



# Social influences on parents health service use when their child is sick: barriers to timely treatment?

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# Context

# Parents lens on their help seeking in acute childhood illness

- Primary concern is to 'do the right thing' for their child
- No parent wants their child to suffer because they failed to seek help
- Social expectations of parents with a sick child are often unclear, leaving parents uncertain about where, when & how to seek help
- Professionals, concerned with rising demand, need to understand what influences parents service use rather than simply imply criticism



#### **Patient Stories**

Below are a selection of patient stories that have inspired the work of Mother's Instinct and we will be adding more soon.



Jasmine's Story

We lost our daughter, Jasmine Elizabeth Ann Hughes on 15th February 2011. She was 20 months old.

Jasmine was the centre of our world, a very funny, very feisty, very pretty little flower!

At Christmas 2010 she got a virus. She got 'better' but wasn't hersel afterwards. Just over a month later, after a great number of breakdowns in communication within the 1HS teams looking afte her, a late of attention to some of her basic observations, and an apparent lack of understanding of safety protocols by those responsible for administering her treatment, she died.

READ MORE





#### The three studies

| Authors   | Aim   | Methodology   | Sample   |
|---|---|---|--|
| Neill 2008, 2010,<br>Neill et al 2013   | Explore psychosocial<br>influences on family<br>management of acute<br>childhood illness at<br>home                               | Grounded theory<br>Unstructured interviews<br>4 sets of data collection | <ul><li>15 families (mainly white British)</li><li>25 interviews</li></ul>   |
| Spencer & Neill 2013  | Inform social marketing<br>strategies relating to<br>Choose Well in<br>Northampton.   | Focus groups  | 23 mothers (white<br>British, Bangladeshi,<br>Polish)  |
| Neill, Jones, Lakhanpaul,<br>Roland, Thompson (ASK<br>SNIFF team) in press<br>Jones et al 2013,2014 | Explore parent's and<br>HCPs' use of information<br>resources during<br>decision making in acute<br>childhood illness at<br>home. | Focus groups &<br>interviews  | <ul><li>27 parents (white British,<br/>South Asian, Travelling<br/>families)</li><li>16 first contact clinicians</li></ul> |





### Social influences

- Social expectations
- Family and social support
- Service design & its impact on access to services

Repeatedly found to influence parent's help seeking (Neill 2008, Jones et al 2013, 2014, Spencer & Neill 2013)





# Social expectations

Informal social rules for parents with an acutely ill child

 Doing the right thing includes wanting to be seen to do the right thing by others – to conform to social expectations or informal social rules (ISR)

> The key ISR is to: contain the illness within family life unless the illness is serious when they are expected to seek help.

(Neill 2010)





#### Social expectations Other ISRs include expectations that:

- the family unit will be defined as parents and dependent children
- parents will assume traditional gendered roles for illness management purposes
- normal/minor illness will be contained within the family
- medical attention will be sought for 'real' illness
- Parents are then tasked with defining whether the illness is 'real' or normal/minor. Their ability to do this is dependent on their knowledge, experience, their own health or tiredness.





European Commission DG ECHO http://www.flickr.com/p hotos/69583224@N05/ 8140796091/

dreamstime.





#### 'Do I, don't I, seek help?'

 Parents try to balance doing the right thing for their child with doing the right thing in the eyes of those from whom they may seek help.

**'You don't want to waste their time and you don't want to harm him...It's a fine line.'** White British Dad



http://research.blogs.lincoln.ac.uk/2011/11/09/esrc -demand-management-consultation-favoursresearcher-sanctions/





#### Why do parents worry about asking for help?

The desire to avoid criticism, felt or enacted, is the primary motivator for decision making in acute childhood illness, apart from parent's obvious concern for the child's health (Neill 2010, Neill et al 2013, Spencer & Neill 2013).

- Leaves parents feeling that their moral character has been judged and found wanting.
- May reduce parents' self-esteem and self-efficacy.
- > Parents using strategies to avoid criticism.





### So what is felt or enacted criticism?

• Felt criticism is perceived & communicated through healthcare professionals attitudes whilst enacted criticism is direct verbal criticism (Neill et al 2013).

'We've all taken a sick child to the doctor only to be pooh-poohed away, you know, Calpol for the next 2 days and the child will be fine and then you feel silly.... So I think you get a reluctance that builds up.' (White British Mum)

'you actually feel that, you know, the doctor says "oh this is really minor you didn't really need to come here".' (South Asian father)





# **Consequences of felt or enacted criticism: Strategies to avoid criticism**

#### **Keeping quiet**

Parents avoid mentioning things they feel may be criticised
Delaying seeking help

... I'd left it too late and then I was **made to feel amazingly silly** for having not done anything......luckily for me his final like (gasps) of breath was while he was sat on the GP's knee who had already called an ambulance ..... and then I felt terrible because I hadn't taken him to the doctor's until he'd got, you know, quite serious so - **you can't win**. (white British Mum) **Using alternative sources of help** 

- Advice from non-critical sources such as family members or lay experts
- Other services such as A&E





#### Family and social support Impact on parents decision making & health service use

- Perception of support is more important than using that support system.
- When perceived availability of support is low parents are more likely to consult – e.g. At night, on holiday
- Virtual / social media networks seem to be increasing access to emotional support
- But information from lay sources is not trusted unless the individual is deemed to be a 'lay expert'.

(Neill 2010, 2013, Spencer & Neill 2013, Neill et al 2014)









# Family and social support

# Impact on parents decision making & health service use

- Generally support accessed is for practical help rather than advice
- Cultural differences do exist
- Travelling families do access support from 'experts' in their community
- South Asian families may have extended families within the household





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Stop, Think

#### Service design: access to services **Navigating health services**

Parents report that their main problem is access to primary care services, including:

- practical difficulties
- inconvenience of services
- call back systems creating delay
- lack of bus services to out-of-hours services
- inappropriate use of receptionists

Parents are confused about which service to use out of hours

need access to information about childhood illness & services

Lack of continuity > loss of trust in HCPs

Possible causes of increased use of A&E services.

(Spencer & Neill 2013, Neill et al 2014)





#### Summary: Social influences on parent's health service use

- Health services use in acute childhood illness is driven, primarily, by parent's understanding of informal social rules.
- Fear of *felt or enacted criticism* leads parents to use strategies to avoid criticism such as delay & using services where they are not known.
- Reductions in perceived support increases service use
- Convenience of access to services, information about services and childhood illnesses also significant factors.
- Finally, parents consistently report that the loss of continuity of relationship with their HCPs influences their likelihood of accessing &/or trusting their local services.





#### Conclusion: Implications for health care professionals What needs to be done?

- All health care professionals need to become aware of sources of criticism & develop skills in facilitating positive learning encounters (Neill 2013).
- Services for children need to provide access to services when & where families can access them.
- Easy to access information safety netting information is needed before and after consultations (Jones et al 2013, 2014)
- Finally strategies are needed to increase continuity of relationship between parents and HCPs – an old, but important, underpinning value in health care.





# A short TED-style talk on the impact of criticism on parents is available on: <u>http://www.england.nhs.uk/ourwork/patientsafety/re-act/talks/</u>

Thank you for listening Any questions?

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