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IMPROVING ACCESSIBILITY FOR PEOPLE WITH MENTAL HEALTH CONDITIONS

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ABSTRACT

In England, 26% of all adults report having been diagnosed with at least one mental illness. Making journeys requires a number of skills that are used at different stages of the trip, such as concentration, interpretation of information, and the confidence to take decisions and interact with other people. Mental health conditions can affect these abilities and so can affect the ability to travel. The purpose of this paper is to discuss these issues by drawing on preliminary results from a survey carried out recently by the author, and then to discuss ways in which the effects of anxiety during journeys can be ameliorated. Addressing anxieties while travelling is about increasing the self-confidence of the traveller, for example, by enhancing their travel skills through travel training and schemes to provide experience in travelling. Communication difficulties with people encountered during journeys can be addressed through effective staff training and campaigns to educate the public. Anxieties about wayfinding may be partly addressed by providing clearer navigation information, before and during the journey on paper and electronically. Mobile phone apps can be particularly useful for those able to use them because they can show the user where they are and routes to the destination.

Key words: mental health, wayfinding, confidence, travel training, accessibility, anxiety, mobile phone apps

INTRODUCTION

In England, 26% of all adults report having been diagnosed with at least one mental illness, while a further 18% say that they have experienced a mental illness without being diagnosed (1). More women than men report having been diagnosed with a mental illness. The prevalence is highest between the ages of 27 and 74, peaking in the 55-64 age group.

Mental health conditions (2) include:

- Agoraphobia, which is a fear of being in situations where escape might be difficult, or help would not be available if things go wrong.
- Anxiety, which is a feeling of unease such as worry or fear. It can have a psychological impact, which can include lack of concentration and loss of self-confidence.
- Bipolar disorder, formerly known as manic depression, is a condition that affects moods, which can swing from one extreme to another.
- Depression has psychological symptoms including finding it difficult to make decisions and loss of self-confidence and self-esteem.
- Obsessive-compulsive disorder (OCD) is a mental health condition where a person has obsessive thoughts and compulsive behaviours.
- Post-traumatic stress disorder (PTSD) is an anxiety disorder caused by very stressful, frightening or distressing events.
- Psychosis is a mental health problem that causes people to perceive or interpret things differently from those around them.
- Schizophrenia is a long-term mental health condition that causes a range of different psychological symptoms, including muddled thoughts based on hallucinations or delusions and changes in behaviour.

Making journeys requires a number of skills that are used at different stages of the trip, such as concentration, interpretation of information, and the confidence to take decisions and interact with other people (3). Mental health conditions can affect these abilities and so can affect the ability to travel. The purpose of this paper is to discuss these issues by drawing on preliminary results from a survey carried out recently by the author, and then to discuss ways in which the effects can be ameliorated.

THE SURVEY

The survey was carried out on-line by distributing a link to a questionnaire that used Opinio software made available through UCL. The link was distributed by 18 organizations using social media (mainly Twitter), websites and newsletters. The organizations included ones dealing with mental health including SANE, Anxiety UK and the Mental Health Action Group, and transport organizations such as Transport for London and Transport Scotland. In addition, three individuals with a range of contacts in the mental health field distributed the link. Responses were received between 15 May and 26 July 2018. The survey had previously been given ethical approval by the UCL Research Ethics Committee.

There were 389 responses to the survey. Four were removed, two because they were blank and two because they were from people without a mental health condition, leaving 385 useable responses. Carers completed 22 of the responses on behalf of other people with a mental health condition. Of the respondents, 24% were male, 72% female, and 4% preferred not to state their

gender. There was a wide age range with 11 under the age of 18 and 2 over the age of 70. Over half of the respondents were in the range 18 to 40.

The mental health conditions of those in the survey are shown in Table 1. Most people reported more than one condition. Anxieties, including social anxiety and panic attacks, were reported by 90% of the respondents and 68% reported having depression. Other conditions mentioned included post-traumatic stress disorder (PTSD), obsessive-compulsive disorder (OCD), agoraphobia, and bi-polar disorder.

