

## **‘Read this, it’s good for you!’ Using qualitative methodologies to explore service user needs and strategic aims.**

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### **Introduction**

This paper aims to produce a comprehensive analysis of the use of qualitative methods to investigate consumer health information and treatment schemes in UK public libraries. It posits the need to examine the strategic aims of the schemes, alongside the experiences of the service users, to identify gaps between perceived service provision and service user needs. The paper explores this qualitative methodology in the context of the more typical quantitative user statistics, and demonstrates that using qualitative methods can help to identify areas for improvement in services. The paper focuses on the use of interview analysis, participant observation and document analysis. The importance of including the voice of the service user in service design and delivery has grown in the UK in recent years, and this paper explores one method of ensuring that this occurs, within a context that enables service providers to think reflectively about their aims, objectives and implementation.

Focusing on a more inclusive analysis can aid health information specialists by creating a locally-situated piece of research that emphasises a variety of perspectives and allows service provision to be service-user led. In this case, the views of service users with long-term mental health conditions will aid the development of a more robust model of bibliotherapeutic practice. This paper also engages with the wider interdisciplinary debates concerned with service evaluation, examining their role in the provision of health information. It encourages healthcare information providers and librarians to think more widely about the performance indicators they utilise and encourages a more in-depth approach to service evaluation to ensure improvements in services are linked to service user needs. To provide a context for this work, the paper will begin with a brief discussion of the concept of bibliotherapy, and a short explanation of how such schemes contribute to current healthcare policy initiatives in the UK.

The paper will conclude that, while there is a place for evidence-based practice in healthcare information provision, this can silence the voice of the service user, and produce one-dimensional research in which the experiences of those who use services are not considered. It also demonstrates the need to shift away from purely statistical analyses of library service evaluation, which can gloss over the experiences of service users and stifle service innovation.

### **Hierarchies of evidence: a context**

Currently, there is a trend in the UK towards the use of Evidence Based Medicine (EBM) to define treatment options. While this can be said to be a positive step, placing emphasis on building a strong basis of research, there are some issues that need to be considered with this approach. Initial criticisms of EBM noted the limited role of clinical expertise and experience, and observational data (1). Other researchers note flaws in the evidence base itself, including publication bias leading to an overstatement of the effectiveness of a treatment (2). However, more recent criticisms focus on the absent voice of the service user (3), and it is this concept on which this paper concentrates.

Researchers in healthcare who are aware of EBM will also be aware of the model of a hierarchy of evidence, with systematic reviews of randomised controlled trials (RCTs) considered to be 'gold standard' or 'grade A' evidence. Recent work notes that these hierarchies have outgrown their usefulness (4), and can be considered to only represent one set of assumptions about the concerns of research – that of the effectiveness of treatment. Whether or not a treatment actually works is obviously important, but as Booth discusses, there are other considerations that need to be taken into account, including the saliency, acceptability and appropriateness of the treatment (4). The use of qualitative methods focused on the exploration of the service user experience aims to fill this current gap in the evidence base.

A number of Department of Health (DH) reports informing National Health Service (NHS) practice in the UK have also been influential in encouraging researchers to think differently about the data they collect and analyse (5-8). While the RCT remains important to consider questions of effectiveness, cost effectiveness and safety (4), there is also a need to capture data that cannot be represented statistically. As Williams and Martinez (9) comment 'services are re-thinking *what* they offer – and *how* they offer it'.

This paper aims to explore some of the reasons for the need to examine the service user perspective, taking examples from the UK healthcare system, in which a shift in acceptable evidence has begun to occur. It will also look at some issues with this shift, and raise concerns of researchers involved with collecting and analysing the service user perspective. It will analyse reasons for using these methods, and think about how they can be used in the wider context of providing evidence for healthcare information and library service evaluation.

### **Bibliotherapy: a brief introduction**

Bibliotherapy services are often run in partnership between healthcare services and public libraries, and thus their evaluation needs to be acceptable to both healthcare providers and library services. While there has been more of an acknowledgment of the role of service user in healthcare research, and to some extent it is present within the sphere of librarianship service evaluation in practice, there is still a focus on the collection of statistics; for example, book issue figures, visitor numbers, and enquiry types. These numbers can be said to under-represent the role of the library, and negate an understanding of the breadth and depth of its role in information provision and management.

Several influential reports focusing on evaluating public library services do use qualitative methods, but these techniques have not yet been applied to bibliotherapy schemes in any depth (10, 11). This paper therefore posits a different approach to service evaluation, which is also in line with the revised focus on the healthcare evidence base. It presents the perspective that there is a need to talk in depth with service users to ensure that the impact of service provision is captured in a representative format.

