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Experiences of inpatient mental health services: systematic review

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Abstract (247 words)

Background: In-patients in a period of crisis report poor experiences of mental health care not conducive to recovery-focused care. Concerns include coercion by staff, fear of assault from other patients, lack of therapeutic opportunities and limited support. There is little high quality evidence on what is important to patients to inform recovery-focused care.

Aims: To conduct a systematic review of published literature to identify key concerns salient to improving inpatients' experiences of inpatient mental health care.

Method: A systematic search of three online databases (Medline, PsycInfo and CINAHL) included primary research published between January 2000-January 2016. All study designs from all countries were eligible. A qualitative analysis was undertaken and study quality was appraised. A patient and public reference group contributed to the review.

Results: 72 studies from 16 different countries found four key dimensions which were consistently related to significantly impacting on inpatients' experiences of crisis and recovery-focused care: the importance of high quality relationships, averting negative experiences of coercion; a healthy, safe and enabling physical environment and ward milieu; and authentic experiences of patient-centred care. Critical elements that patients wanted to see were trust, respect, safe wards information and explanation about clinical decisions, more therapeutic activities, and inclusion of family in care.

Conclusions: A number of experiences hinder recovery-focused care and must be addressed in order to provide high quality inpatient services. Involving staff in delivering high quality care, is key. Future attempts to evaluate the quality of services or to develop practice guidance should embed these four key dimensions.

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Background

Patient experience is a vital source of evidence that can drive the provision of high quality health services [1-2]. Mental health inpatients report a range of experiences including fear of assault, concerns regarding coercion, limited recovery-focused support, and lack of therapeutic activities [3-8]. A triennial review of mental health services in England by the Care Quality Commission (2017) [9] highlighted several serious concerns about inpatient care, including wards located in older buildings not designed to meet the needs of acute patients, unsafe staffing levels, and overly restrictive care in wards far from service users' homes and families.

The NHS is under pressure to deliver timely, effective and affordable care with increasingly constrained resources. NICE, the NHS National Quality Board and others have re-stated core principles of patient-centred care including dignity, compassion, choice and autonomy [3–5,5–8] and called for a strengthening of the patient voice. Healthcare providers are now required to collect data to assess patients' experiences of care [9,10] [11, 12]. However, the impact of this data collection on services is unclear [13] because of: the diverse and poor quality feedback methods; [14] a lack of consensus about which experiences are most salient (and hence should be asked about), and limited evidence about how patient experience data can guide service improvements [13, 15]. Such challenges highlight the need for robust evidence to inform best practice, with clarity about the experiences of most importance to patients.

In response to this need, this systematic review aimed to identify the most salient experiences of people using inpatient mental health care, to inform the provision of high quality services.

Methods

The review was divided into a scoping review to ascertain the nature and size of the evidence base, and the main systematic review.

Protocol and registration

The systematic review was registered: PROSPERO 2016: CRD42016033556

Scoping review

Prior to the systematic review taking place, a scoping review was conducted to ascertain the extent, range and nature of studies, to map emerging key themes without describing the findings in full or performing a quality check [16] and to inform the main review. Six key authors known to be experts in mental health patient experience were contacted for new or unpublished reports and studies.

Patient and Public Involvement Reference Group (PPIRG)

The Patient and Public Involvement Reference Group included 10 service users recruited by the Mental Health Foundation with experience of inpatient care or caring for someone who had been an inpatient. They were invited to two meetings; firstly, to obtain their views on the themes identified in the scoping review, with the potential to add further concepts they felt had not been identified, and secondly, to obtain their opinions on themes identified in the main systematic review, and to contribute to interpretation of our findings. A full description of the patient involvement in the study is reported using the GRIPP2-Short Form Checklist in table 1.

Identification of studies for the systematic review

Guided by the themes that emerged from the scoping review, search terms and a search strategy were developed and applied to: MEDLINE, CINAHL, and PsycInfo, with an example of search terms and results reported in figure 1. Reference lists of included papers were scanned. The search deviated from the protocol in that only 3 of 5 databases were searched due to the large numbers of abstracts retrieved.

