

Pathways to where? Some thoughts about care pathways and recovery

There are many different agencies that offer support to people with mental health challenges, but too often the system is characterised by confusion, repetition, delay, duplication of efforts and gaps:

A person's care may be provided by several different health and social care professionals, across different providers. As a result people can experience health and social care services that are fragmented, difficult to access and not based around their (or their carers') needs (Department of Health, 2014, p. 1).

This situation has led to a number of initiatives to achieve better integration of care[1]. In 2016, NHS organisations and local councils came together to form 44 "Sustainability and Transformation Partnerships" covering the whole of England. In some areas these partnerships are developing even closer collaboration in an "Integrated Care System" and "Vanguards" have been identified to lead on the development of new care models.

In order to achieve better integrated care for individuals, "integrated care pathways" have been developed[2]. The aim is to describe a chain of care "to meet the needs of patients with a certain condition by linking primary care, hospital care and community care through care pathways, based on local agreements between providers" (Kings Fund, 2011, p. 5). The idea is that everyone with a particular diagnosis receives evidence-based support within a defined period of time, "post code lotteries" become a thing of the past and systems are streamlined.

While, at first sight, this makes sense, such streamlined care pathways have not been without their problems (see, e.g. Hall, 2010; Schrijvers *et al.*, 2012). Among the potential disadvantages identified by Schrijvers *et al.* (2012) are reduced patient choice and "dehumanisation": "the relationship between health professional and patient is less personal [...] If experienced professionals rely too much on routine [...] there is a chance of increasing indifference, cynicism and reduced empathy with the patient" (p. 6). Similarly, the literature review conducted by Hall (2010) indicated that integrated care pathways were "useful for focusing on technical procedures whilst the human elements, the therapeutic relationship and interpersonal aspects were potentially overlooked" (Hall, 2010, p. 69).

However, there are other major challenges, especially in the field of mental health. For example, what about those who have multiple conditions? What about those who have long term fluctuating conditions? Where are these pathways leading?

The problem of condition specific pathways

As an integrated care pathway relates to people with a specified condition, problems arise when people have multiple conditions which may span a range of ongoing physical and mental health challenges:

Multimorbidity matters because it is associated with reduced quality of life, higher mortality, polypharmacy and high treatment burden, higher rates of adverse drug events, and much greater health services use (including unplanned or emergency care). A particular issue for health services and healthcare professionals is that treatment regimens (including non-pharmacological treatments) can easily become very burdensome for people with multimorbidity, and care can become uncoordinated and fragmented (NICE, 2016, p. 17).

Following separate protocols for each condition can be detrimental to the person and costly for services. NICE Guidance on multimorbidity (NICE, 2016) emphasises the importance of a personalised assessment and an individualised management plan (in line with person's individual needs, preferences for treatments, health priorities, lifestyle and goals) in "improving quality of life by reducing treatment burden, adverse events, and unplanned care" (NICE, 2016, p. 8).

The problem with linear pathways

Typically, care pathways are linear in nature: crudely, the assumption is that a person will be diagnosed, receive treatment and support in line with the care pathway, and then be discharged. The reality is that many (if not most) mental health conditions fluctuate. Traditionally, when people remained within specialist community mental health services, the support they received could be adjusted to accommodate these fluctuations. With a move to primary care as the focus of long-term support, people will need to move in and out of secondary services as their needs dictate.

This means that there must be strong links between primary and secondary care and it must be easy to move into and out of secondary services. In order to make this efficient, it is important that a person can go back to the team who knows them when their problems become worse. Yet increasingly this is not possible. People can re-access secondary mental health services, but usually through some form of "single point of access" or other initial assessment portal through which everyone who accesses the service must go.

On the one hand, this means that people cannot leave the service secure in the knowledge that they can come back to see those who know them when their problems get worse. This makes many people reluctant to leave services: as one person's mother said to us "we would be happy to go if we knew we could come back to the people we know, the people who know us, if things get worse".

On the other hand, it too often means that, when someone is in crisis, the whole process of assessment and treatment starts anew and previous knowledge of the person and the challenges they face is lost. For example, when someone is admitted to an inpatient ward, typically a standard assessment is performed and a new care plan developed. Then when they are discharged, the same thing happens in the community team. This is fine if the person is new to the service, but if they have been admitted (often multiple times) it is not.

