Developing a protocol for reporting chronic exposure to environmental contaminants

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Outline

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Introduction

- **Changing risk profiles**
  - Environmental contaminants
  - Chronic diseases
- **Previous studies**
  - Oujé-bougoumou / Nemaska, Nunavik
- **Multi-community environmental health study**
  - Mistissini pilot
- **Need results reporting protocol**
  - Community expectations
  - Consent form
  - Political context

Objectives

- Improve patient understanding of results
- Prevent unnecessary anxiety & depression
- Empower individuals and communities
- Avoid additional burden on clinical services

Methods

- **Initial exploratory phase**
  - Consultation with key informants
- **Protocol development phase**
  - Literature reviews, expert consensus panel
- **Protocol testing phase**
  - Consultation with end users
- **Use and evaluation phase**
  - Interviews with patients and staff

Results – exploratory phase

- **Protocol welcomed**
  - promote communication
  - standardize information
  - minimize areas of uncertainty
  - facilitate clinical work
  - ensure accountability
- **Challenges ahead**
  - Cultural and language issues
  - Logistical and workforce issues
  - Evidence base limited – non-acute, non-occupational

Results – development phase I

- **Define roles and responsibilities**
  - Responsibility of researchers vs clinicians vs PH
- **Determine which tests to report and how**
  - 40 laboratory and 10 clinical tests performed
  - Every participant can discuss results in person with MD
    - Category A – notified in person (e.g. BP)
    - Category B – notified by phone (e.g. holter)
    - Category C – notified by hand-delivered letter (e.g. lab tests)
      - Biochemistry (glucose, lipid profile, OGTT, thyroid studies)
      - Contaminants (Cadmium, Lead, Mercury, PCBs)
    - Category D – group reporting only (e.g. research purposes)

Results – development phase II

- **Develop clinical algorithms**
  - For contaminants only
    - Only existed for chronic exposure to lead (Nunavik)
    - Needed to be developed for cadmium, mercury, PCBs
- **Generate educational messages**
  - Coherence with previous messages
    - Mercury “fish map”
  - Simple but sufficiently directive, respect traditions
    - Pregnant women and children should not eat walleye or pike

Results – testing phase

- Lengthy iterative process
  - **Research team**
    - Timeline for test availability, expert responsible for results
  - **Clinicians**
    - Reinforce need for clear algorithms, or “won’t happen”
  - **Clinical support staff**
    - Share the workload, reinforce “COMMON MESSAGE”
  - **Community representatives**
    - Culturally acceptable (format of letter simple, not “scary”)
    - Feasible (patients may not be available if “in the bush”)

Results – evaluation phase

- **To be carried out by evaluation rep**
- **Key element of the process, necessary to:**
  - Give stakeholders a voice
  - Determine what worked or didn’t work
  - Raise fundamental concerns about the research
  - Improve the research protocol as well as the results reporting protocol for next year
    - “perennial document”

Conclusions

- **Protocol itself important**
  - Ethical imperative in reporting results
  - Maximize likelihood of successful outcomes
- **Protocol development process important**
  - Raises fundamental issues about the research
  - Promotes collaboration and teamwork
    - Researchers and Clinical team

Limitations

- **Protocol development started late**
  - End of the data collection period of the study
- **Time constraints**
  - Ready by the time results available
- **Bound by the consent form**
  - Can “do better” than what is written
- **Complexities of players involved**
  - Research, clinical, community, etc.

Recommendations

- **No reporting if insufficient evidence**
  - Support interventions and advice
- **Greater involvement of community**
  - Spot on research steering committee
- **Greater focus on communication strategy**
  - Individual reporting
  - Group reporting

Issues for further debate

- **Bridging the gap between research & clinic**
  - Individual approach vs population approach
    - Rationale of tests performed
  - Research rarely incorporates implementation
    - Lack of rewards beyond publishing papers
    - Limited mention in timeline, not budgeted for
- **Throwing out the baby with the bathwater?**
  - **CON** : Research “stirring-up problems”, complicated
  - **PRO** : Desire of community to learn about environment