

Patients' and Carers' Journeys through older people's mental health services: powerful tools for learning

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Abstract

Mapping the patient journey is a way of investigating the experiences of people using older people's mental health services, particularly those with a dementia. It is a useful concept for patients and their families and enables them to tell their stories in a way which carries the potential for improving and developing the service. Similarly it is a useful concept for health and social care professionals in giving them the opportunity to understand, and reflect on, how their services work in practice for users and carers and how they might be improved. The collaboration between patients, carers and professionals may itself bring about broader benefits and changes in culture for the individuals and services involved. The West Midlands Older People's Mental Health Collaborative has encouraged the use of mapping by Collaborative teams in order to identify areas for improvement work.

Keywords:

Care pathway; patient journey; process mapping; older people's mental health; user and carer involvement.

The population is ageing, and the proportion of older people living with a long-term illness or disability increases with age (Office for National Statistics, 2005). Increasing numbers of people are living in the community with illnesses which impact on their everyday lives, and with predicted demographic changes this will increase further over the coming years (Toofany, 2008). Within older people's mental health services, dementia is an example of a progressive life-changing illness: however other illnesses, which may be less commonly associated with later life, e.g. recurrent depressive illness, schizophrenia, impact powerfully on the people living with them and their families (Age Concern England, 2007).

There is growing interest in patients' and carers' stories (narratives). These stories have several potential roles:

- They can be valuable to users and carers in helping them share and make sense of their experiences,
- They can be powerful tools in educating staff working in health and social care (Bleakley, 2005).
- They can be used as a way of analysing health and social care services provided in an attempt to improve and develop both the services and the ways in which the staff work within them (Blickem & Priyadharshini, 2007).

Context: Stories, narratives, journeys

There are different ways of investigating the experiences of patients and their families. Divinsky (2007) writes that 'stories offer insight, understanding and new perspectives, and argues that they can help people see different ways of doing things. She goes further in arguing that narrative medicine carries the potential for ameliorating the burnout, exhaustion and disillusionment of healthcare staff, by preserving, or even teaching, empathy. Charon (2007) argues that narrative training enables students to form stronger therapeutic alliances with patients and to have greater understanding of patients' and others' perspectives.

Wilcock, Brown, Bateson, Carver and Machin (2003) describe a process for listening to patients and carers and interpreting their experiences in order to improve care (the Discovery Interview Process): their focus is on local quality improvement projects. A similar concept is mapping the patient journey (Cayton, 2004): a way of looking at a person's experiences over time.

When someone first develops symptoms of what proves to be a dementia, they, and their families, start on a journey which only ends when they die. There is a growing realisation that the journey itself is as important as the beginning (first symptoms, recognising there is a problem, seeking help, getting a diagnosis) and reaching the end (death): quality of life is at least as important as the length of life (Lapsley & Groves, 2004). A series of policy documents and reports over the last few years have highlighted the need to

provide easy access to services, an early diagnosis, and to manage the transition from the uncertainties of mild cognitive impairment and changes in personhood through to the losses that dementia brings (Audit Commission, 2002; Department of Health, 2001; Woods et al., 2003).

Patients' stories or narratives have attracted increasing interest over recent years (Frank, 1998; Greenhalgh & Hurwitz, 1998) and can be a potent learning tool (Benbow, Taylor & Morgan, 2008). They are known to offer a way to make sense of the strong emotions which may accompany a chronic illness (Greenhalgh & Hurwitz, 1999). One way of structuring a patient's narrative and using it in analysing and developing services is to use process mapping (CSIP, 2008a).

Process mapping can be a useful diagnostic tool for examining how a service is functioning and where problems are occurring, and also a helpful tool for individual patients, carers and professionals. We describe the uses of patient/carer journey mapping from the perspective of an older people's mental health collaborative in the West Midlands using dementia as an example of a chronic progressive illness.

Is the patient journey a useful concept for patients and their families?

For many patients and their families the illness journey is a new experience through uncharted territory: there is no A-Z or road atlas and Koppel & Dallos (2007) have described it as a journey into the unknown. From diagnosis,

through treatment and to the end of life, the path often is not easy, and may be seen as a biblical journey of epic proportions by those facing it. No-one can predict the twists and turns of the journey or how long it will last.

