- Physical Examination
- Explanation and planning
- Closing the Session
- Providing Structure
- Building the relationship
THE EXPANDED FRAMEWORK

Initiating the Session
- preparation
- establishing initial rapport
- identifying the reason(s) for the consultation

Gathering information
- exploration of the patient’s problems to discover the:
  - biomedical perspective
  - patient’s perspective
  - background information - context

Physical examination

Explanation and planning
- providing the correct amount and type of information
- aiding accurate recall and understanding
- achieving a shared understanding; incorporating the patient’s illness framework
- planning; shared decision making

Closing the Session
- ensuring appropriate point of closure
- forward planning

Building the relationship
- using appropriate non-verbal behaviour
- developing rapport
- involving the patient

Providing Structure
- making organisation overt
- attending to flow
In your workplace in the last week?

• Raise your hand if you have taught or provided feedback on a clinical task, procedure?

• Raise your hand if you have taught or provided feedback on a communication?
How to teach....

Facilitator centred
- Reading, lectures, group exercised

Learner centred
- Skills spotting, workshops, discussion exercised
- Role play, feedback

Didactic – interest, knowledge, frameworks

Experiential, reflection, discussion, deeper understanding

Experiential – leading to action/behaviour change

Knowing

Doing
Pair activity

What are the characteristics of effective feedback?
Effective feedback

- Centred around goals and objectives (self-assessment)
- Descriptive – based on observation
- Non-judgemental
- Balanced
- Timely
- Specific
- Actionable – area of defined focus
- Considered and well intentioned
At the end of this session....

Commitment to change.....

• One commitment you are going to make to change your own behaviour to make your communication in healthcare more effective.

• One commitment you are going to make to share your learning with colleagues so that they may benefit, and contribute to effective communication in healthcare.

• #commitmenttchange #2018WCC #healthcomm #CancerCongress
Compassionate Communication

Matthew Links
Director of Clinical Training Gold Coast University Hospital
Professor of Medical Education Griffith University
On Behalf of Gold Coast Compassionate Communication

@cancersolutions
Constructing Communication

Clinical Skill/Competency
• Behaviourist
• Reductionist
• Standarisable
• Sellable
Constructing Communication

Clinical Skill/Competency
• Behaviourist
• Reductionist
• Standarisable
• Sellable

Exchange/Relationship
• Constructivist
• Holistic
• Creative
• Difficult to “commodify”
Communication Training—How

Characteristics of skills training
• Uni-directional
• Simulation
• Emotion acknowledged
• Relationship is acknowledged
• empowerment

Characteristics of relationship training
• Multi-Dimensional
• Feedback
• Emotion is central
• Relationship is central
• empowerment
Communication - Who
A Compassionate Pause
Mindfulness is a way of “Being”

Practice > Skill
Attentiveness to the other
Attentiveness to self
Integrates with Conversations around Self care
Compassion is relational connected to empathy. Clinical benefits are appropriate to action-oriented conversations.
Loving Kindness Meditation

Commit to Act

Compassion Self

Compassion Other

Take a deep breath
Brief Interventions
Translating into Practice

• Committing
• Remembering
• Monitoring
• Evaluating
Skilful communication

• Who as well as how

• A compassionate pause is a simple evidence based intervention
  • Focus attention
  • Bring our compassionate self
  • Act with compassion

• Implementation
  • Commitment
  • Remembering
  • Monitoring and evaluation


What will you try?
Tweet you commitment to
#compassionate_pause
#2018WCC
linksmj@protonmail.com
Facilitating effective FAMILY engagement

A/Prof. Ilona Juraskova

Centre for Medical Psychology and Evidence-based Decision-making (CeMPED)
School of Psychology, The University of Sydney, Australia
There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.
In the consultation.....

• Until recently, focus mainly on doctor-patient interactions

• **But there is often another person (or persons) present**...

