

# Describing meningococcal disease: understanding, perceptions and feelings of people in a regional area of NSW, Australia

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## Key points

- Community understanding of invasive meningococcal disease (IMD) is generally low
- Perceptions of invincibility, as well as racism and cost of care, are potential barriers to people with IMD seeking help when acutely unwell
- Public health practice may be improved by adopting new methods of communication to prompt early recognition of the signs and symptoms of IMD in ways that are acceptable, accessible and appropriate for higher risk groups

## Abstract

**Objectives:** To explore understanding, perceptions and feelings about meningococcal disease in members of higher risk groups. To explore what people say are the most important health messages and communication preferences about invasive meningococcal disease (IMD).

**Methods:** Three focus groups and two semistructured interviews were conducted with people at higher risk of IMD in Hunter New England Local Health District in New South Wales.

**Results:** Participants generally had a low understanding of IMD, but described intense feelings about the disease and empathy for those who had experienced the disease. Fear of stigma and the impact of stigma were identified. Participants identified reasons for delaying presentation for care as perceptions of invincibility (particularly among young people), the cost of care (for all groups), and racism (particularly for Aboriginal people). These issues were both potential and experienced barriers for participants accessing help when acutely unwell. Factors for effective communication to improve understanding of IMD included the communication being acceptable, accessible and appropriate.

**Conclusions:** IMD is a serious but uncommon disease that has a range of impacts on people, families and communities. Higher risk groups may benefit from receiving more appropriate and accessible information about early signs and symptoms of IMD. Communication and understanding about the disease could be improved by working with new technologies and partnering with key people in high-risk groups. Use of text messages and social networking for urgent communication could be considered and trialled in public health practice. It is also important to recognise the potential direct or indirect experience of racism and stigma for patients with IMD and their families. Management of IMD could be strengthened by connecting people and families with support groups or services to reduce the impact of the disease.

## Introduction

Invasive meningococcal disease (IMD) is a serious but uncommon bacterial infection that usually presents as meningitis or septicaemia. Serious complications, including amputation, hearing loss and neurological problems, can occur. IMD has a case fatality rate of 7% for meningitis and as high as 19% for septicaemia alone.<sup>1</sup> Parents of children who have lived through IMD experience major emotional stress and, although health professionals have some insight into the experience, they are largely naive to the enormity of the situation for affected families.<sup>2</sup>

The most recent annual report of IMD notifications in Australia, in 2014, reported 0.7 cases per 100 000 population per year.<sup>3</sup> A number of population groups have a higher risk of IMD. Aboriginal people are known to have a two- to three-fold increased risk of IMD in New South Wales (NSW).<sup>4,5</sup> Children younger than 4 years of age have the highest incidence of IMD, with a secondary peak in incidence in adolescents.<sup>6</sup> IMD is a notifiable condition in Australia, with each case requiring timely public health action to reduce ongoing risk to the community.<sup>7</sup> Early diagnosis, treatment and public health management of IMD improve patient outcomes and highlight the need for the public to be aware of the disease.<sup>7,8</sup>

Identifying what members of the public understand about IMD and their perceptions of the disease may help to inform better public health practice and reduce risk. This is the first study of its type to explore current understanding, perceptions and feelings of people in higher risk groups about IMD in a regional area of Australia.

This study aimed to:

- Explore understanding of IMD in higher risk population groups, including Aboriginal people, young people and parents of young children
- Describe the perceptions and feelings about IMD of people in high-risk groups
- Investigate the most important messages about IMD for higher risk groups
- Understand ways that people would like to hear about IMD.

## Method

Focus groups from population groups at higher risk of IMD and semistructured interviews with key community informants were conducted in a regional area of northwestern NSW. Purposive sampling was used to direct the formation of the focus groups from community networks known to the researchers. This included parents of young children (aged less than 10 years), young people (18–25 years), community members of lower socio-economic areas, and Aboriginal people.

Participants were asked what they knew or had heard about IMD and where they got this information. They were

also asked how they would feel, or had felt, if someone close to them had IMD. The focus groups and interviews explored what messages were important and how these could most effectively be disseminated within their communities.

The focus groups and semistructured interviews were conducted by the lead researchers (JK and PM), recorded and transcribed. Group observations and notes were made by two researchers (KT and MO). The participants determined the most convenient date and time for the project team to conduct the research at a venue comfortable for participants.

