Information Transfer

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Introduction

There are many aspects to patient care, but continuity sits at the heart of them all. Many of the chapters in this book discuss the challenges of caring for patients who have complex healthcare needs. Experience tells us that there is a very important relationship that forms between the patient, their family and the paediatric healthcare team. The knowledge of the patient's condition and the complete understanding of treatment delivered is, clearly, very important in this. When a patient moves from paediatric care in to an adult environment, they will set their standards based on experiences so far. In short, they (not unreasonably) will expect the same standard of care.

With the above in mind there are two important points. The first, each professional that undertakes this work in adolescence and adulthood has to ensure they are well trained. This includes a complete understanding of the paediatric conditions that will come under their care. It is also important that they understand the treatment delivered in paediatric care. This allows explanation to patients about what they have and has happened to them—when they ask questions in later life. If there is to be a long-term healthcare relationship these elements are essential to success. These patients and their parents are usually expert in their condition and their treatment—and if they are not, they are certainly very well acquainted with the medical profession and how it has managed them, so far. They will quickly compare a new carer with their previous experiences—if the new team appears to fall short, it will be very difficult to gain trust going forward.

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The second component is that the information given is accurate and reliably transferred from the previous team to the new team. This chapter aims to examine the importance of this, potential methods of transfer and some of the challenges in data transfer.

Patient Role

At the core of transition is the development of the patient's own ability to contribute an increasing role and responsibility in their own healthcare. As their own understanding of what has happened to them grows their role in communicating information to doctors both present and future expands alongside this. The purpose is not to suggest that a patient becomes responsible for all medical information, but their position is greatly empowered the more information they have and the better they learn to use it.

Many of us working in fields that require transition have encountered patients with a rare diagnosis or specialist forms of treatment. These may be much less familiar to healthcare professionals outside of specialist centres. There are three ways patients can help with their own healthcare in this setting, on understanding that a doctor does not know about their condition—the patient can become their own expert and explain what they have and (if possible) how the current problem has been managed before. Most sensible professionals will respond positively to this and at least use the information given to support their own enquiries. The second way is to bring written information with them when meeting a new healthcare professional. This might be hospital letters, their own summary report, a health passport (where they exist), some form of electronic record—or a combination of the above. The third, most common, way is for the patient to direct the doctor—either to their own (existing) healthcare team or to other electronic resources that offer information about their diagnosis or care. We have all listened to anecdotes where this has not gone well—often (from a patient perspective) because a doctor has appeared not to listen or to be reluctant to take on board the guidance that is being offered. This creates friction, a loss of trust and the relationship quickly deteriorates. The converse is also true—I have encountered very good doctors who have tried to treat such complex patients, but they are met with a wall of resistance often on grounds that are unreasonable, e.g., their own doctor not being available (during weekends, leave, etc.) or not agreeing with a diagnosis despite good evidence for it. It goes without saying that when patients are reacting in such a way the doctor has to do their best to establish why and to try and support the patient—after all, they are the professional and this is their job. Patients may be unwell and frightened and therefore less able to manage themselves than normal. Perspective is very important as both sides can get it wrong—the importance is to maintain an open mind—this is the probably the easiest path to the best outcome.

Health Passport

There have been many examples and attempts to achieve this and it meets with vocal enthusiasm when suggested. There is even an example using the acronym HEALTH (Helping Everyone Achieve Long Term Health; https://www.nice.org.uk/sharedlearning/the-health-passport-helping-everyone-achieve-long-term-health).

Despite apparent enthusiasm, this has not yet gained widespread adoption or acceptance. Some healthcare systems in Europe have adopted a 'smartcard' which can be inserted into a computer—allowing immediate access to a patient's records.

There are a range of potential opportunities for a health passport. The most obvious is the portability of information—allowing a patient to carry their own record with them. This means whoever sees them will have immediate access to their medical charts. It also allows the healthcare team currently seeing the patient to contact other teams involved either historic or present day.

Above and beyond historic medical information the ideal passport will allow the patient to interact with it. During the approach to transition part of the preparation could be staged. First, for the parent to agree with their child questions that might be asked at an upcoming appointment. As the child understands this and develops—they may begin to discuss things with their parents and then write their own questions in the passport—the development to them raising their own concerns and asking their own questions would ideally follow, with the passport playing a part in that process.