Bibliotherapy contributes to mental health care and can be defined as using either fiction or self-help books as a treatment for mild to moderate depression and other mental health issues (12). The self-help books used are clinically recommended, based on principles of cognitive behavioural therapy (CBT) and contain exercises and specific techniques to control anxiety and negative emotions. There are several lists of clinically-recommended books that can be used to run a self-help bibliotherapy scheme and there are over one hundred schemes currently operating in the United Kingdom and Ireland (13). These schemes typically operate

through the local public library, and involve lending self-help books, based on the recommendation of a medical professional, and are often referred to as *Books on Prescription*.

Bibliotherapy can also involve using fiction and poetry, and is referred to here as creative bibliotherapy to separate it from the self-help model discussed above. Creative bibliotherapy also aims to help people with conditions like depression, but it does not necessarily contain advice or talk about depression specifically. There are fewer creative bibliotherapy schemes in the UK, and work can be conducted with individuals or in groups. The service user is then encouraged to discuss the book, either with the bibliotherapist or in a group environment. These schemes are often run in the library, for pragmatic reasons of access to a collection of literature.

There are several gaps in the evidence base surrounding bibliotherapy. While there are a large number of RCTs, several systematic reviews, and meta-analyses of its effectiveness in clinical treatment (14-16), it is more difficult to examine the use of this treatment in practice. Public library service users often self-prescribe books in self-help schemes, meaning there is limited (if any) contact with medical professionals. No RCTs of creative bibliotherapy have been conducted to date, but previous research demonstrates that the methodologies utilised within evidence-based practice do not provide the most suitable format for investigating the impact of bibliotherapy (17). Evidence-based practice is biased towards biomedical conclusions, and that the reliance on RCTs means that 'subjective, personal experience' is lost (17). The relationship between the reader and the text needs to be investigated to ensure that the voice of the individual is included (17).

This leads to a number of questions regarding the evaluation of bibliotherapy schemes. In libraries, there is a trend towards evaluation via statistical representations of the number of books borrowed, or the number of people attending a group. Again, the 'subjective, personal experience' is missing from this evaluation (17). Arguments have been presented for revising the scope of measurement, with qualitative researchers asking: 'how can book issues in an inner city community tell us anything of what those books are being used for when borrowed?' (18). A changed focus, moving away from statistical issue figures, is especially important in an era in which the role and value of many library services is under debate (19). As Albert Einstein commented 'sometimes what counts can't be counted, and what can be counted doesn't count' (20). This quote emphasises the difficulty of assessing the impact of bibliotherapy schemes, though it does not negate the necessity of doing so.

### **Changing agendas, changing methods: the UK context**

While EBM has become the dominant model for demonstrating the effectiveness of healthcare treatments, in the UK a number of different agendas in healthcare have led to a shift in thinking about the role of the service user. These agendas can be defined as:

- personalisation
- choice
- expertise/ knowledge
- empowerment

These changing agendas have been affected by external factors, for example, the increased amount of healthcare information available via the internet has changed the doctor-patient<sup>1</sup> interaction, with the healthcare service user sometimes questioning treatment options and

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<sup>1</sup> While the dominant model within the healthcare sector still refers to people who use its services as 'patients', for the purposes of this paper, the more neutral – and library-friendly – term of 'service users' will be used.

asking for alternatives. There have been numerous deconstructions of the revised doctor-patient relationship (21, 22) in healthcare literature. While this could be seen to undermine the role of the clinician, several studies have reported that this trend towards empowerment and knowledge actually benefits the relationship (23).

Service user empowerment has been formalised in the UK under the banner of the Expert Patient programme (24) and the Patient Choice agenda (7). This aims to provide information to enable service users to manage their long-term conditions like depression, diabetes, and COPD independently, enabling them to make informed decisions about their healthcare and lifestyle choices. However, there are questions about whether service users want to take responsibility for their health in this way (25). Previous research has concluded that in some cases, service users had 'problems delineating what was just part of ordinary life and what was a sign of disease. They relied on doctors to sort out the problem and frame a diagnosis' (26). This problematises empowerment and choice, as the option 'not to choose' is not available to service users.

