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What do patients want? Generalists versus specialists and the importance of continuity

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Patients have benefitted enormously in recent years through the rapid growth in medical knowledge and the development of new technologies and treatments. The result has been better clinical outcomes and quality-of-life improvements for most patients. A consequence of all of this is that patients are living longer and living with complex comorbidities which put immense strain on health and social care resources. Specialisation and sub-specialisation have changed the way physicians work and the decline in the number of generalists has led to many patients, particularly the elderly, experiencing problems around a lack of continuity of care. They end up attending many different hospital clinics and departments to see different specialists, usually acting in isolation for each condition, and become frustrated at having to tell their stories over and over again. They argue that care programmes are often disjointed and they feel that no one is in charge of their overall care plan.

The Patient and Carer Network (PCN) of the Royal College of Physicians (RCP) has over 60 members and they were recently asked to give their views on the problems patients are facing through the rapid growth in medical specialisation and a diminishing number of generalists. Members of the network reported that the biggest problem they experienced or witnessed was a lack of coordination of care. This was often a problem not only between different medical specialists but also between hospitals and departments. They reported that when having many hospital appointments over a period of time for a single condition they ‘saw quite a few doctors but never the named consultant’. One member felt that as patients get older and comorbidities grow, the continuity issue is more of a problem. She added that:

> *Patients want to see a specialist in the bit of you that is going wrong but what would be welcomed would be seeing a doctor who sees a patient as a whole person like a geriatrician or paediatrician.*

She cited an example of good practice from her late husband's care where a nurse specialist within respiratory medicine/lung cancer was linked to the three different consultants her husband saw. Access to this nurse was highly valued. Another member told of her journey during a hospital admission lasting 21 days. This member said she felt like a parcel being passed around the hospital. She spent time on five different wards, was seen by a surgeon and two different specialist physicians, and recounted how disjointed her overall care was. When arriving on a new ward she was left by the hospital porter and felt that there was no appropriate hand over to the clinicians who would be taking over her care. She added:

> *Although I was very sick I had to do my own hand over on each ward. Had I been under the care of a generalist and with good IT support a lot of wasted time would have been avoided and I would have felt safer and reassured I was receiving the best quality of care.*

This same member cited poor communications between the hospital and her general practitioner (GP). Her GP received an inaccurate discharge summary which did not give the proper medical diagnosis or advice on future medication, and which appeared to have been written by someone not acquainted with her previous medical history. She said:

> *In my mind, had a generalist or care coordinator taken an oversight of my overall care and treatment then my GP would have found it much easier resuming responsibility for my ongoing treatment in primary care and I would have had much more confidence in the system.*

Patients say that what they really need from the healthcare system is for primary, secondary and social care to come together in a properly coordinated way to take care of the whole person. They dislike use of the word ‘discharge’ and would much prefer to see the introduction of the concept of ‘transfer’ of care. This would necessitate one person in the overall system taking responsibility for the patient at all times. The current system sometimes leaves hospitalised patients feeling they are no longer the responsibility of the ward they were admitted to as they sit in a holding lounge awaiting transfer to another part of the hospital. They say that at these times no one seems responsible for them despite them needing help with feeding, hydration, personal care etc. With the advent of self-management and whole person-centred care the idea of accessing separate organisational systems without a care coordinator leaves many patients feeling vulnerable and nervous about taking more responsibility for their own care. Patients in general do want to assume more responsibility for their own treatment but the system seems to discourage

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this. An example was given of patients managing their own medication at home and then on admission to hospital having their medication taken away only to find that ward staff frequently administered it at the wrong time of day and in some instances gave the wrong medication. Patients feel that a dedicated care coordinator would be in a good position to assess the patient's capability to self-medicate while in the hospital and this in turn would encourage them to take more responsibility for their future care needs.

So what do patients and carers see as the solution to these many and varied problems? Most patients with long-term conditions and comorbidities are very clear in their view that the rapid expansion of specialisation has led to a fragmentation of care, and they want access to someone who understands their medical history and who can coordinate the delivery of holistic care. This could be a physician or nurse, or maybe a physician associate. It would allow patients to build up a relationship with someone able to pick-up on problems that may go unnoticed by clinicians who are treating only a part of the patient's many and varied conditions. The care coordinator would be ideally placed to support the introduction of self-management and provide the necessary support for this. They would work in partnership with those responsible for different aspects of care and take responsibility for ensuring good communication between different departments and agencies. The result would be patients feeling safe and confident that they were being treated with dignity and respect. The care coordinator would of course need proper support in terms of seven-day access to primary and social care but one result would probably be a significant reduction in hospital bed blocking.

Many patients and carers believe that better sharing of clinical information between specialists and hospital departments could be achieved by greater use of patient-held records. A particular issue identified was that of poor communication with principal carers when these people were not the next of kin. Data protection legislation often gets in the way of good communication with family members who are delivering the bulk of care at home. Perhaps a system whereby patients with complex needs are asked on admission to hospital to sign a disclaimer saying information could be shared with named individuals other than next of kin would get round this problem. Another suggestion is the introduction of a care summary sheet left at the end of the hospital bed to allow family and carers to be kept in the loop.

Patients also feel that for those with long-term conditions a system of self-referral to their medical specialist or to a specialist nurse would not only be better for them but would also help ease the pressures on accident and emergency (A&E) departments. They say that out-of-hours care in an emergency does not always give them the most effective and efficient treatment. The default position is that they are advised to go to A&E where the whole process of being assessed and referred on to other clinicians starts all over again. Surely this must be a waste of scarce resources, as well as being distressing for patients.

In summary, patients want access to clinicians with an expertise in their particular illness, but at the same time would like to benefit from some of the advantages of seeing a generalist. Future training models for physicians may well result in specialists also having greater generalist skills and this would be welcomed by patients. Of more immediate concern for patients with complex conditions is the need to develop better systems of delivering integrated care across the health and social care landscape. The PCN of the RCP hopes that some of the ideas outlined in this commentary will be examined in more depth as part of the Future Hospital Programme development initiatives. ■

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