



PRACTICE

WHAT YOUR PATIENT IS THINKING

#TalkAboutComplications

Renza Scibilia and Chris Aldred write about how to take the blame out of complications and their determination to reframe the way complications are discussed

Renza Scibilia, Chris Aldred

People with diabetes and other chronic conditions know all about disease related complications. They are told about them by healthcare professionals, organisations, charities, public health campaigns, and the media. Often the information is presented in such a way as to suggest that the affected individual is to blame for the development of complications because he or she failed to manage the condition “correctly.”

In our combined 45 years of having type 1 diabetes we have had less than ideal conversations about complications with our healthcare professionals.

Blame, shame, and complications

Last year I (Chris) received a diagnosis of a foot ulcer. Using social media and the hashtag #TalkAboutComplications, I started to tell the story of my experience after this diagnosis. The huge response from people wanting to share their stories showed the interest in discussing complications in an open way.

A recurring theme was feeling “blamed and shamed” by healthcare professionals when a complication had occurred. It made individuals feel that they had in some way failed. I (Renza) have already done work to explore the complex but clear link between the choice of words when discussing complications and how people feel about their complications and their willingness to speak to peers and healthcare professionals. The use of blame and shame language results in people feeling unable to talk about their concerns to anyone.

Healthcare professionals often tell people with diabetes that complications can be prevented by self management within a prescribed target and undergoing regular screening. This then leads to the belief that if complications do develop it is because someone has not “looked after” herself or himself properly, and hence this is a failure in self care.

Reduction rather than elimination of complications

A subtle change in the way words are used could make a difference. Often the focus and language around complications are on prevention rather than on risk reduction. The

understanding is that no matter how well a condition is managed, there is always some risk that a complication could develop. Even if the self management of diabetes is not ideal, there is no value in apportioning blame. People can become demotivated if they feel blamed or that they have “failed”; rather than seek treatment they might stop seeing the healthcare team completely. Any presumption that people have not “looked after themselves” only adds more distress to a potentially difficult situation.

Complications should not be a sugar coated topic of conversation, but equally the topic should not be avoided. Some groups are reluctant to talk about complications. For example, parents might not want to have these conversations with or around their children with diabetes in case it scares them. Complications need to be talked about as openly as possible but in such a way as to encourage people to join the discussion.

“Care” rather than “complications”

Changing the language used from “complications” to “care” can perhaps reduce the fear and turn the focus to risk minimisation. Visits to ophthalmologists are carried out to care for eyes and daily foot checks are done to care for feet. Encouraging and acknowledging this sort of care helps in the understanding that people have done all they could to minimise risk and to not feel blamed or blame themselves. Then energy can be spent on treating complications.

As #TalkAboutComplications grew, it was interesting to discover how many people had never spoken about complications. Something we have learnt through years of interaction with other people with diabetes is that if they do not talk about certain issues and topics among themselves, they are not likely to be talking about them with their healthcare professionals. Complications are a reality for many people living with diabetes; and the possibility of complications is present all the time. If choice of words focused on care, people with chronic conditions such as diabetes would be more engaged with their own care and feel more supported. They would then feel encouraged to work with their healthcare professionals to minimise the risk of complications, and to treat early and effectively those that do occur.

Find Renza and Chris on Twitter at @RenzaS and @Grumpy_Pumper

What you need to know

- Language which implies that complications are preventable can make people feel blamed if a complication develops
- Talking about reducing complications and making clear that they can happen despite best self care could encourage people to speak more openly and understand that they are not at fault
- Talking about daily care rather than the prevention of complications, is an alternative to encourage day-to-day attention to reducing the risk of complications

Education into practice

- How do you encourage patients to try and reduce the risk of complications?
- What language can you use to talk about complications?
- What support or services can you offer patients who have developed a complication?

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