What can we learn from service user memoirs? Information and service user experience

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Summary Service user memoirs are frequently reviewed in *The Psychiatrist* and other related journals. Some academic publications include first-hand accounts of mental ill health, and there is a lively market for autobiographical books and articles about mental illness. But clinicians already have extensive contact with service users and it might seem unlikely that they have much to gain from reading memoirs. In this article I suggest that the greater depth of reflection in published memoirs means clinicians do in fact have something to learn. I illustrate my argument by showing how memoirs cast a light on the world of information and conclude by suggesting reasons why memoirs raise issues that are of increasing clinical importance.

Declaration of interest None.

In a section called ‘What to expect of your psychiatrist in the UK?’, the web page of the Royal College of Psychiatrists summarises what it is that psychiatrists do (www.rcpsych.ac.uk/mentalhealthinfo/treatments/psychiatrists.aspx). It presents psychiatrists as being highly trained medical professionals who have a number of special skills. These skills are described as the ability to assess a person’s state of mind using the biopsychosocial model, diagnosing mental illness, and using a range of psychological treatments and medications to help a person recover. We might see this list of attributes as being accurate and fair, a reasonable summation of the day-to-day work of psychiatrists. We might also harbour some reservations based on perceived discrepancies between this summary and what it is we think psychiatrists may be expected to do. What is clear is that it is also written with a view to what the reader expects. The list of skills is not information transmitted into a vacuum of ignorance. Instead, and quite properly, the website takes into account the knowledge, assumptions, preferences, beliefs, and even prejudices that we might take to be typical of users of the website and, perhaps, widely distributed in the general population. In other words, it considers the needs of the audience.

In this case it appears that one perceived audience need is to be reassured that although psychiatrists are fully trained medical doctors, they do not just think biologically, and do not just prescribe pharmaceuticals. This emphasis makes sense not solely in relation to what psychiatrists do, but also in relation to what people think psychiatrists do. It is a corrective to what may be widespread concerns in the general public about mental healthcare being too narrowly focused on symptoms and medicines. I suggest that the phrasing of this section on the website is a small demonstration of the complexity of the issues connected to information and communication. To communicate effectively, we need to know not just what information we wish to communicate, but what the audience already knows, or thinks they know. We need to know what we might call their information needs and information preferences as a prerequisite of successful communication.

Understanding patient accounts

In this article I suggest that one of the benefits of reading service user memoirs is that they can teach us about information preferences and information needs. Although the genre is quite varied, all memoirs tend to discuss what the writer knows and does not know about their illness, how they understand and use information provided by clinicians and how this mixes and merges with other sources of information and advice. Seen in this light, service user memoirs provide privileged access into a world of information that clinicians need to be aware of to communicate successfully. By reading them, clinicians can learn more about how patients seek and process information and, perhaps, in the process learn how to communicate better.

There is a substantial and diverse research literature that addresses patient accounts of their own illness, including published memoirs. Typically, work in this area stresses that understanding a patient’s personal illness narrative is a difficult task that medical science alone is not fully equipped to deal with, but that it is nonetheless a clinically important one. To improve our capacity to understand an illness narrative, writers borrow from other disciplines, such as social anthropology, cultural studies, literary theory, sociology and philosophy. Arthur Kleinman,[1] Arthur Frank,[2] Cheryl Mattingly[3] and Alan Radley[4] may all be viewed as important figures. Much of this work is very valuable, but the field is fragmented because the borrowings are so diverse. It can be difficult to digest work that is embedded in different academic disciplines or divergent intellectual traditions. Arguments often draw on technical vocabulary, theories or discursive forms that have a considerable conceptual hinterland. This should not obscure the broad consensus among researchers that extended patient narratives, such as published service user memoirs, have great potential to the clinician. A better understanding of the world of the patient means better communication and improved clinical relationships. In fact, Rita Charon argues that clinician and patient are in a position of 'active conflict' because they understand the world in such different ways.[5] Her solution is to use conceptual tools from literary theory to help us understand patient accounts of their illness and so bridge the gap, to some degree at least, between worlds. Even if we have doubts about the way Charon frames her argument, the potential benefits to clinicians of reading service user memoirs are clear. Their depth and detail can directly reveal something of the lived experience of mental illness and, in so doing, promote good clinical practice.