TABLE 1 The mental health conditions of those in the survey

	Number of respondents with the condition	% of respondents
Anxiety (including social anxiety and panic attacks)	346	90
Depression	262	68
Post-traumatic stress disorder (PTSD)	83	22
Obsessive-compulsive disorder (OCD)	69	18
Agoraphobia	53	14
Bipolar disorder	30	8
Other conditions	85	22
Total	982	100

Total number of responses: 385

Since 90% of the respondents have anxiety, the rest of this paper will focus on its effect on travel. The respondents were given a list of possible causes of anxiety whilst travelling, based on evidence in the literature and were free to indicate as many as they wished (3). The causes of anxiety when going out that were reported in the survey by the respondents are shown in Table 2.

The top reason given was ‘What other people think about me’, cited by 69% of the respondents, followed by ‘Feeling out of control’ and ‘Having to mix with strangers’, both mentioned by 67%. Other factors cited by more than half of the respondents were ‘Feeling claustrophobic and unable to escape’ and ‘How other people behave’. It is clear from Table 2 that many factors cause anxiety while travelling.

The respondents were invited to give examples of how anxiety affected their journeys. Sometimes the effects can be long term. For example, a man aged 41-50 said:

‘I was on a train, travelling to London I became so anxious that I just got off at the next stop and had no idea where I was at all. It took me over an hour to regain any sort of calm and control. I then had to get back on the train to be able to go home again. I have never been able to use public transport again since. That was 20+ years ago’.

TABLE 2 Causes of anxieties that the respondents have when they go out

	Number of respondents reporting each cause of anxiety	% of respondents
What other people think about me	261	69%
Feeling out of control	257	67%
Having to mix with strangers	254	67%
Feeling claustrophobic and unable to escape	221	58%
How other people behave	197	52%
Feeling disorientated	181	48%
Failure of the bus, train or car	180	47%
Having to talk to staff such as bus drivers	175	46%
Finding suitable toilet facilities	154	40%
Getting lost	149	39%
Having to take decisions about where to go	141	37%
Not being able to obtain help	132	35%
Remembering where I am going to	76	20%
Using ticket machines	70	18%
Handling money	53	14%
Something else	55	14%
Total	2556	99%

Total number of responses: 381

The reasons cited can be grouped under themes, for example:

- Interacting with other people:
 - What other people think about me
 - Having to mix with strangers
 - How other people behave
 - Having to talk to staff such as bus drivers
- Factors associated with wayfinding:
 - Remembering where I am going to
 - Having to take decisions about where to go
 - Feeling disorientated
 - Getting lost
- Factors influenced by the actions of travel operators:
 - Failure of the bus, train or car
 - Finding suitable toilet facilities
 - Using ticket machines
 - Handling money
- Factors stemming from their mental health condition:
 - Feeling out of control
 - Feeling claustrophobic and unable to escape
 - Not being able to obtain help

It should be noted that some of these are combinations of factors: 'Feeling disoriented' and 'Not being able to find help' may be combinations of an effect of the person's mental health

condition and of wayfinding; ‘handling money’ may be to do with interacting with other people or to do with the way the transport operator requires travellers to handle money.

Interacting with other people is a major issue, for example through overcrowding:

Train became severely overcrowded at Clapham Junction. Caused a massive panic attack. I was crying, sweating, shaking etc. Someone kindly offered me a seat when my legs buckled. Someone else gave me a bottle of water’. [Female aged 41-50].

And:

‘I was in a station and the noise and crowds made me feel very anxious and disoriented - I felt like I was trapped and couldn’t see away out - I ended up crouching on the floor and crying’. [Male aged 41-50].

Strangers can be helpful:

‘I’ve had panic attacks when travelling which leave me exhausted, embarrassed and confused. I’ve needed to rely on the help of strangers to help me and get me home’. [Female aged 31-40].

However, they can also take advantage of a fellow traveller:

‘I have offered people money to give up their seat for me. Last time it cost me £30’. [Female aged 41-50].

Sometimes people suffering from anxiety feel the need to conceal their difficulties:

‘Severe panic attack on Motorway. Had to pull over and pretend the car was faulty’. [Male aged 51-60].