• Family attend most cancer consultations with an adult patient (63-86%)

• Little known about family involvement in cancer consultations

‘Family’ = those related to the patient biologically, legally, or emotionally
Self reflection

Please take a moment to reflect on your own attitudes towards family carers of patients

Refer to handout to complete the reflection activities

When I think about my experiences with family carers:

- Negative experiences dominate
- Positive experiences dominate

[Diagram showing a scale with an X in the middle, indicating a neutral position]
The influence of culture

• Our research program/guidelines have been developed in Australia, where legal/ethical focus is on:
  • Patient autonomy / individual informed consent
  • Family is often considered as a "support" to patients

• Guidelines have been developed to encourage family engagement while still complying with Australian law/guidelines

• In other countries/cultures
  • Family may be more central to provision of care
  • Clinicians may be more open to family’s ‘control’ over medical preferences
What is the general approach to a patient’s family in your country?
Review

Physician-patient-family: A systematic review

R.C. Laidsaar-Powell1,2,*, P.K.J. McCaffery2, H.L. Shemwell3

1Centre for Medical Psychology and Evidence-Based Decision-making (COMPEED), St Hilda’s Hospital, The University of Sydney, Sydney, NSW, Australia.
2Department of Clinical Psychology and Evidence-Based Decision-making (COMPEED), School of Psychology, The University of Sydney, Sydney, N.S.W., Australia.
3Department of Community Medicine, The University of Sydney, Sydney, NSW, Australia.

Oncologists’ and oncology patients towards family involvement

K. Laidsaar-Powell1,2,*, R.D. Butow3, A. Fisher1, I. Juraskova1

1Centre for Medical Psychology and Evidence-Based Decision-making (COMPEED), St Hilda’s Hospital, The University of Sydney, Sydney, NSW, Australia.
2Department of Clinical Psychology and Evidence-Based Decision-making (COMPEED), School of Psychology, The University of Sydney, Sydney, N.S.W., Australia.

Medical decision making

Family involvement in cancer treatment: A qualitative study of patients, family experiences

Rebekah Laidsaar-Powell1,2,*, Phyllis Butow3, Alana Fisher1, Ilona Juraskova1

1Centre for Medical Psychology and Evidence-Based Decision-making (COMPEED), St Hilda’s Hospital, The University of Sydney, Sydney, NSW, Australia.
2Department of Clinical Psychology and Evidence-Based Decision-making (COMPEED), School of Psychology, The University of Sydney, Sydney, N.S.W., Australia.
3Department of Community Medicine, The University of Sydney, Sydney, NSW, Australia.
Snapshot of what we found

Oncologists and nurses qualitative study (n=21)
- Family are an important resource and part of multidisciplinary team
- But... challenges (conflicting treatment wishes, anger, dominance, non-disclosure requests)

Patient (n=30) and family (n=34) qualitative study
- Most appreciated family involvement- particularly info. support
- Some family members perceived as too dominant- most patients wanted family support/partnership
- Patients appreciated when clinicians included the family
- Many family members were deferent the doctor- self-censored, not wanting to waste Dr’s time
- Appreciated clinicians communication and connection
Snapshot of what we found

Consultation interaction analyses of 72 oncology consultations involving patient & family

- Range of family roles - providing information, asking questions, discussing decision, advocating for patient
- Few oncologists initiated communication with family
- When family caregivers initiated discussion, most clinicians were responsive
- However... several family caregivers asked permission to speak and many were passive throughout
“Very often the surgeon would answer my husband’s questions by looking at me... I don’t think he completely appreciated that the past 18 months was a mutual thing.

Yes, I was a patient who had the surgery, the chemo... but it affected him almost as much as it affected me. And I don’t think [the surgeon] quite got that, so he wasn’t all that open to bringing [husband] into the conversation...