I intend to use the category 'service user memoir' quite liberally. I do not here propose to establish what counts as a genuine service user memoir by means of inclusion or exclusion criteria, nor do I suggest a canon of excellence or authority. By service user memoir I simply mean descriptions of experiences and events presented as having some biographical accuracy, written by people who describe themselves as experiencing mental health problems, including those written by carers or family members. There are many such memoirs now widely available. Several have found a large readership and have become bestsellers. Notable examples include William Styron's moving *Darkness Visible*[6] and professor of psychiatry Kay Redfield Jamison's examination of her own bipolar disorder in *An Unquiet Mind*.[7] Other significant works include Andy Berhman's hair-raising tales of the excess and intensity of the lifestyle of a person with bipolar disorder in *Electroboy*,[8] and an account of a life of extraordinary inner struggle in *The Center Cannot Hold*[9] by Elyn R. Saks.[a] In *Prozac Nation*, Elizabeth Wurtzel seeks to contextualise her depression and find a wider social meaning.[10] Michael Greenberg has written an unflinching description of his daughter's bipolar disorder in *Hurry Down Sunshine*[11] that might usefully be compared with *Henry's Demons* by journalist Patrick Cockburn and his son, Henry Cockburn, who has schizophrenia.[12] An impressively insightful memoir later made into a film is *Girl, Interrupted* by Susanna Kaysen.[13] More homespun works, with smaller print runs and lesser literary ambitions can prove equally useful, for instance Brian Adams' *The Pits and the Pendulum*.[14] Ross David Burke's *When the Music's Over*[15] is rather gruelling, but it does capture something of the experience of thought disorder and of a life lived under its shadow.

Taken collectively, memoirs cast a revealing light on the wider experience of life lived as someone who is mentally unwell. This is irrespective of distortions and inaccuracies that might undermine particular works. Written at length, away from the clinician's gaze and for a wider readership, memoirs can provide insight on aspects of patient experience that may be obscured or remain hidden to busy clinicians. It is salutary to observe that many of the service users who write memoirs do not feel well understood by the clinicians who care for them. Reading these memoirs suggests there are aspects of service user life that may not be highlighted in clinical priorities, or might be neglected in the pressured realities of service delivery, but which are important to service users themselves. Memoirs are a way for service users to set the agenda, to show their priorities, and they serve as a lens through which we see the bigger picture of how their illnesses affect their lives. Some of what we see through that lens may be surprising. Stigma, for example, seems to be relatively unimportant.[16]

Information preferences and information needs

It should come as no surprise that seeking and processing information is discussed at length by more or less all memoirs. People who are unwell naturally want to know what is happening to them, why they feel as they do or have the experiences they have. In fact, memoirs concerning ill health in general medicine often take the form of a search for information.[17] Mental health is no different. Service users want information so that they can understand what their strange and painful experiences are, what they mean, what causes them and what can be done about it.

The quality of information presented to mental health patients is a cause for concern. In memoirs we frequently find patients grappling with multiple, conflicting, contradictory and competing approaches to mental health. There is a high level of disagreement and the frequency and seriousness of these disagreements is striking. A person with cancer may seek information on whether chemotherapy or radiotherapy is his or her best treatment option. There could easily be some expert disagreement about this. But they will probably not find doctors or academics telling them that cancer is mythical, or that mainline treatments are useless, or worse than useless. His or her religious leader is unlikely to suggest that cancer is caused by sin, by possession by demons, or is a meritorious spiritual state. Alternative and complementary practitioners are less likely to challenge and attempt to repudiate and displace medical knowledge. And his or her neighbour is less likely to put it all down to being weak-willed, immature or impulsive.