The transcribed interviews and the notes were reviewed and thematically analysed using a modified grounded theory approach to developing an explanatory theory of basic social processes within the environments in which they occur.<sup>9</sup> Grounded theory can give voices to those who are otherwise rarely heard<sup>10</sup>, such as participants in this research, and is well suited to the aims of this study, where the questions guide the research without being either static or confining.<sup>10</sup> Emerging themes and linkages from early interviews were explored in subsequent interviews.<sup>10</sup> Researchers separately coded the data, and the coding system was refined iteratively as the notes were reanalysed. Coding was deconstructed – breaking the data down into categories that described the content – then reconstructed, framing the themes or codes within existing theory, evidence and practice. Once the coding system was finalised, all notes were recoded. Relationships between codes and categories were then assessed across the notes. Quotes illustrating the themes were then drawn from the notes. All authors participated in discussions resulting in the themes, and tested these with outlying cases across the sample groups' informants.

Study rigour was improved by having two researchers independently conduct the data analysis and then discuss emergent themes with the remaining authors. This improved 'reflexivity', where researchers reflect and examine their influence on the assumptions, analysis and formation of themes.<sup>11,12</sup>

The Hunter New England Human Research Ethics Committee (10/11/17/5.02) and the Aboriginal Health and Medical Research Council Ethics Committee approved the study.

## Results

Three focus group discussions were conducted with 8–10 people in each, and semistructured interviews were conducted with three key informants. Participants' ages ranged from 18 to 50, and females and males were evenly represented in the young people's group and the lower socio-economic community group. The parents of young children and the three semistructured interviews involved female participants only. At least three of the participants were Aboriginal people.

Even though IMD is an uncommon disease, and participants were not chosen for exposure to disease or experience of someone affected by IMD, at each focus group there was at least one person who had extended family or community experience with IMD.

Four main themes emerged from the data: “it’s not just normal sickness”; stigma; “just wait and see”; and acceptable, accessible and appropriate communication.

### “It’s not just normal sickness, it can be life threatening and scary with such disastrous consequences”

Participants reported that they “really didn’t know that much about meningococcal disease” but knew that “it’s not just normal sickness”. Participants described the importance of needing to know something about this disease. One young person said, “you know, stupidly I still do not know, really, the signs of meningococcal”. Individual knowledge of signs and symptoms was acknowledged by the participants as being poor, but, collectively at each focus group, the understanding of the illness was more complete. Rash was identified as a common symptom of IMD in each focus group and interview. Participants also described the speed at which a person with IMD could deteriorate: “it hits so suddenly” and “all of a sudden ... they can be unconscious the next minute”.

Each group and interview described IMD as serious (“such a tragic thing”) and knew that “it can kill”. Emotional aspects became important to participants – a young person said they “feel pretty helpless, like what on earth can you do about it?”.

Participants frequently described sadness in response to IMD: “just feel really sad ... then you feel sad for that family” and they feel “bad and sorry, you know”. Along with describing the disease as life threatening, genuine concern for both those experiencing IMD and their families was described; as one participant said, “it would be a very hard time for them as well”. One parent participant summarised the conflict of interest that may take place when a child has been in contact with a person with IMD: “you’ve got to be a parent for your child but maybe also still that friend for that person [who has the illness]”. The participant spoke with some intensity on this point, and this intensity was mirrored in other participants with nods of their head or affirmations.

### Stigma: “don’t go near them because you’re going to catch the disease”

Throughout each focus group and each semistructured interview, stigma associated with IMD emerged as a strong theme. It was described on two levels: fear of stigma and reported stigma.

One young person likened the fear of stigma from IMD to stigma from a sexually transmitted disease: “you’re a bit ashamed about it ... don’t want to tell anyone”. A

participant described their memories of a child who had recovered from meningococcal disease returning to school and what ensued: “teased because they’ve had it ... don’t go near them because you’re going to catch the disease”. This stigmatisation went on for many months or even years. Participants in two groups then shared how they believed those experiencing IMD stigma may feel “very isolated”, and another participant shared how family members experiencing the impact of the disease coped within their community: “no[-one] talking, they just sat and listened” because other parents were “afraid to send their children to school”.

### “Just wait and see”

Participants in the youth focus group spent some time relating the feeling of being carefree and invincible. The “whole notion of being invincible” and “not really thinking about fatal diseases” was described. The young people expressed their freedom at this stage of their life where they are able to “go out and do whatever they want”, and where they “might get a bit lazy in relation to caring for yourself” and seeing a doctor when sick.

Other groups and participants described reluctance to attend a general practitioner as “either too reluctant or too lazy, or that they couldn’t afford to go to the doctor” so would just “wait and see”.

Another barrier for participants in presenting to a health centre, leading to reticence to seek help, was racism. An Aboriginal participant described her community members not presenting to health centres because of a lack of cultural safety. This resulted in parents waiting; she said, “if a child is sick at whatever time of ... night, they’ll linger it out with Panadol if they can” and “a lot of Aboriginal people don’t go to health centres unless they have to”.

