Meeting the needs of families: Facilitating access to credible healthcare information

This article summarises an EBN Twitter Chat on facilitating access to credible healthcare information, led by Dr Christine Chambers (@DrCChambers) and Dr Abbie Jordan (@drabbiejordan). The Storify® version of the Twitter Chat can be found at: http://bit.ly/2dOeVyl, and the pre-chat Blog at http://bit.ly/2dU4giu.

Background

Following an increase in the use of the internet in everyday life, research has identified that individuals are increasing turning to the internet as means for identifying information about healthcare conditions (Rozenblum & Bates, 2012). One study identified that 98% of parents surveyed used the internet to search for information about their child’s condition (Pehora et al. 2015). Whilst the use of the internet as an information seeking source is not problematic in itself, a substantial proportion of information has been identified as not being credible, meaning that families are often faced with poor quality non-evidence based healthcare information (Khoo et al., 2008). Compounding this problem is the fact that families typically don’t have access to the traditional academic sources in which research studies are published, and there is a lengthy 17 year gap between publication of research findings and implementation of findings in clinical practice (Morris et al., 2011). In order to address these issues, a Twitter chat took place to explore how we can better reach families with evidence based healthcare information.

Key messages from the Twitter chat (#ebnjc)

Working collaboratively with families

There was overwhelming agreement amongst chat participants about the importance of ensuring that families are able to access good quality evidence-based information about healthcare. Initial discussion focused around the nature of the relationship between families and healthcare professionals. In particular, participants emphasised the importance of health care professionals viewing patients as partners rather than as passive recipients of information that is passed on by healthcare professionals (Figure 1). The collaborative nature of this relationship is important in terms of how healthcare professionals think about issues surrounding families’ accessibility to evidence based health information.

Figure 1: Working collaboratively with families
Access to information: An issue of credibility

Participants talked at length about the types of healthcare information available to families, typically parents, and how families process this information. Individuals contributing to the Twitter chat described how families often face an overwhelming amount of healthcare information from a variety of different sources. This was identified to be particularly problematic with instantaneous access to online information and the proliferation of many unregulated online sources of healthcare information. Participants explained that access to such a large amount and range of health-related information made it difficult for families to determine what information was credible and what was not credible (Figure 2). As perhaps expected, the consequences of some families selecting poor quality information were experienced by the families themselves in terms of them not being able to access appropriate evidence based healthcare information but also the healthcare professionals who work with these families.

Figure 2: Judging the quality of internet information

Making information accessible to families: issues of how, when and where.

Participants identified that families experience difficulty in accessing the good quality evidence based healthcare information that is available. Participants highlighted that publishing work in high quality peer reviewed journals was of no immediate use to patients in terms of providing patient access to this information due to use of complex language used in such publications and a lack of family access to academic journals (Figure 3). With this in mind the formats of evidence based healthcare information that can be provided to enable access and use by families were discussed, which included moving beyond previous established practices of relying on placing patient information leaflets in waiting rooms. Participants identified problems with this approach including information becoming quickly out-dated and access to such information was dependent on being in waiting rooms. A key message from the Twitter chat was that information should to be provided in a manner that can be easily accessed by families when they need it, for some this will be across the 24-hour timeframe.

Figure 3: Ensuring information is appropriate to patients

Fitting the format and content of information to meet the needs of families

Following agreement by participants in the Twitter chat of the importance of evidence based healthcare information being available to families at all time points, the chat progressed to focus on how and where families look for healthcare information. Participants identified an increased use of social media platforms used by individuals to search and access healthcare information. Participants emphasised the value of sharing information in places that families already use rather than having
websites or apps that need actively searched by individuals when they wish to identify information about their healthcare condition (Figure 4). The ‘It Doesn’t Have to Hurt’ campaign was highlighted as a good example of making evidence based healthcare information accessible to parents by locating the information it websites and social media platform that parents are likely to visit which also ensured that information was accessible to parents at all times.

Figure 4: Ensuring information is accessible

Whilst social media was identified as a useful medium for providing evidence based healthcare information to families, participants agreed that a ‘one size fits all’ approach is unlikely to work as individuals have different preferences for the format of the information. As some participants described, some families may wish to use social media, others may wish to look at leaflets and others may prefer videos in terms of accessing healthcare information. With this in mind, a key message from the Twitter chat included ensuring that evidence based healthcare information needs to be provided to families by targeting the needs of particular audiences, resulting in a need for information to be placed in a variety of different of mediums.

Conclusion

The Twitter chat identified that in changing times, healthcare professionals, academics and others responsible for providing evidence based healthcare information to families really need to think carefully about how and where information is provided to families with regard to improving accessibility. In particular, attention needs to be paid to ensuring that evidence based healthcare information moves beyond publication in peer reviewed journals and is provided in an accessible real time manner in online and real life spaces that are accessed by families. Discussion of the ‘It Doesn’t Have to Hurt’ campaign (It Doesn’t Have To Hurt, 2015) highlighted the success of social media in terms of meeting the needs of families for good quality and universally accessible healthcare information. To enable changes in the way that families can access credible healthcare information, a need for good quality training for healthcare professionals and academics was identified to enable individuals to develop a clear and comprehensive strategy for communicating with families.
Resources
Twitter: Follow Abbie Jordan at @drabbiejordan and Christine Chambers at @DrCChambers

References
Morris, Z.S., Wooding, S. & Grant, J. (2011). The answer is 17 years, what is the question: understanding time lags in translational research. Journal of the Royal Society of Medicine, 104 (12), 510-520.