In contrast, take the memoir *Hurry Down Sunshine* by Michael Greenberg. Greenberg's daughter Sally is seriously unwell and has been admitted as an in-patient. She has florid psychosis and has just received the diagnosis of bipolar disorder. The psychiatrist prescribes haloperidol, the effects of which Greenberg expresses in sardonic military language: 'One phase of the war against mania has officially been won: a resounding victory over the riot in the frontal cortex of the brain's limbic system' (p. 76).[11] This is how Greenberg describes things in 'purely chemical terms', which are terms that he takes to be perfectly valid, but partial and incomplete. He is prepared to accept the biochemical plane as being an aspect of what is going on, but he is aware of critiques of this sort of approach from

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[a] Elyn Saks was interviewed in *The Psychiatrist* in 2011, **35**: 280.

psychiatry critics (among other sources) and is discomfited by the variety of other understandings available.

Not all of these critiques and alternatives sit happily with neuroscience and pharmacology. On the ward is an ultra-orthodox Hassidic Jew whose family regard his distress as a kind of spiritual advancement. This recalls for Greenberg his own religious upbringing. They say their son is holy, but, apparently, the rabbi disputes this. He says their son is ill. Greenberg's ex-wife, Sally's mother, also looks at things very differently. She is presented by Greenberg as being sympathetic to what might slightly disparagingly be called 'New Age' practices and beliefs, and she blames their daughter's bipolar disorder on the unnatural pressures of city life. She is sceptical, even hostile, to pharmaceuticals and instead would prefer a homeopathic regimen and treatment based on 'polarity therapy'. Everyone Greenberg meets seems to have a different view on what his daughter's problems are, what caused them, and what to do about it. This is not just a matter of contextual colour that is without clinical implications. When discharged, Sally is asked to maintain a self-management plan based on a particular biomedical and evidence-based understanding of her experiences. If she doubts this approach, or engages with competing or contradictory readings of her experiences, she is less likely to fulfil the requirements of her self-management plan.

Many memoirs present the onset of mental disorders in this way, with patient and carer priorities dominated by information needs as they struggle to understand new and painful experiences. Life as an ongoing service user is often characterised as an extended, and, sadly, a sometimes rather desperate search for information. The provision of information is an established part of the role of clinicians. It is believed to be associated with health benefits. Quite apart from the specific theories of 'narrative medicine' or 'therapeutic emplotment', the detailed reflections of memoirs show that, for many patients, knowing what is wrong is often almost as important as knowing what to do about it. As a person faces, perhaps for the first time, troubling and confusing experiences, they seek an explanation, a sense that these experiences are known and understood, as well as that there are effective treatments. Successful communication about this can be reassuring. More than that, it can improve clinical relationships and treatment adherence which are linked to successful outcomes. This is a longstanding reason why the information needs of patients, revealed by service user memoirs, are of great importance in psychiatry.

The truth is out there? The unintended consequences of service user encounters with information

When reading memoirs, it is the complexity and unpredictability of the world of information that leaps out. Information formally presented in clinical appointments and written materials, such as patient information leaflets, may be carefully attended to by a patient. Service users may also draw conclusions clinicians are unaware of, and they may note occasions when members of their care team disagree or have contrasting approaches. But once out of the hospital setting, information has a life of its own. Its impact is difficult to anticipate. This is where memoirs are invaluable. They show that patients are rarely passive recipients of information and are never without their own ideas, values and beliefs through which new information is filtered and interpreted. They are active consumers; they appropriate information, putting ideas together in distinctive and creative ways. They produce idiosyncratic hybrids, personal schema that may be unstable, may be responsive to external influences or subject to change that defies any known patterns, may be vague, inchoate or fuzzy. The rich detail provided in memoirs serves as a warning to health researchers. It shows how hazardous it is to use typologies to classify beliefs about mental disorders or experiences of ill health. Likewise, scales and measures of understanding, knowledge or satisfaction may be necessary, but memoirs show how subtle and nuanced the reality is and what a difficult task it is to describe that complexity.