The Patient Choice agenda can be defined as the UK Governmental policy to 'empower patients, reduce inequalities in access to healthcare, and improve health outcomes for all patients' (7). This programme aims for doctors to provide information to service users to enable them to make informed decisions on their treatment. Nevertheless, there are conflicts between the *Patient Choice* agenda and EBM. As Mol (27) states: 'there is a strange tension between the movement for evidence-based medicine and the call for autonomy of the patient.... Either you take it that making good decisions is a professional task... or you do not engage in weighing and evaluating, but turn your data into 'information'. Thus you shift from a professional mode into a market model and offer choices to your patients'.

This 'market model' implies an acceptance of the service user as consumer. However, the structural model of access to healthcare in the UK still posits the General Practitioner (GP) as a 'gatekeeper' to secondary services. This means that the goal of 'choice' still operates within a bounded system, in which the GP chooses to refer the service user to secondary services. This focus on choice has contributed to the idea that each service user should experience a personalised service, with services tailored to their needs and conditions. A primary outcome of this shift has been the provision of personalised Information Prescriptions in the UK (28), which aim to discuss treatment choice and empowerment.

### **Service user involvement in research**

These changed agendas have led to a need for a revised set of methods. Key to these changes has been the inclusion of the service user within research and evaluation. This has not been an unproblematic development. While the importance of service user involvement in service planning is often noted, there needs to be a shift in clinical attitudes to ensure that this is conducted successfully; 'leasing power to service users as 'expert patients' is one thing. Handing back power to service users in a real and meaningful way is something else' (29). This reinterpretation of service users as 'experts by experience' means that there is a move from medicine as 'kept knowledge to shared knowledge' (29). Lupton's work (30) on the doctor-patient relationship and the asymmetry of information also reaches similar conclusions.

Reasons for involving service users in research can be succinctly defined; 'a service user's experience of distress and... service usage brings a perspective to research that could not

otherwise be achieved' (31). Nevertheless, there is still an issue that the views of one person do not represent the views of all service users (3).

Other concerns about service user involvement in research include the 'know-do' gap (32), which is concerned with the difference between what researchers wish to do, or know they should do, and what it is possible within the time and other constraints of the research project. Issues of how – and when – to involve service users have been widely debated, with some researchers suggesting that 'action research' in which service users define the research agenda and see real-time improvement in their experiences is the most ethical form of research (33). There are concerns that for some researchers, involvement with service users is simply a 'tick-box' exercise, in which genuine involvement is precluded (32). A lack of supportive infrastructure – including training, financial support, and pressures of deadlines – was also cited as a concern by researchers (32). However, these concerns show a need for the instigation of more rigorous focus on enabling researchers to work closely with service users in a fashion that will ensure that their voices are heard, otherwise researchers will not find it possible to conduct challenging yet inclusive research.

Trivedi and Wykes (34) propose ten questions concerned with research practicalities that need to be considered when thinking about involving service users in research. These questions provide a helpful focus for those thinking of involving service users in research and are listed in Table I.

Table I: User involvement in research: ten important considerations

What is the value of user involvement?	How will users responses be considered?
How will users be involved in the research process?	Will research partnerships with users be formalised?
What projects might be suitable for user involvement?	How will the proposal be jointly assessed?
What proposal will be prepared for presentation to users?	How will the project be written up?
How will the initial approach be made to users?	How will dissemination occur?

**An applied case study: connecting bibliotherapy and qualitative methods**

Bibliotherapy schemes currently operating in the UK contribute to a number of agendas defined in the above discussion of healthcare agendas. Bibliotherapy can be used to provide information to service users. It can contribute to providing a greater treatment choice for service users, moving away from purely medication-based treatment. The self-help nature of the intervention also means that bibliotherapy can be said to empower service users, who take control of their own treatment and work through the literature at their own pace. The self-referring nature of many bibliotherapy schemes also removes the 'healthcare-professional-as-gatekeeper' step of access to services.

Returning to concepts of evaluation, the previously defined difference between what can be measured and what is experienced, needs to take account of the view that 'qualitative methods such as observation, interviews and group discussions are valuable in exploring participants' experiences and perceptions of their involvement... but these methods do not easily lend themselves to routine evaluation' (35). With reference to bibliotherapy schemes, the expense of evaluation may outweigh the overall cost of the project (36). As one of the reasons for

adoption of bibliotherapy schemes is their cost effectiveness, the cost of evaluation problematises the evaluation of services, and appears to discourage the collection of in-depth views on service users.

More traditional medical research like RCTs focus on measurable symptom reduction; 'we do not hear what depression feels like, what it means to receive an 'official' diagnosis' (37). The reliance on statistical measurement reflects current mental health care practice in the UK, in which perceived symptoms are measured without reference to life histories, means that this context is absent. Moving away from this construction of measurement to one of contextualisation is controversial, as it means that the researcher is not the expert, regardless of how much they have studied – the participants in the research are the experts on their own situation (38).