Inclusion and exclusion criteria

All study designs were considered if papers included experiences of current or former inpatients of mental health institutions. No restrictions were applied based on country. Articles were included if they reported primary research, were peer reviewed and published in English between January 2000 and January 2016. Papers were excluded if they were not primary studies; based on pre-2000 data; included children and adolescents (aged under 18 years); or not in the English language. Where study participants included both in- and outpatients, only data regarding inpatient experiences were extracted. Reviews (table 2) were noted and reference lists scanned, but excluded from the review to avoid bias.

Study selection

Titles and abstracts were screened (CM, GC) of which 20% were independently cross checked for agreement prior to obtaining full text articles (SS and CM). Full texts were obtained where the abstract was unclear. Any disagreements could be resolved by consensus (CM, GC and SS) but no disagreements occurred.

Data extraction

Using Microsoft Excel (version 2013), the data extracted included citation details, sample recruitment and research methods, findings related to key concepts and any other emerging concepts were added (CM).

Quality and risk of bias in individual studies

The quality of the studies were evaluated using the Critical Appraisal Skills Programme (CASP) qualitative checklist [79] undertaken by CM. Due to the heterogeneity of the included studies, many of which were descriptive in their approach, this checklist provided an appropriate basis for comparison between studies. The only question change in the CASP checklist was: 'Is the qualitative methodology appropriate for this study?' to 'Is the methodology appropriate for this study?'

Data Analysis

The scoping review informed the development of a thematic framework, which guided but did not restrict the Review. A narrative synthesis of the themes was undertaken [18]. As the researcher read each study an initial preliminary synthesis of the study was undertaken and emerging sub-themes identified. The researcher was then able to compare themes and sub-themes within and across studies and further develop them into the main themes. Themes were summarised in a descriptive form, allowing for the findings of all review studies, regardless of study design, to be aggregated and summarised. We used the concept of data saturation to help us decide when to complete data extraction. Saturation of data is judged to have happened at a point where no new themes are being identified in the studies when

compared with what has already been extracted [7]. It is a useful approach for large reviews where the addition of further papers is unlikely to change key findings.

Main findings

Patient and Public Involvement Reference Group (PPIRG)

Key themes identified in the scoping review were discussed in detail by group members who critiqued their content and identified additional areas such as boredom. The PPIRG provided content and face validity for the identified themes and provided real life examples of the themes from their own experiences. PPIRG also provided an opportunity to check the relevance of themes from international studies resonated in a UK context. A description of the PPI in the Review is reported in table 1 using GRIPP2.

The systematic review

A total of 4979 abstracts were screened and 116 papers fulfilled the inclusion criteria (figure 2). Two consecutive sifts were conducted due to an error in the first search of the PsycInfo database omitting 2980 hits which was identified after the first sift was completed. The first sift of 1999 hits resulted in 72 relevant papers for the review. Eleven papers were from same studies [19-21; 22-24; 25-27; 28, 29]. Following this, the second sift of 2980 abstracts resulted in an additional 44 studies fitting the criteria (total n=116). Drawing on the principles of data saturation[30], additional studies that repeated themes already identified were excluded from the main review. In total, eight studies added new themes and were included at this stage.

Sixteen systematic reviews (table 2) which investigated inpatient experience were identified. In total, 72 studies were included in the review, of which one-third were from

the United Kingdom (UK) [24-47] (n=24) [19-21, 25, 27, 31-49] (table 3). While studies using qualitative methods were most common (Table 2), studies using patient experience questionnaires and patient record data were also included. The CASP checklist identified many of the papers as being of medium to poor quality (Table 4).

Timing of data collection in included studies

Little information was provided about the timing of data collection in over one-third of papers (37%), other than describing participants as inpatients at the time [25-27, 31, 32, 35, 36, 43, 44, 48-63]. Data were mostly collected just prior to [28, 29, 45, 64-73], or immediately after discharge [20, 45, 59, 74, 75], or from former inpatients [22, 23, 34, 37-39, 41, 42, 46, 47, 63, 76-80]. This suggests that patients were recovering when experiences were elicited. In three studies, data collection coincided with a ward event (e.g. refurbishment) [81-83]. A number of studies (n=12, 17%) collected data shortly after an event such as admission [19, 21, 84-86], seclusion, sedation or restraint [24, 33, 87-92] .