Fernandez, Cortes & Tarragona (2007) offered a useful metaphor when they described their learning journey poignantly as 'making the path as (they) walked': translated from Antonio Machado as follows

Traveller, there is no path

You make the path as you walk.

Some people are experts in their illness, others aren't and some people don't want to be expert in their condition (Shaw & Baker, 2004). Despite this, the experience, life skills, coping styles, family supports and expertise that patients and carers have is valuable to understanding their views and situation, and influences their journey. They may well be relying on health and social care professionals to provide them with information about the route, and support as they move along it (Woods et al, 2003). The process of mapping their journey can give patients and their families the opportunity to tell their stories, to make sense of their experiences, and to reflect on what has happened to them in the company of family and supportive professionals (Dartington, 2007). In addition, knowing that they have contributed to identifying ways in which professionals and health/ social care organisations can improve their services can be worthwhile outcomes for all concerned. It involves service users and carers becoming more than passive receivers of care (Calnan, 1997).

Is the patient journey a useful concept for professionals?

With a complex disease process such as a dementia, there is clearly no single patient journey, although the concept of an ideal journey is seductive. Ideas of the 'ideal' journey differ between healthcare professionals, people with dementia and their carers (Woods et al., 2003). The majority of literature available that provides examples of the patients journey or what Aronson calls 'autopathography', fails to discuss dementia at all (Aronson, 2000). Mapping their journey with a patient or their family can give information about that person's experiences which may, in turn, give useful information about how the services they have been using have worked well, have failed them, or have been sorely lacking. Understanding the process from patients' and carers' perspectives is essential if the patient's journey is to be well managed by the professionals working with them and the organisations involved (Lapsley & Groves, 2004). Potentially this information can also be used in service development and improvement: it is in any case essential feedback for service providers and their commissioners and lets those who deliver (and commission) a service understand the journey from the patient and carers perspective (CSIP, 2008b).

Process Mapping as a useful tool along the journey:

There are many different sources of information to help to map the journey, and which sources are selected will depend to some extent on what the intended outcomes of the process are. Potential sources include:

- looking through records
- physically following a person's journey
- interviewing the person
- interviewing their carer
- getting views and information from key personnel
- getting all staff involved in the journey together (CSIP, 2008a; CSIP, 2008c).

The West Midlands Older People's Mental Health Collaborative has encouraged members to carry out mapping in conversation with patients and/or their carers in order to look at how their services are operating, to consider what could be done to improve the experience for both patients and carers and to look at what actions project teams might concentrate their improvement efforts on. This has been done in varying ways from a formal structured way to an informal facilitated conversation. It is helpful to consider different ways of setting up the mapping exercise. Questions to consider (NHS Modernisation Agency, 2002; CSIP, 2008a; CSIP, 2008c) include:

- Where should the mapping be carried out? The process needs careful planning and management with involvement of the whole team needed.
- How might the environment facilitate or constrain the conversation? Process mapping and recreating the patient journey needs to happen in a situation and environment such as an 'away day' or series of events to allow the team to focus without distractions and be productive. Some individuals may

also need to work alone or in small groups depending on their role and needs.

- How do we help patients and carers to feel at ease? Examining practice and process is not complicated but it needs to be viewed from the patient and carers perspective rather than from a professional's viewpoint. The involvement of service users and carers during the process is vital, as is listening to their views on service provision and delivery.
- Who should be present and how will they affect the mapping process? Involving a cross section of relevant professions and disciplines from grass roots level is important. A range of service users and carers from all cultures is also necessary to ensure a broad range of experiences and journeys.
- How long should the process take: would it be better carried out in several interviews/ sessions? The length of time taken will depend on the wishes of those involved, the needs of the service and the journeys being mapped: more than one session will ensure that mapping is comprehensive and inclusive.
- How will the journey be captured/ recorded? Having an idea of where the journey starts and ends is useful, although patients and carers may have their own views on this. Flip charts, post it notes and a roll of wallpaper or similar are good ways of capturing ideas and mapping the journey. Journeys need to be mapped before a preliminary action plan can be created.

- Who needs to be involved in order that actions can result?
Project leaders and change agents need to be respected managerial or clinical staff who can facilitate, support and lead the process. Sponsors are those individuals who sanction the mapping event and ensuing action plan: they ultimately create an environment that allows change to happen. Champions are respected clinical staff who believe in the process, influence and reach those who are not so keen on change and contribute expertise and experience.
- How will any outcomes be communicated to the patients and carers? It is vital to think about involving service users and carers all the way through the process. Each process mapping team will need to identify the best and most effective ways to feedback to all involved and ensure that feedback takes place.