Bus journeys can also be challenging:

‘I have experienced severe anxiety, when traveling on a bus. I believe I had a panic attack. The panic attack was so bad that I had to get off the bus to get some fresh air, so I could calm down’. [Male aged 41-50].

MAKING TRAVEL BY PEOPLE WITH A MENTAL HEALTH CONDITION EASIER

There are various ways in which some of the issues arising from the anxieties that affect people with a mental health condition when travelling can be ameliorated. For example, one of the main areas of concern is the need to interact with other people when travelling, both fellow travellers and staff such as bus drivers and ticket office staff. One of the main ways to improve communication between staff and people with mental health conditions is by providing suitable training for staff. Some schemes in Great Britain include training about assisting people with mental impairments (4). This can include awareness of hidden disabilities, training in how to talk to people with mental health issues and cognitive impairments, awareness and understanding of their needs and ways of presenting information in appropriate ways.

A second way to improve communication between passengers and staff is the use of Travel (or Journey) Assistance (or Support) Cards which travellers can show to staff to indicate their disability or particular needs. Some cards have a pre-printed messages such as ‘I have a hidden disability’ while others have a blank space for the user to write in his or her specific message to the bus driver. This enables the traveller to communicate with a bus driver without needing to speak, enabling them to explain briefly and discretely the nature of their health condition.

It is more difficult to improve the nature of interactions with fellow travellers. The issue of the attitudes and behaviour of the public is much wider than the transport field, but travelling is an area where strangers need to mix together and sometimes need to co-operate so there needs to be tolerance of people whose behaviour seems to be unusual. One issue is the behavior of other people such as playing loud music that can cause distress. One approach is to use publicity campaigns to increase the understanding of the public about hidden disabilities including mental health conditions, since there is evidence that people with mental impairments suffer from more discrimination and prejudice than people with physical and sensory impairments (5). They are also more likely to have been victims of hate crime.

An example of a successful scheme to help people with hidden disabilities using public transport is the 'Please offer me a seat' badge introduced by Transport for London (6), which not only shows that the wearer of the badge would welcome being offered a seat, for example to avoid being in very close proximity to other travellers, but also sends out the message 'I have a hidden disability and so would appreciate some understanding without having to explain why'.

A second set of factors that cause anxiety for people with mental health condition are those associated with wayfinding. Two aspects mentioned in Table 2 are 'Remembering where they are going to' and 'Having to take decisions about where to go'. Like other travellers, people with mental health conditions require clear information both on the internet and in paper form such as maps and timetables. People with specific needs such as avoiding overcrowding would find information tailored to their needs useful. When travelling there is a need for clear information both physical and virtual, for example, mobile phone apps. This is particularly important because nearly half the respondents said that feeling disoriented was an issue for them. Reducing street clutter, simplifying the urban landscape and providing clear and consistent signposting can all assist to reduce disorientation. On buses and trains, AVI (audio-visual information), for example, stating the final destination and the next stopping point, can provide reassurance and enable the traveller to prepare to alight. In the survey, it was found that many respondents use mobile phone apps to navigate and find information such as the arrival time of the next bus or train, which can provide useful reassurance.

39% of the respondents said that getting lost was a cause of anxiety. Carrying a mobile phone can help to address this issue by showing the user their current location and how to find the way to their final destination. It can also enable them to communicate with a family member or friend for reassurance and advice. There are apps available that enable a carer to keep track of where a traveller is and to set off alarms for the carer if the traveller deviates from their proposed route, so that they can communicate with the traveller and provide advice (7, 8).

'Safe Place' schemes are another way to provide to assistance to people who become lost. These involve the person carrying a card stating their carer's contact details, and local shops and service providers carrying the Safe Places logo and having trained staff. A cardholder with difficulties can ask the member of staff to contact their carer and wait while they come to collect them, if that is their desired course of action, or they can sit in a quiet space until they feel better.