There have been attempts to produce electronic applications (apps) to facilitate information transfer between patients and their healthcare teams. Assuming the technology exists to allow this and maintain the security of patient data and thus strict confidentiality—this may be a very good way to facilitate immediate communication with a patient's medical team. These avenues will, no doubt develop. This appears to create an excellent resource for patients—with the intention of obtaining immediate advice and potential treatment advice. Indeed, as I write this chapter it is likely that this aspect will become outdated almost as soon as I finish this sentence!

Whilst electronic communication is an excellent ideal it opens a healthcare team up to a much wider pool of potential enquiries in the front line of healthcare. In order to fulfill the expectations of patients that will, in turn, become more immediate and the healthcare team must be adequately resourced. There are two fundamental aspects—the first centres on personnel, how different health systems deliver such a service will vary. The development of technology to bring the patient closer to healthcare is, almost certainly, inevitable. There must be staff availability and training to take on this work—a range of models could be designed—and additional staff time may be required. Systems may, for instance, decide to allocate specific times of the day or week for answering or responding to enquiries through these means—even then they have to ensure there is specific staff time to do so. We all need to understand that simply because we have sent a message, we cannot assume it has been received or actioned. Therefore, the message sender retains a degree of responsibility for pursuing an enquiry until the information needed has been obtained.

The portability and availability of information is an important part of modern healthcare and is an area that is likely to develop. It will develop as a specific part of this area of healthcare—the transition from one healthcare environment to another under these circumstances or others. It will also develop because it can, and we are, to a degree, subject to the expectations of patients in delivering care. It will be our job to deliver it and regulate it.

Hospital Record

Ideally, the paediatric record should be open to the team that are going to look after the patient in adolescence and adulthood. This is important at the point of first meeting and if there are subsequent joint meetings. It is useful to have a summary of the overall information, if the patient is due to move to another team or location. It remains important that the full record is available to the adult team.

Data Protection

Data protection laws will vary across the world. Each practitioner needs to be mindful of those that relate to their own country and healthcare and environment.

As a set of principles, the information must be kept in a secure place and should be shared only with those people who need access to it.

Geography

It is obvious that if a patient remains within the same hospital the information from previous care will remain will be readily available to all teams involved. Indeed, the paediatric team also have access to the long-term data that allow them to examine progress after they have handed over care. This will facilitate their understanding of the long-term outcomes of their treatment. If a child has to move facility of their adolescent and adult care both aspects are more difficult. Each system will need to establish its own approach. The entire healthcare record can be copied and transferred. A good summary may be enough. Either way the team assuming care should not have their ability to look after a patient compromised through a lack of information. The reciprocal is that the adult team needs to find a way of feeding back information on long-term care to the paediatric team. This may be on a case-by-case basis—if individual or complex problems arise. The additional component should be the examination of cohorts of patients and a broader look at their outcomes. This will be designed to give a better perspective to the paediatric team of their long-term outcomes.

Summary

It is clear that good care for these patients relies on full and coherent information being available to all teams involved in looking after them. This information will rely on clear documentation throughout paediatric care and secure but accessible transfer to the adolescent and adult team. Data protection must be preserved.

Patients can play a very important role in this with their own expertise and account of their condition and treatment. It may be that with time more patients are given some form of personal and portable record to carry for themselves and give to professionals as they meet them.

The development of electronic records may improve the portability of information. As technology develops healthcare teams are called upon to respond appropriately to electronic requests from patients and other healthcare professionals. Expectations need to be managed to ensure that where immediate responses are required the resources are available to provide this and when the need is less urgent the enquiry is managed proportionately.

In the long-term paediatric teams must be given access to their long-term data. This allows them to assess the outcomes of the diseases they care for and the treatment they have delivered. This may be on an individual basis or from reporting of datasets to inform a particular team or the paediatric community as a whole.

Further Reading

IT Governance. GDPR compliance checklist for health and social care. https://www.itgovernance.co.uk/healthcare/gdpr?gclid=EAIaIQobChMIn9vUwrPA3gIVjrDtCh1cHgdCEAAYASAAEgKciPD_BwE. Accessed 7 Nov 2018.

National Institute for Health and Care Excellence. The HEALTH passport: Helping Everyone Achieve Long Term Health. https://www.nice.org.uk/sharedlearning/the-health-passport-helping-everyone-achieve-long-term-health. Accessed 7 Nov 2018.