Investigating Prion Disease Risk Perception in Medical Laboratories

Aiza Waheed
Alexis Crabtree
Dr. Bonnie Henry
Dr. Michael B. Coulthart
Dr. Jane A Buxton

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Roadmap

- Context
- Methodology
  - Survey development and administration
- Results
- Next Steps
What is Prion Disease?

- Abnormal protein, aggregates in tissues, causes damage and death
- CJD (humans), BSE, Chronic Wasting disease
- Prions are very stable (difficult to inactivate)

Medical Lab Safety

- Most Canadian labs handle specimens from patients with potential prion disease to rule out differential diagnoses (eg. viral hepatitis)

- No National Guidelines specific for prion handling at Medical Labs

- The NML tests for prion diseases
  - 14-3-3 CSF and post mortem brain tissue
Research Questions

- What factors influence risk perception regarding prion diseases among Canadian medical laboratory staff?
- What protective actions are workers taking?
- Is there a role for the federal government in encouraging appropriate precautions?
Methodology

- Develop knowledge, attitudes and behaviour survey for lab staff – 3 steps
  - Interviews
  - Delphi Process
  - Pilot test of survey
- Administer survey and analyze results
- Document analysis of individual lab protocols
- Plan to present results to national experts to potentially inform the extension of existing clinical guidelines or the development of new national guidelines
Step 1: Key Informant Interviews

- Interviews - audio taped
  - 12 interviews + 1 focus group
  - Semi-structured format

- Interviewees
  - Laboratory workers, administrators, and policy makers from a variety of types of labs (regional, provincial, federal, and research)

- Two independent coders → consensus
Interview Results
The Health Belief Model

- Cues to action
  - Follow protocol vs. extra steps
  - Challenges: post-hoc identification

- Perceived Severity – an “ugly disease”

- Perceived Susceptibility – guidelines “no single set of rules”

- Perceived Barriers – lack of experience and information relevant to medical labs (equipment)

- Perceived Benefits – Is a quick diagnosis worth the risk? “Is the patient still alive?”
Step 2: Developing Survey

- Using the health belief model and interview results to develop questions = sample survey

- Used modified Delphi method to refine this questionnaire - 5 experts gave feedback
Why use Delphi?

- Used to reach consensus and refine group judgments
- Anonymous, so that one person does not dominate the discussion
- Expert opinion to ensure focus is on the topic of interest (Dalkey 1969)
- Experts can contribute on their own (no meetings are necessary)
Delphi Results and Pilot Test

- 2 rounds of the Delphi to reach consensus
- 100% response rate
- We found a Cdn survey host to publish our questionnaire online

- **Step 3: Pilot test with 4 laboratory workers**
  - Made the necessary changes based on testers feedback before making the survey link available online
Administering the Survey

- Recruited 3 associations to distribute the survey link to their members
  - CSMLS, AMMI Canada, CHICA Canada
- Regional laboratory managers were also contacted to distribute the link
- Sampling frame covered most provinces and types of laboratories
  - Hospital, public health, private, etc.
  - Microbiology, pathology, virology, etc.
Survey Results

- The survey was up for three and a half weeks
- 426 responses
- Most respondents reported receiving survey from supervisors/managers (not associations)
- Responses from all provinces and two territories
- Unable to calculate response rate because of method of distribution.
Demographics of Respondents

- 65% Medical Lab Technologists
- Time in current position
  - 34% worked in current position <5 years
  - 41% worked in current position >15 years
- 82% of respondents were female
Background & Current Practices

- 37% receive specimens less than once a month
- 37% report specimens not appropriately labeled
- Often not told at all or find out after processing
- 37% report their facilities process specimens
  - 60% special protocol, 25% follow usual practice
- 20% do not process, send away (e.g. 45% NML)
Current Practices – Processing

- Determining the likelihood of prion risk (n=155)
  - 17% call the ordering physician
  - 10% others: wait for more tests/direction

- Medical Laboratories have differing protocols for handling/shipping specimens

- But often, prion risk identified post-hoc (?due to improper labeling)
What is the Risk Perception?

- 18% reported feeling at risk of prion transmission
- 14% feel protocol does not protect them
- 51% experience anxiety when processing
- 23% of respondents have used extra precautions

n=155
Factors of Risk Perception

- Around 1/5 of our respondents directly work with prion specimens (n=83)
  - 51% concerned about contracting a prion disease

- 44% of respondents said facilities adequately equipped to process prion specimens (n=426)

- Half of respondents report not adequately trained
  - E.g. 56% of workers who directly handle prion specimens have received no training for handling such specimens.
Risk Perception Cont’d

- High risk perception and few benefits

- 78% of respondents indicated receiving specimens was inconvenient

- 81% would be more comfortable processing specimens if there was a national guideline
Lessons Learnt!

- Medical laboratory specific guidelines for handling specimens from patients with potential prion disease are needed
- Stuff happens! - Challenges of research and getting input from lab personnel with arrival of H1N1
- Next steps
  - Present results of all phases to national experts (PHAC, NML) to use in updating clinical guidelines or developing medical lab guidelines
Questions?
References
