A PATIENT-CENTERED APPROACH TO MEDICAL TERMINOLOGY IN WRITTEN HEALTH COMMUNICATION:

EXAMINING THE EVIDENCE AND CONSIDERING THE CONSEQUENCES

Antoinette Fage-Butler
&
Matilde Nisbeth Jensen

Department of Business Communication
School of Business and Social Sciences
Aarhus University
Denmark
OVERVIEW: THEORETICAL

Theoretical frameworks for our research:

a) The overarching health communication paradigm for our research of patient centeredness ➔ in written health texts (Fage-Butler, 2011, 2013)

b) Lay-friendliness in medical translation (Nisbeth Jensen & Zethsen, 2012; Nisbeth Jensen, 2013)

c) Terminology (Fage-Butler & Nisbeth Jensen, forthcoming)
OVERVIEW: EMPIRICAL

Sites of our research:

a) Patient information leaflets
b) Email use in patient-doctor communication
c) Written communication in a palliative healthcare setting
d) Online patient forums
1. PATIENT CENTEREDNESS

- Recognized aspects of patient centeredness:
  - Intended for the clinical setting...
  - The patient is a person (Balint, 1969)
  - Patient’s needs and perspectives are central
  - Doctor-patient collaboration
  - Doctor not just a “mechanic” of the body

- Advantages:
  - It can improve experience of healthcare for the patient
  - It can help to avoid dangerous healthcare situations (benefits everyone)
  - Lead to better job satisfaction
  - Ethical – intrinsically (deontologically) right
PATIENT CENTEREDNESS FOR TEXTS (FAGE-BUTLER 2011, 2013)

› Texts can also acknowledge the human implications of diagnosis, treatment, prognosis

› Texts can reflect and integrate patients’ needs and their perspectives

› Texts can be “patient-friendly” in their style (language, font, layout)
2. MAKING THE LANGUAGE SUIT – MEETING PATIENTS’ NEEDS
LAY-FRIENDLINES IN TRANSLATION

› Patient Information Leaflets (PILs)
  › Available in all EU languages
  › Legally must be easy to understand for patients (European Parliament, 2001) = lay-friendly
  › Danish PILs translated from English are more linguistically complex than their source texts (Askehave & Zethsen, 2002)

› Why are translations more complex? (Askehave & Zethsen, 2002)
  › Quality checks based on accuracy criteria
  › Linguistic differences between English and Danish medical register
  › Many PILs are translated by pharmacists
TRANSLATORS VS. PHARMACISTS

Mixed-methods study (Nisbeth Jensen, 2013)

STUDY 1
Contrastive textual analysis
54 PILs - EN-DA (27-27)

STUDY 2
Focus groups with PIL translators (2)
Pharmacists & Professional translators
RESULTS (1)

› Translation competence plays a role (Nisbeth Jensen & Zethsen, 2012)
  › Pharmacist corpus: significantly more medical terms transferred
    › ST: XX is recommended for women who have had their menopause
    › TT: XX anbefales til kvinder efter menopausen
    › Explanation: Lay Danish: overgangsalderen [transition age]

› P-Katja: My point of departure is to make the language more expert term-based. I think that is probably the easiest to handle when it becomes more expert term-based instead of being...it becomes too much like a novel.

› Curse of expertise (Hinds 1999):
  › inkontinens and akne
RESULTS (2)

- Contextual constraints play a major role (Nisbeth Jensen, 2013)
  - Status of the source text as the authorized text
    - T-Lone: “that version is authorized so you can’t change it”

- Lack of transparency (flexibility) for translators

- Expertise and power
  - Translator not allowed to be expert
    - T-Jonas: “some doctors have said that it is called like that”
3. TERMINOLOGY: POSITIONING AND PRINCIPLES

With a focus on context and communication (Cabré, 2000), parole (Temmerman, 2000), pragmatics and discourse (Cabré, 2010)

Terminology and the opaque relationship between words and knowledge as possessed (e.g. Temmerman, 2000; Engberg, 2003, 2010). Terminology gives (only) an impression of what patients know (Sarangi, 2001—lay expertise or expert laity?).
BACKGROUND FOR PRESENT STUDY

› Medical terminology should be avoided when communicating with patients (Dahm, 2012; Groves & Fitzgerald, 2010)

› Patients deemed to struggle to understand medical terms (Bromme, Jucks, & Wagner, 2005; Bromme, Rambow, & Nückles, 2001; Koch-Weser, Dejong & Rudd, 2009)

› Fage-Butler & Nisbeth Jensen (2013): Patient-patient communication in online patient forum:
  › Use of biomedical terms and acronyms
  › No “translation” or simplification or clarification for even newly diagnosed patients

› Terminology and empowerment: E-patient – “Knowledge is power. [...] I know the terminology and the options.” (Ferguson, 2007, p. 15)
PILOT STUDY

Nature of data:
- Online patient forum
- A patient commences a thread by posting a comment, question or story - other members reply
- Unmoderated

Pilot study:
- One thread from an online thyroid patient forum
- General discussion area (but due to have thyroidectomy)
- 45 replies
- 9 different contributors
- Various levels of experience: 16 to 17,253 posts
TERMS IN OUR PRESENT STUDY

1) **Dictionary-defined medical terms** (Latin/Greek based words, as well as non Latin-Greek based words): ablation, autoimmune, biopsied, collar bone, hematoma, lymph nodes, metabolism, papillary carcinoma thyroid cancer, paratracheal lymph nodes, prognosis, surgeon

2) **Context-defined medical terms** (require context to become medical terms): drain, monitoring, procedure, removal, replacement, shots, staples, suppress, test, uptake

3) **Medical acronyms**: RAI, T-3, T-4, TSH, U/S

4) **Medication brand names**: Cytomel; Synthroid; Thyrogen

5) **Colloquial technical terms**: endo, frees, hypo, hyper, meds, path (report)
COMMENTS ON FINDINGS

1) Dictionary-defined medical terms
2) Context-defined biomedical terms
3) Medical acronyms
4) Medication brand names
5) Colloquial technical terms

• These categories reveal the kinds of terms that patients are familiar with and use:
  e.g. *paratracheal lymph nodes, uptake, RAI, hyper, Cytomel*
• Used in the communicative situation without glossing, assuming other patients’ knowledge
• “Colloquial technical terms” – abbreviated terms, not in dictionary. This is a new category of term in relation to existing literature.
DISCUSSION

› Terms are defined as features of the *discourse of avowed professional experts*, BUT:
  › A less sender-oriented definition of terms is more appropriate
  › Patients are colonizing the language of biomedical experts (Fage-Butler & Anesa, in review; Fage-Butler & Nisbeth Jensen, 2013).

› Patient centeredness, patient empowerment, and health literacy:
  › When to use patient-centered terms depends on the audience (mass, group, individual)
  › Patients empower themselves and each other using terms
  › Patients are becoming health literate in X
AREAS FOR FURTHER STUDY

› Follow-up study using a larger, broader data-set:
  › Other chronic types
  › Chronic vs. acute
  › Focus on prolific contributors - the “expert patients” on online forums

› Problems of under- and overshooting in relation to terminology and health literacy. Challenges for best practice in health communication practice....
REFERENCES


REFERENCES (CONT'D.)

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Thank you for your attention!

Antoinette Fage-Butler
fage-butler@asb.dk

Matilde Nisbeth Jensen
matnj@asb.dk