There are two phases to process mapping. Phase 1 involves understanding what happens to the patient, where it happens and who is involved by constructing a map of the process. The process map is then examined to assess where problems with service design and delivery may be occurring (NHS Improvement Network East Midlands, 2008a; NHS Improvement Network East Midlands, 2008b). Initially the best way to process map is to do a quick mapping exercise with essential staff choosing clearly defined start and end points. There is an argument in favour of concentrating on 'high volume runner groups' (see Table 1 for explanation of terms) which are the most commonly presenting conditions with a higher number of patients who share common characteristics (CSIP, 2008a; CSIP, 2008c) but services must

be able to accommodate all those who use them and it is possible to learn from the experiences of any users. Patients and their carers are fundamental to the whole process. Once the process is mapped, taking into account hand-offs, multiple staff involvement, changes in location, loops and parallel processes, the journey must be 'walked' (see Table 1 for explanation of terms).

Mapping one patient journey is a useful exercise. However, mapping a number of patient journeys provides much more information and more clues about how a service operates and how it could be developed (Dementia Services Collaborative & CSIP, 2008). The literature suggests that looking at a group of new referrals as they come in is a useful tool. This will involve examining where referrals are coming from, what happens to them when they arrive and how long the process takes (Dementia Services Collaborative & CSIP, 2008).

Analysing the process map:

Once the journey is mapped there are a number of questions that need to be asked by the process mapping team (NHS Modernisation Agency, 2002; NHS Improvement Network East Midlands, 2008a; NHS Improvement Network East Midlands, 2008b):

- How many times is the patient passed from one person to another ('hand-off')? Are these all necessary?

- Where are delays, queues and waiting periods built into the process?
How could they be minimised? How could an organisation cut waiting times and improve delays in appointments or treatment etc.
- Where are the bottlenecks? How can they be cut out or bypassed?
Where is there a high demand on a service? Asking the question 'why' is essential to gather the information to improve services.
- What are the longest delays? How can they be avoided?
- What is the approximate time taken for each step ('task time')?
- What is the approximate time between each step ('wait time')?
- What is the approximate time between the first and last step?
- How many steps are there for the patient? The team needs to examine where patients join a queue or a waiting list and why.
- Are there things that are done more than once? Is this necessary?
This could include tests and examinations.
- Look for 'rework loops' where activities are taken to correct situations that could be avoided? Processes that reproduce or duplicate work are unnecessary and create bottlenecks and delays for patients and their carers. Looking for ways to reduce these offers the potential for service improvement and making the patient's journey easier.
- Is work being batched? If work is being allowed to accumulate it may lead to a lack of person-centred care as the task is the focus rather than the individual, leading to delays and increased waiting times.
- Where and what are the problems for the patients?
- Where and what are the problems for carers?

- At each step is the necessary action being undertaken by the most appropriate staff member?
 - Where and what are the problems for staff?
 - Finally teams must ask themselves if the patient and carer are getting the most efficient care at the most appropriate time in the right place.
- Throughout this exercise the process must remain blame free!

Patient journeys

Below we outline two patient journeys as described by the nearest relatives of the two patients, both of whom had a dementia.

Mr A

Mr A's daughter first noticed changes in his memory, but this was overshadowed by her mother's terminally illness. Her father's behaviour was unusually negative with arguments. He was visited by his GP who treated his physical health problems and ignored the concerns about Mr A's mental health, indicating it was due to clash in personalities. When Mr A was knocked down by a car and suffered a fractured hip, the ward nurses did not appear understanding to his needs and his daughter was repeatedly asked to visit her dad as he was being abusive to them. This created difficulties for her work, as she had to take time off. When he was discharged, Mr A left hospital with no follow up support. A further visit was made to his GP who referred Mr A back to the Accident & Emergency department from which he was readmitted to the general hospital. An old age psychiatrist was asked to see him there and made a diagnosis of Alzheimer's disease. His daughter was given a contact

number to call if needed and on discharge Haloperidol was prescribed. Again there was no arrangement for follow up or post-discharge support.