If someone's fluctuating condition takes them into and out of secondary services then what we need is not a linear pathway, but a circular pathway. One in which a person can move seamlessly between inpatient, community mental health and primary care. This means they need a support plan that includes primary, community mental health and inpatient care. Rather than doing a new assessment and support plan each time a person moves, these moves could be part of a single plan. Then all that would be required in the form of assessment would be to ascertain whether there were any differences from the previous time that required adjustments to the plan.

Pathways to where?

One of the defining characteristics of care pathways is an explicit statement of goals (Schrijvers *et al.*, 2012). Traditionally it has been assumed that health services are about the elimination of deficits, dysfunctions and problems. However, in an era where long term conditions (for which there is currently no "cure") account for 70 per cent of health and social care spend, such an overarching purpose must be called into question. In his 2014 Reith lectures, Atul Gwande:

We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being – and well-being is ultimately about sustaining the reasons one wishes to be alive.

Medicine must shift from a focus on health and survival to a focus on wellbeing – on protecting, insofar as possible, people's abilities to pursue their highest priorities in life (Gwande, 2014, p. 7).

The traditional focus of mental health services has, like other parts of the health system, been on symptom removal. Therefore most of the evidence base is directed towards ways of reducing symptoms, and this has formed the goal of carer pathways. However, with a greater emphasis on recovery – rebuilding a meaningful, valued and satisfying life – we need to move away from a

primary focus on “getting rid of problems” to a primary focus on “rebuilding a life”. This involves, as Gwande (2014) says, “sustaining the reasons one wishes to be alive” and enabling people “to pursue their highest priorities in life”. Treatment and therapy may be important, but they are not an end in themselves.

With such a shift in focus, the goals of care pathways become less clear: each person has different priorities and reasons for wishing to be alive, and different interventions may be appropriate for different aspirations. Therefore it no longer makes sense to develop pathways for people who have different specific conditions because the purpose of our treatment and support must be to enable people to do the things they value and pursue their priorities in life. Pathways need, therefore, to be highly individualised. They must start by finding out what is important to people and be directed towards helping the person to pursue their priorities.

The “patient in our services” or the “person in their life and community”?

Traditionally, with a primary goal of diagnosis, treatment and symptom reduction, we have started by thinking about “the patient in our services”: what is wrong with them and what we can do to put it right. We have usually only explored the person’s history, strengths, aspirations, values, beliefs and social circumstances, in so far as they inform decisions about diagnosis, treatment, support. We think about a person’s needs in terms of what we have to offer (therapies, supports, care settings), and it is these which are defined, on the basis of the “symptom reduction” evidence base available, in our care pathways. This focus on what services have to offer tends to cut people off from their communities and our prescriptive care pathways render both staff and patients passive recipients of the process (Hall, 2010).

In recovery focussed services we must move from thinking about “the patient in our services” to “the person in their life and community”: where they have been, what has happened to them, where they are now, what they have got going for them, what matters to them and what they want to do in their life. The primary goal is to help people to live the life they want to live, do the things they value and be a valued part of their communities.

This means we need to think beyond what services have to offer. We need to recognise the person’s own resources and resourcefulness, their circles of support outside our services and the resources available in their communities – and how we can use our resources to support their resources. People using services are thus transformed from passive recipients to active agents. Staff providing support also become active agents in working with the person to co-produce plans that enable them to move forward in their lives. Relationships are of the essence: relationships that inspire hope, and help the person to take back control over their life.

A recovery pathway is quite unlike a care pathway. A care pathway describes people’s needs in terms of what we have to offer and is directed towards getting rid of problems. A recovery pathway describes an individual’s journey of rebuilding their life. It may involve services, but it will also involve lots of other things.

Unlike a care pathway which is directed towards people with a particular condition, a recovery pathway is highly individualised. It starts with what is important to the person in life and is directed towards helping them to achieve this by working together: exploring ways of getting around barriers and enabling the person to use their own resources and those available to them in their networks and communities.

Treatment and therapy may be part of this process. We have a duty to share our expertise, and the evidence base for it, with those whom we serve. Yet in doing this we must be “on tap” not “on top” (Perkins, 2012). Instead of directing what people receive based on evidence based care pathways we need to make our expertise available to the people we serve, and work with them to decide whether any of our interventions could usefully form part, but only a part, of their recovery pathway.

Notes

1. www.england.nhs.uk/integratedcare/
2. www.england.nhs.uk/2015/03/integrated-pathways/

References

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Further reading

Department of Health (2013), *Improving the Health and Well-being of People with Long Term Conditions*, Department for Health, London.