### Acceptable, accessible and appropriate communication

Participants described the importance of being informed about IMD to “give yourself a better shot at an early diagnosis and early treatment”. Participants described this as being able to recognise signs and symptoms, so they can help people around them and recommend that “they go get ... checked out”.

An important element of making information more acceptable for participants was a ‘go-to’ person delivering the message. Participants reported that a community nurse, a family member, a friend with health experience, or someone who had experienced IMD would be good examples of go-to people. These people were trustworthy, as were “a government website or medical website”. Participants described two key elements for information to be appropriate: that the language be simple and emotive (“try to keep it as simple as possible” but “get emotionally involved ... then you’re inquisitive”). Participants also identified low or no literacy as a barrier

to receiving information, and thought that graphics would enable people to visualise the signs and symptoms of IMD, and the steps to take.

Participants identified various methods for delivering health messages, depending on the urgency and type of message. They agreed that an acceptable method to deliver urgent public health IMD contact messages would be through text messages and social media. Participants all said that their phones were with them at all times, and that phone plans could include social media platforms, making them an acceptable and accessible mode of communicating important health messages.

For promoting an understanding of IMD for parents, including the signs and symptoms of IMD, a health letter and a pamphlet with their child's immunisation 'blue book' (personal health record) were identified by participants as being acceptable. Other modes of communication varied according to the particular group. For example, the young people thought that posting health messages on screensavers at tertiary institutions, and displaying them in pubs and clubs would be worthwhile. The parents' group and community group identified schools as an acceptable method for giving health messages to parents and students.

There was some concern about the appropriateness of newspapers and television or radio news to get messages to the high-risk groups. Asked why newspapers and news bulletins were not viewed as effective communication by parents of young children, the following responses were elicited: "We're busy at 6 o'clock ... I'm at home feeding children [and not watching the news]" and "we don't get the paper, or, if we do, I just flick through pages and read [the] headline[s]". A community member also said that "no-one watches commercial TV today".

## Discussion

IMD is a serious but uncommon disease that has a range of effects on people, families and communities. For participants who had a lived experience of IMD, the experience continued to be very real, and the depth of emotion about IMD was evident even when it was some time ago. Faber et al. note that human memories that remain the most vivid are usually associated with strong emotional events containing extreme fear, love or rage.<sup>13</sup> IMD can cause this level of fear among family members and the wider community, as described by the participants.

In addition to fear, the focus groups and interviews revealed the need for understanding of perceptions and other feelings about IMD in communities and for healthcare professionals. This need aligns with previous IMD research that has described survivors' challenges with quality of life, and their physical, cognitive, educational and psychological outcomes.<sup>14</sup> Also resonating with the current research were issues pertinent to the journey during and after a child's IMD diagnosis,

previously described by parents.<sup>15</sup> These issues included a need for better education and improved knowledge in healthcare professionals, improved access to information about sequelae, and easier access to follow-up support and advice.<sup>15</sup>

An important finding for public health practice was that individual knowledge about IMD was generally low and indicated some misunderstanding about transmission of the disease. A study by Wang et al. also identified large knowledge gaps about IMD among community members in Australia.<sup>16</sup> Despite low individual knowledge, including about signs and symptoms of IMD, all participants knew about the seriousness of the infection, and that IMD is a frightening, life-threatening illness. This knowledge and fear have been described previously in research showing that IMD is one of the diseases that parents most worry about their child contracting.<sup>17</sup> A rash is a late IMD symptom and was identified in each focus group, yet earlier signs and symptoms (such as very high fever, or cold hands and feet) were not stated. Waiting for late symptoms can increase the risk of poor outcomes<sup>8</sup>; therefore, further public health education may be required to increase understanding of the early signs and symptoms of IMD.

Although participants described meningococcal disease as life threatening and scary, some groups in the community may delay seeking healthcare for reasons including a feeling of 'invincibility', cost of care and racism.<sup>18</sup> Delaying nonurgent medical review because of cost has been reported elsewhere and, in Australia, the proportion of people delaying or not seeing a general practitioner for primary care has increased.<sup>19</sup> Of concern for public health practice is that the people who delay seeking emergency department healthcare may be at higher risk of IMD, such as young people, adolescents, and Aboriginal and Torres Strait Islander people.

Stigma was identified as a strong theme in this research, particularly in relation to seeking help within hospital settings, during recovery and re-entering the public sphere following infection. Treatment with antibiotics clears the bacteria and, once recovered, a person can move back into their community. Unlike IMD infection, the experiences of people living with other infectious diseases, particularly HIV infection and hepatitis C, have been described extensively.<sup>20,21</sup> HIV infection and hepatitis C can be managed or treated with medication, but are often characterised by uncertainty, fear and stigma.<sup>20,21</sup> For people living with an infectious disease, stigma can include shunning, marginalisation, rejection and delayed presentation to a health professional.<sup>22,23</sup> Barriers to accessing healthcare when living with an infectious disease have also been reported, along with social and economic effects.<sup>22</sup> IMD is not a chronic infection like HIV infection and hepatitis C, but stigma associated with IMD has not been reported previously, and the implications of stigma for public health practice have not yet been fully explored. Support for those infected and their families during their hospital stay

and afterwards – with clear messages for communities that, once treated, the person poses no risk to others – may be pivotal in reducing the stigma associated with IMD and must be further investigated.