I would’ve been happier if he had been more open to seeing [husband] as someone who was going through this as much as me, and showing more compassion towards him.”
What do you find (or believe could be) most challenging when interacting with family carers?
TRIO Guidelines

Communicating with family carers:

Practical evidence-based strategies for oncology health professionals
Aims of the TRIO Guidelines

- To develop evidence based, practical guidelines for clinicians communicating with family in consultations to:
  1. Facilitate effective and positive family involvement
  2. Manage challenging/complex family interactions
- To evaluate the strategies using Delphi consensus process with 35 academic/clinical experts (2 rounds to reach >70% consensus)
- To transform strategies into practical clinician skill-based training for clinicians and online education platform for patients and family carers
Guidelines to facilitate **effective** family involvement

<table>
<thead>
<tr>
<th>Guideline TOPIC area</th>
<th>No. of strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider and facilitate practices that are inclusive of family caregivers in inpatient and outpatient <strong>settings</strong></td>
<td>1</td>
</tr>
<tr>
<td>Welcome family caregivers <strong>attendance</strong></td>
<td>3</td>
</tr>
<tr>
<td>Build <strong>rapport</strong> with and show <strong>respect</strong> to family caregivers</td>
<td>2</td>
</tr>
<tr>
<td>Engage in careful <strong>communication of information</strong> when family are involved</td>
<td>4</td>
</tr>
<tr>
<td>Be observant of the patient &amp; family <strong>relationship</strong></td>
<td>4</td>
</tr>
<tr>
<td>Meet family caregivers’ emotional and informational <strong>needs</strong></td>
<td>6</td>
</tr>
</tbody>
</table>
Guidelines for **challenging, complex consultations**

<table>
<thead>
<tr>
<th>Guideline TOPIC area</th>
<th>No. of strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Dealing with <strong>a large number of family members</strong> attending the consultation</td>
<td>3</td>
</tr>
<tr>
<td>• Managing family requests for <strong>non-disclosure of information</strong> to the patient</td>
<td>4</td>
</tr>
<tr>
<td>• Dealing with <strong>family acting as interpreters</strong> for patients with limited English</td>
<td>3</td>
</tr>
<tr>
<td>proficiency and/or severe hearing impairments</td>
<td></td>
</tr>
<tr>
<td>• Dealing with conflicting patient-family <strong>treatment preferences</strong></td>
<td>6</td>
</tr>
<tr>
<td>• Managing <strong>dominant, controlling, or coercive</strong> family caregivers</td>
<td>4</td>
</tr>
<tr>
<td>• Dealing with <strong>aggressive</strong> family caregivers</td>
<td>4</td>
</tr>
<tr>
<td>• Dealing with <strong>family conflict, dysfunction, or abuse</strong></td>
<td>4</td>
</tr>
</tbody>
</table>
The TRIO Guidelines

Communicating with Family Carers
Practical evidence-based strategies for oncology health professionals

Review article
Facilitating collaborative and effective family involvement in the cancer setting: Guidelines for clinicians (TRIO Guidelines-1)
Rebekah Laidsaar-Powell\textsuperscript{a,}\textsuperscript{,}, Phyllis Butow\textsuperscript{a}, Frances Boyle\textsuperscript{b}, Ilona Juraskova\textsuperscript{a}

Review article
Managing challenging interactions with family caregivers in the cancer setting: Guidelines for clinicians (TRIO Guidelines-2)
Rebekah Laidsaar-Powell\textsuperscript{a,}\textsuperscript{,}, Phyllis Butow\textsuperscript{a}, Frances Boyle\textsuperscript{b}, Ilona Juraskova\textsuperscript{a}
The **TRIO** short films

- 8 short films
- Cover variety of TRIO Guideline topics
- Early stage and advanced cancer
- Designed to be relevant to **doctors** and **nurses**
- Reflective exercises incorporated
Example of TRIO strategies and TRIO training

Conflicting patient-family treatment preferences
Conflicting patient-family treatment preferences

- Angela & husband Richard
- Advanced breast cancer diagnosis
- Treatment  
  Currently: IV chemotherapy, significant side effects, good tumour response
  Proposed: Oral chemotherapy, fewer side effects

ANGELA

Preference: change to oral chemotherapy (Capcitabine), ‘sick of feeling sick’

RICHARD

Preference: stay on IV chemotherapy (GemCarbo)
Conflicting patient-family treatment preferences

- Explore patient and family member **understanding** of situation and their **concerns**
- With empathy, **explore emotions** behind the views of the patient and FM

“Now that we have clarified everyone’s understanding, I’d like to hear more about your concerns regarding [decision]. [Patient] what are your main concerns about [decision]… [Family carer], can you tell us more about your concerns?”