Some of the factors that cause anxiety are partly under the influence of transport operators. Using ticket machines makes 18% of the respondents feel anxious. Machines that sell tickets for trains in Britain are often confusing. It would be sensible to have identical machines at all railway

stations, so that a user who has learnt to use the machine at one station, can use a machine at any station. The machines should be intuitive to use, so that someone who lacks confidence or has a poor memory can find their way through the ticket buying system easily. Handling money is an issue for 14% of the respondents. This may be partly to do with the attitudes of staff receiving the money not being as patient as they might be, because they lack understanding of the difficulties that some travellers have. These two causes of anxiety could be overcome by using stored value cards that enable the traveller just to touch the card onto a card reader. A major issue for the operator is the need to be able to charge the appropriate fare for the journey made, but this issue has been overcome in many cities including London where the Oyster system has worked successfully for many years. Alternatively, people with mental health conditions can be provided with free travel passes.

Finding suitable toilet facilities is an issue for all travellers, but may be a significant cause of anxiety for people with mental health conditions. Investment in the construction and management of more toilet facilities can help to overcome this issue. If the lack of such facilities is deterring some people from travelling because of their anxiety, investment in such facilities should generate more ticket revenue since it will enable more people to travel.

Failure of the bus, train or car affects everyone, but may be particularly distressing for people with a mental health condition who may feel disorientated if they need to make a different journey from the one that they are used to making. In the case of public transport, the operator needs to provide understandable information about what has happened and how to reach the destination for each traveller. Some people may be able to do the latter for themselves using mobile phone apps, but they need to have the confidence to do this, and may feel stressed even they can do so. A person suffering a failure on a car journey, for example the car breaking down, will need access to help from a person who has received suitable training.

Some of the approaches described above may help to address anxieties associated with feeling out of control and not being able to obtain help. Issues associated with feeling claustrophobic and unable to escape may be assisted by changes to the design of vehicles, such as having doors and windows that can be opened manually, but this may conflict with other concerns of designers such as passenger safety and comfort.

Another approach to improving the confidence of travellers is through enhancing their travel skills through travel training and schemes to provide experience in travelling. Travel training provides tailored and practical help in travelling by public transport, on foot or by bicycle. The objective is to help people travel independently with confidence. The term 'travel training' is used to refer to a range of comprehensive schemes or programmes and can take various forms. Travel training usually involves classroom exercises and journeys with a trainer on a one-to-one basis to provide experience and to give people with mental impairments and others the confidence to make unaccompanied journeys. There are also travel buddy schemes that offer one-to-one training, usually concentrating on practical aspects of making a journey. They are usually aimed at people who are able to use public transport but who require extra short term support, boosting their confidence and capability and enabling them to be independent. Another approach is to provide experience of using particular aspects of a journey such as travelling on a train or using a bus station by offering group tours so that people with particular concerns can gain experience and become more familiar with various aspects of travelling.

CONCLUSIONS

Many people in Britain have a mental health condition. This paper has examined the travel needs of people with mental health conditions, particularly those who suffer from anxiety when travelling. A survey carried out by the author has revealed how complex some of the issues faced by such people when travelling. Two of the main areas where they have difficulty is interacting with other people, both staff and fellow travellers, and wayfinding. There are also some issues associated with travelling such as dealing with ticket machines and handling money. Other issues include finding toilet facilities and failure of the train, bus or car.

The paper has shown that there are various ways in which some of these difficulties can be ameliorated, for example, staff can be given better understanding through effective training. It is more difficult to educate the public, but campaigns may be effective and there are schemes such as the 'Please offer me a seat' which may encourage the public to be more empathetic. Anxieties about wayfinding may be partly addressed by providing clearer navigation information, both before and during the journey, both on paper and electronically. Mobile phone apps can be particularly useful for those able to use them because they can show the user where they are and routes to the destination. Some apps allow a carer to track where a traveller is and to indicate if they deviate from their planned route.

Addressing anxieties while travelling is about increasing the self-confidence of the traveller. This can be done directly by enhancing their travel skills through travel training and schemes to provide experience in travelling.

Overall, there are a number of ways in which the anxieties that some people with mental health conditions have when travelling can be ameliorated, but probably the more effective is to increase the understanding of staff and the public that many people need help and support whilst travelling even though the cause of those needs is not visible.

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