The health of Aboriginal people in Australia is poorer than that of non-Aboriginal people.<sup>24</sup> The lived experience of racism is an important driver of poorer health status.<sup>18</sup> The negative impact of racism was described by one Aboriginal participant as causing parents of young children to delay presenting to healthcare facilities. Delay in seeking care because of racism may not be the experience of all Aboriginal communities or people, but any delay in seeking healthcare for IMD can affect the outcomes of the disease. This is a clear challenge for individuals and the healthcare system as a whole.<sup>18</sup> Steps towards addressing this challenge may include recognising and tackling institutional racism, developing fairness and compassion, and ensuring that culturally safe and appropriate healthcare is available.<sup>25</sup>

Communication – including what types of messages about IMD should be provided and the delivery methods for these messages – was a complex part of this research. Participants wanted information that was acceptable, accessible and appropriate. Each group said that understanding the signs and symptoms of IMD, and what actions to take, was important. Participants emphasised that ‘go-to’ or key people in a community were important to ensure that the dissemination of information is acceptable, as has been shown in other work.<sup>26</sup> Go-to people are thought of as trustworthy by those affected, and as understanding the dynamics at work in their community. Communicating with higher risk groups using key people in the community requires further attention from public health practitioners.

Health services have traditionally used newspaper and television or radio news interviews to raise awareness of the signs and symptoms of IMD. These methods are potentially effective for some sectors of the community, but traditional sources of information were viewed by participants as outdated. Participants thought that use of technology, such as social networking applications and the internet, would be more effective and available at the precise time they were needed, and would assist with remembering disease details. This variety of methods acceptable for health messages may highlight the need for public health practice to continually adapt to the needs of different groups and levels of literacy, and to use new and emerging technology.

One element of research using a grounded theory approach is that researchers can bring their own history and cultural context into the research, which in turn can shape the researchers’ view of the data and generation of themes. To improve objectivity, all researchers were involved in separately coding data, and then coming together on multiple occasions to challenge and review themes and understanding. Researchers used diaries, reflective entries and examination of their own life experience in those entries to improve reflexivity.

Collecting data through community-based focus groups enabled participants from three high-risk groups, with a variety of literacy levels, to share information in a comfortable environment. Social interaction, and maximising the group dynamic to stimulate sharing, were facilitated by having groups with similar socio-economic and cultural backgrounds. A weakness of the methods used is that the results may not be representative of the wider population, because the number of participants and groups was small. The participants were identified through existing contacts of the research team, and the study was confined to one Local Health District. However, the results provide valuable insights for public health practice for notified cases and their affected communities.

## Conclusion

Understanding of IMD was generally low among participants, with later-stage IMD symptoms better known than early-stage symptoms, which may result in delayed presentation to hospital. Other reasons described for delay in presentation for people in higher risk groups included cost, young people’s perceived invincibility, and racism. The need for clearer health messaging needs to be considered, along with addressing racism as a barrier to accessing health services.

Fear was a strong element of how people felt about and perceived IMD. Fear of stigma was felt to be important, particularly in relation to seeking help and during recovery from IMD. Public health practice around IMD might be strengthened if people and families are connected with support groups or other services to reduce the impact of IMD. Increasing understanding of how IMD is transmitted and treated, while addressing the feelings of fear and the perceived potential risk to others in communities, may have some impact on stigma for those affected. Communication about IMD may be improved by partnering with ‘go-to’ people – key people in high-risk groups who can help to reach communities where traditional modes of message delivery might not work. New technologies and social media were viewed as a more acceptable and appropriate method of communication about IMD for members of high-risk groups.

The findings from this small study may be used to generate hypotheses for further research. Lived experiences of IMD could be fully explored to inform further development of public health policy and practice, and encompass the understanding, perceptions and feelings of people in groups at higher risk for IMD.

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## Competing interests

None declared

## Author contributions

JK was responsible for ethics preparation and submission, protocol development, facilitation of focus groups, thematic analysis and compilation of the manuscript for publication. PM was responsible for study conception, study design, overseeing data analysis, and reviewing and editing the manuscript. KT was responsible for cultural oversight, and reviewing and editing the manuscript. MO was responsible for reviewing and editing the manuscript. MM was responsible for providing methodological advice, and reviewing and editing the manuscript.

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