“This is a difficult decision, and it has a big impact on both of you. I think it would be helpful if we spoke more about the reasons why you would prefer [decision], and how you are feeling about it. Patient, perhaps you could talk first, then [family carer].”
Managing conflicting patient-family treatment preferences
WHAT WOULD YOU DO NEXT?
Conflicting patient-family treatment preferences

- Attempt to **find shared values and common ground** between patient and FM

  “It seems that you both want to be happy as a family and enjoy life together, but [patient] wants quality of life and [family carer] wants more time”.

- Attempt to **negotiate a mutually acceptable path** for patient and FM

- If consensus not achievable, **respect patients wishes** without being dismissive of family

- If consensus not achievable, **allow time** for the patient and family to **process the decision** at home

  “This [decision] doesn’t have to be made today. Do you want to think on this more, talk at home, and we can meet again next week?”
e-TRIO: Implementing the TRIO strategies (in progress)
eTRIO RCT: AIMS

• To translate the TRIO guidelines & videos into two online education training modules:
  1) e-TRIO for NURSES and ONCOLOGISTS
  2) e-TRIO-pc for PATIENTS and CARERS

• Test the effectiveness of both modules in:
  • Increasing family involvement in consultations
  • Improving confidence in communication with family carers
  • Improving psychological wellbeing for patients & carers
PART 1: The Importance of Family Carers
1.4 Who should be involved in a patient’s care?
2% COMPLETE

Putting together a “core” caregiving team

It may be beneficial to map out who will be involved in providing care for the patient. A diagram, like the example below, can help you visualise your loved one’s caregiving team.

Example: Lucy’s caregiving team
Lucy has been diagnosed with breast cancer. She is divorced with two adult children.

<table>
<thead>
<tr>
<th>Primary carer/main support program</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Andrew (son)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Close support people</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Harriet (Sister)</td>
</tr>
<tr>
<td>3 Zoe (Daughter)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other and friends who can offer support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Nieces &amp; Nephews</td>
</tr>
<tr>
<td>2 Neighbour</td>
</tr>
<tr>
<td>3 Colleagues</td>
</tr>
<tr>
<td>4 Tennis club</td>
</tr>
</tbody>
</table>
e-TRIO clinician module
Family carers …’invisible backbone of the healthcare system’

- Family are an underserved population with high unmet informational and emotional needs, low support, poor psychological & physical wellbeing

Ultimate aims of the TRIO program

- Develop sustainable, accessible education for clinicians, patients, and carers
- Foster greater recognition of and respect for family
- Help clinicians manage stressful family interactions
- Empower family carers to be effective care providers and advocates for patient safety and quality healthcare
- Shift healthcare to “patient and family centred care”
Thank you and Acknowledgements

Dr Rebekah Laidsaar-Powell
Prof Phyllis Butow

Consumers
Julie Claessens
John Stubbs

Research assistants
Rachael Keast
Stella Bu

Collaborators and co-investigators
Prof Fran Boyle
Prof Amiram Gafni
Prof Vikki Entwistle
Prof Judy Kay

Email: ilona.juraskova@sydney.edu.au
Family meetings in cancer care: Practical steps

- Preparing for the meeting:
  - Get the patient’s permission to arrange a family meeting and find out if they have any concerns they’d like discussed.
  - Gather information on the family members who will be attending the meeting
  - Select a suitable facilitator from the meeting
  - Determine which health professionals should attend, based on the patient/family’s needs
  - Book a private space at a mutually acceptable time
Family meetings in cancer care: Practical steps (cont.)

- **Conducting the meeting:**
  - Have introductions and establish how the meeting will work
  - Confirm the purpose of the family meeting and find out if the patient/family has any other concerns they’d like discussed.
  - Determine the patient/family’s understanding of issues and provide information/additional resources as required
  - Check throughout the meeting as to whether the patient/family feel their concerns are being addressed
  - If necessary, offer referral to members of the MDT
  - Conclude by summarising any decisions made and clarifying the plan for moving forward