### *Interviews*

For this research project, the use of individual and small group interviews, rather than questionnaires, was formulated in light of evaluation of another bibliotherapy programme (39). In this, service users commented that they would prefer to talk about their experiences, and would be more open about them if asked in person than they would be in questionnaires. The contribution of service users to the research design may not always be possible, but in this case it provided valuable information about methods of data collection. Despite the sensitivity of the subject of mental health, which might encourage a researcher to consider anonymous questionnaires, the experience of those involved in this evaluation (39) shows otherwise. While it might be more difficult to gain access to service users and establish a rapport with them in an interview, a greater depth of understanding and richness of data may also be gained.

A decision was made to ask participants in the research for topical life histories, which was in part motivated in response to the dominant medical discourse; 'symptoms are merely categorised in a disease taxonomy, and their relation to the entire life history of the patient is fragmented and obscured' (40). As previously discussed, there is a perception that there is a missing voice within the literature; 'personal meaning is the first biggest casualty of the biomedical model' (40). Davidsen's (41) work on primary care mental health notes that clinicians often interrupt stories told by patients when they have gathered appropriate clinical data from them. However, within the telling of stories and explanation of personal meaning in interviews, the interviewee constructs their own version of their life history and it need to be noted that narrative is shaped in ways that can be said to be flawed (42).

Many texts examining the role of interviews note the importance of establishing a rapport between the participant and the researcher, and it was felt that this could be achieved in this instance by explaining the position of the researcher and the research aims and objectives to the participant, to situate levels of understanding (43). Empathy and assurances of confidentiality in interviews are always important considerations, to ensure that the participant is at ease, but it was felt that they were especially important in this instance as the topic in question was a sensitive one.

When interviewing, researchers also need to remain conscious that 'the overly-directive researcher can cut off the most interesting leads and rich data' (44). Interviews were thus allowed to flow in the way of a conversation as much as possible, allowing the experiences of the participant to emerge as they wished to share them. This can be referred to as 'directed conversation' (45) and it was this ethos which was utilised within the interviews in this

research. There needs to be a degree of flexibility within an interview schedule to ensure that new angles introduced by participants can be accommodated (46).

There are several problems with conducting interviews. They are time consuming to conduct; they produce large amounts of data; this data is then time consuming to analyse. In this case, interviews were digitally recorded, and then a transcription of the interview was produced. While these transcripts were often long, the richness of the data within them was felt to justify the time taken to collect and analyse the data. Another challenge is that of trustworthiness of the data presented by the researcher (47). Audio recording of the interviews means that the researcher made a commitment to representing statements made by the research participants honestly.

### *Participant observation*

As creative bibliotherapy projects often involve group work, it was decided that it was appropriate for the researcher to observe and participate in these groups, as well as to interview group members, to provide a further understanding of service user experiences.

Participant observation can be said to allow the researcher to:

- Establish a direct relationship between the researcher and participants
- Examine the natural environment of actors
- Observe and describe behaviour
- Interact in everyday ceremonies
- Learn the code that enables the understanding of meaning (48)

The researcher was able to participate in a number of different groups, and to observe one group for an extended period of time. This approach could be applied to a number of situations, with service evaluations conducted via participant observation of enquiry desks or other services, which would help to examine the day-to-day concerns of service users, and could help to identify gaps in service provision. In order to understand the service user experience of bibliotherapy, the participant observations focused on:

- Interaction between group members
- Interaction between individuals and literature
- Use of literature to reflect on events in life.

Again, there are issues with conducting participant observations. The 'Hawthorne Effect' may mean that behaviour of service users is overly shaped by observation (49). Recording participant observations, either by making notes in situ, audio, or video recording can disrupt the flow of the group discussion, or make participants feel self conscious. When considering interview and observation analysis, it is important that the finished product must be both coherent, and understandable to research participants, representing their experiences in a way that they understand (50).

### *Document analysis*

When examining the views of service users, it can also be useful to reflect on the aims of the service providers. Looking at what services set out to achieve, in line with the expectations and experiences of service users can be linked into several models of analysis, including the Service Quality Model (51) and Norman Denzin's Interpretive Interactionist approach to research (50). It can be beneficial for library staff to reflect critically on perceived strengths and weaknesses of services. When contrasted with the experiences of service users, this can help to identify any gaps in service provision and improve services overall.