For example, Brian Adams writes his memoir after several decades of life that have been dominated by bipolar disorder. Over the years he has encountered a lot of information. He writes, as a consequence, in a language that sounds very much like a layman's account of biomedicine. It would be easy to classify him in this way, as if his understanding is a simplified or reduced version of the current state of the evidence. In a questionnaire, an interview or a focus group he could come across that way. But a closer examination of his memoir suggests something else. In some passages he identifies with his illness ('I am manic depression and manic depression is me', p. 155),[14] but at other times he seems to have a bifurcated sense of self, as if he is two people, with a bipolar self that he identifies with in a reduced sense, and for which he has reduced responsibility. Adams seems here to have appropriated biomedical language and information to express a non-biomedical view that owes as much to spirit possession as it does to science. Also striking is a 'flattening' of experience that we may suspect is related to thinking in terms of quantified mood and might be considered an unintended consequence of information provision. Adams regards disagreeable inner states such as grief, sadness, alienation, heartache and ennui as being essentially the same state that varies only in quantity and which may be accurately represented by a 'mood score.' In contrast, Andy Behrman can scarcely comprehend the concept of mood and fails to see how it applies to him: 'During the third session [the psychiatrist] starts talking about moods. Mood swings. Highs. Lows. Cycles. What is this mood thing she's talking about?' (p. 187)[8] When Behrman accepts his diagnosis, it appears to have the opposite effect than for Adams, increasing his sense of responsibility. But, in writing the memoir, he does not ever think comfortably in terms of mood.

Two processes suggest that information issues will become increasingly clinically significant over the coming years. The first process is the trend in mental healthcare towards patient self-monitoring and self-management. In particular, care for long-term conditions is increasingly being shifted to the sort of self-management that Sally in *Hurry Down Sunshine* was required to follow as part of her discharge. The positive effects of quite modest behavioural or cognitive changes structured around a self-management plan are increasingly being recognised as a likely means of reducing relapse, limiting symptoms and promoting health for individuals with many types of psychiatric disorder.[18,19] As we have seen, self-management plans are vulnerable to contradictory information or advice. The second process is the revolution in the availability of information. The internet and other technological advances have made vastly more information about mental health accessible.[20] In doing so they have unsettled the relationship between doctor and patient. Patients are now in a position, if they are able and willing, to access pretty much the same information as the doctor. A striking example of this is found in *The Center Cannot Hold*, where the author, diagnosed with schizophrenia, prepares for a clinical assessment by reading academic articles published by her assessor, including one which reviews questions to ask in a clinical assessment. It seems that the questions the assessor had argued for in the article were exactly the questions he asked in the assessment. Saks found herself forewarned and forearmed. These two processes make it probable that information and communication will become more salient in clinical practice and research. A tolerant neglect of the issue might have been safe in the past, but it certainly is not now.

Conclusions

What these examples remind us is that something is perhaps missing from the list of skills on the Royal College of Psychiatrists' website mentioned in the introduction. As well as observing and asking questions to gain an impression of a patient's mental state, memoirs show how important another part of the psychiatrist's role is: provision of information. It is easy to forget the amount of information encountered by patients outside the consulting room and how this has a fluid and unpredictable life of its own. Memoirs contain extended reflections that far outweigh anything that may be communicated in routine clinical appointments. This is something that psychiatrists can learn about from service user memoirs and use to improve clinical communication.

Patients also draw on service user memoirs when trying to understand their own illness. Information issues as they affect patients are a strong example of what can be better understood if we do attend to published memoirs. The rise of self-management and the information revolution mean we can expect information issues to be of increasing importance in coming years.

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