Mr A's daughter contacted the local social work team to ask for help and a social worker was allocated but only gave information relating to financial support which she found to be unhelpful. Describing her father's journey she could not recall how the Community Mental Health Team became involved in his care, but she felt the assessment had been more like a social chat than a formal assessment. By this time her father was becoming disorientated and getting lost on occasions. When he was beaten up the police were unhelpful, giving the impression that the case was unproductive and just led to more paperwork having to be completed. She wrote to the social worker expressing concern and asking for support as the only alternative she could see would be to send her father to live with a relative abroad. The social worker suggested that Mr A should move to residential care, but his daughter felt she was not ready for this yet and requested assistance during the night time period. She described how the social worker asked "who will pay for this" and she felt that the social worker was implying she could be accused of negligence if she declined the option of residential care. A CPN became involved again and arranged an emergency placement at a local Resource Centre followed by day care. Problems continued: the timing of transport varied between 8.30-10.00 a.m. and Mr A's daughter needed to plan her work schedule. On one occasion Mr A was dropped off when there was no-one in the house. The only option appeared to be to use a taxi. Mr A then started on regular periods of respite in a local Home.

Mrs B

At the age of 75 her closest relative noticed that Mrs B was becoming forgetful and repetitive in conversation, repeatedly asking for the day and the time. She also started to leave taps on in the house and to wander out of the house during the night. When she wandered out at night, the neighbours were helpful: they took her in and contacted the police, who were also friendly and very helpful. Her relative took Mrs B to see her GP who advised that nothing was wrong. A social worker became involved and supported the family in asking the GP to take Mrs B's problems seriously. Mrs B was referred to a specialist and eventually had a brain scan. The whole process took 12 months. A CPN became involved and the family was advised that the memory difficulties were result of old age. Problems continued and Mrs B was later referred to an old age psychiatrist and attended a local Memory Clinic. There her memory was formally assessed over a 3 month period because her scores were varying. The assessment concluded that she had Alzheimer's disease and she was offered treatment with an anti-dementia drug.

Action points from the patient journeys

When staff reflected on the journeys described by these two relatives (and others) they identified a series of action points, including the following:

- It would be helpful to identify a key worker for each service user and their family.
- Information available to patients and carers should be reviewed along with how and when it is made available to them. Information packs might be helpful but would need to be tailored to the family's needs.

- Direct Payments had never been considered with any of the carers involved and the staff have therefore requested teaching for the team about direct payments.
- Night services are almost non-existent in the locality involved and this is something which the managers are raising at a higher level.
- Transport to day care is not flexible enough to meet the needs of working relatives: possibilities for introducing flexibility (eg using volunteer drivers in association with a local voluntary organisation) are being explored.
- Carers had not been given information about Power of Attorney – this is being addressed as part of the information review.
- Families from BME communities did not feel that their cultural needs had been met. The issue of employing BME workers is being raised with managers at a higher level in the organisation.

Conclusions

Mapping the patient journey offers a way that health and social care professionals (and the organisations they work for) can learn from the people using their services and can generate valuable information for improving the services offered. The methodology fits in with current policy initiatives (eg greater patient choice (Department of Health, 2006); patient and public involvement (House of Commons Health Committee, 2007); healthy active democracy (Andersson, Tritter & Wilson, 2006) and links in with work on

developing care pathways and integrated care (Care Services Improvement Partnership, 2005).

In addition patient journey mapping engages users and their families with local organisations in a collaborative endeavour to develop services more appropriate to local needs and may even have wider benefits in altering the relationship between users, carers and those professionals working with them by showing the practical benefits which come from listening to users and carers and respecting their views.

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Table 1: Definition of terms used in the text (from NHS Modernisation Agency, 2002).

Term	Definition
High Volume Runner Groups	Patient groups who present with the same issues/ problems in large numbers whose appearance is predictable on any given day, week or month. Their care could be standardised based on good evidence based practice. Their care could also be relatively quick if the waits and delays were removed from the system. Their care could also be mainly pre-scheduled.
Hand-off	When the patient is passed on from one healthcare professional to another
Multiple staff involvement	One patient may see multiple healthcare professionals in multiple locations throughout any one journey.
Loops and parallel processes	Different activities that take place in the same time period.
Backlog	Previous demand on services that has not yet been dealt with, showing itself as a queue or a waiting list.

Bottleneck

Part of the system where patient flow
is obstructed.