The Service Quality Model (51) looks at the expected service that customers imagine they will get, and the service that service providers perceive exists. It defines five gaps between expectation and perception, and tries to identify factors contributing to these gaps in order to improve the service. It is predominantly focussed on quantitative evaluation, yet can be utilised to shape thought about evaluation from a qualitative perspective. For purposes of this research on bibliotherapy, NHS white papers, library service plans and other documents were used to investigate whether or not these schemes met their stated aims. The process also helped to identify several hidden benefits of bibliotherapy schemes, in which service users acknowledged ways in which the schemes helped them that had not been originally considered as advantages of the scheme when services were planned.

Documents can be seen as 'trace' artefacts, enabling the researcher to access indirect representations of the views of those who wrote them (52). There are a number of advantages and disadvantages to this approach, including the usefulness of documents as cross-validation, contrasted with the difficulties of identifying those responsible for writing the document (52). Again, this can leave the researcher with a large amount of 'voluminous, unstructured, and unwieldy' data (53).

Document analysis is typically a supplementary method, used to provide longitudinal information, for triangulation and enrichment of the data collected via other methods (52). In this instance, the necessity of the use of documents to analyse constructions of strategic aims was noted early in the project. The official representation of the views of the organisations inscribed in the documents provided an alternate construction of the strategic aims of schemes to that presented by, for example the individual staff who could also be interviewed to provide information about the strategic aims of the project. These documents inscribe the aims and values of the organisation under evaluation, and so can be useful to think critically and reflectively about these aims.

#### *Drawing methods together*

Interpretive Interactionism (50) is an ethnographic approach, concentrating on trying to understand individual experiences and needs, which can then help to identify gaps between experiences and service provision. This approach 'allows interpretation to emerge from the stories that are told. It reveals the conflictual, contradictory nature of lived experience and suggests that no single story or interpretation will capture the problematic events that have been studied' (50). It is designed as an 'evaluative' research method, examining whether 'policies and interventions actually benefit the people the schemes target' (54).

Interpretive Interactionism looks to contrast the 'private troubles' or experiences of individuals with 'public issues' and to connect the two (50). This work on Interpretive Interactionism can also be said to examine 'gaps' between provision and experience (50). In this case, while the interviews and participant observations aimed to gather the perspectives of service users, the document analysis aimed to focus on the 'public issues' and note potential gaps between the two.

When considering validity and verification of evaluating in this manner, there are several issues. As previously discussed, RCTs and quantitative methods produce a 'certain kind of science, a science that silences too many voices' (55). It is the concern of the researcher that her work should not reflect this silence, and should instead fill previously defined gaps in the evidence base. The aim is, therefore, not to produce data that can be retested to prove validity, as per experimentation. Instead, issues such as 'verisimilitude, emotionality, personal



responsibility, an ethic of caring, political praxis, multi-voiced texts and dialogues with subjects' are considered to be evidence of the quality of research (55). There is thus a tension between the positivist criteria for valid and reliable research, and what can be defined as the 'new language' of qualitative research (47). The use of a variety of methods can also be seen as 'a strategy that adds rigour, breadth, complexity, richness, and depth to any inquiry' (55).

## **Conclusion**

The title of this paper, 'read this, it's good for you' reflects some of the benefits of focusing on the service user experience; namely the in-depth perspective that can be examined when using qualitative methods. The quote, taken from an interview with a bibliotherapy service user, was part of her reflections on mental health treatment and the independence of libraries from this treatment as an important aspect in her recovery. While it appears to be a positive quote, suggesting that someone can be told to read a specific book as it will benefit them, when taken in context, it was actually part of the service user's construction of her experience of mental health services as negative. Instead, the service user commented that she used her local public library to self-educate, using authors like Dorothy Rowe (56) to move away from a biomedical construction of mental health problems and treatment. In fact, the last thing she wanted was to be told what to read, or that it would be 'good' for her, as she facilitated recovery on her own terms.

This paper has argued for a holistic approach to both healthcare research and healthcare information service evaluation. It has examined the changed values and meanings in healthcare that have led to an acceptance of the inclusion of the service user voice in research. It has discussed promoting a commitment to community involvement that both contrasts with, and complements, EBM. The paper has examined the way in which the service user voice can be excluded from the hierarchies of evidence and the focus on statistical data which make up the majority of the current evidence base, and presented a number of alternate methods which allow the researcher to both reflect critically on their own practice, and successfully gather the perspectives of those who use their services. The use of such methods will enable healthcare to become more client centred, and to enrich current service evaluation.

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