Identification of key themes

Patient experience themes were categorised into four overarching themes or dimensions of experience: the importance of high quality relationships; averting negative experiences of coercion; a healthy, safe and enabling physical environment and ward milieu; and authentic experiences of patient-centred care.   These key themes accompanied by sub themes are described in detail below.

The importance of high quality relationships

The importance of high quality relationship was the most consistently reported theme. Important factors in developing high quality relationships with staff included being treated with respect, feelings of stability, recognising empathy and high quality communication [19, 23, 24, 27, 28, 35, 36, 38, 39, 51, 55, 60, 61, 63, 78, 87, 90] with staff who patients felt were trustworthy, reliable [35, 63, 69] or helpful [27, 51, 54, 62]. Good staff/patient relationships facilitated the inpatient care pathway in mental health institutions [28, 35, 39, 51, 68], and reduced the use of coercive measures [35, 45, 78]. Ward rounds were an important setting for staff-patient interaction and patients reported these as helpful and informative[44].

Potential barriers to therapeutic relationships included: *gender-specific problems* - male nursing staff were not welcome if the patient had a history of abuse by male perpetrators [36, 78] or where gender-specific cultural barriers existed (e.g. a Muslim woman supervised by a male nurse) [68]; *lack of meaningful communication* – where communication was compromised due to differences in culture, language, religion [34, 39, 57, 68], through use of coercive measures [33, 60] or where technical language used by staff was not easily understood [19]; *absence of regular ward staff* - patients were upset by the absence of regular ward staff due to office duties, shift working, or reliance on temporary staff [23, 24, 27, 28, 35-37, 39, 45, 46, 51, 54, 55, 63, 69] and having extended waits to speak to staff [24, 36, 46, 54, 77, 80, 82] particularly at ward rounds [43]; *poor staff attitude* – where patients complained that staff ignored them [57, 87, 88, 91], displayed indifference [24] or insufficient understanding of patients [78]; *inconsistent staff behaviour* – reports of staff interpreting ward rules inconsistently, causing confusion [19, 23, 27, 31, 33, 36, 46, 49, 82, 91]; *staff abuse* – some patients reported abuse by staff, including provocation, bullying, shouting or belittling of patients [19, 23, 27, 28, 33, 39, 56, 62, 78, 79, 83, 87, 88].

Relationships with other patients, and with relatives

Patients relied on other patients for information about ward activities and rules, to share experiences, and when debriefing after group sessions [22, 45, 77, 82, 83]. However, arguments and violence between patients [36, 39, 48] generated fear and isolation for some, causing them to retreat to their rooms for safety, or to abscond [23, 37, 39, 49, 65, 80].

Isolation from family caused distress, and patients reported that having a friend or family member with them would have helped with orientation [79] and as informants, to help staff with assessments and treatment plans [22, 38, 53]. However, family members felt left out of decision-making about care [92].

Averting negative experiences of coercion

The second main theme was concerned with experiences of coercion. All patients expected to be treated as 'normal human beings' [24, 29, 77] and addressed professionally, including during restraint [87]. Patients wanted the reasons for coercive measures to be communicated so they could understand them as this helped some patients trust staff and feel safe. [46, 67, 75, 79, 87]. Patients valued persuasion over threats of force [60] and coercion [78] which could bring back memories of past history of violence and neglect [33, 88, 89].

Where coercive measures were discussed in the studies, these included experiences of sedation, seclusion and restraint. It has been reported that black and minority ethnic patients are more likely to experience coercion than white patients.

Ethnicity: Two studies examined the commonly held perception that black and minority ethnic patients experienced more coercion on admission than other patients [21,74]. The

findings were not conclusive: although hospitals in the UK with higher proportions of minority ethnicity patients employed more coercive practices, although this was independent of individual patient ethnicity [2174].

Sedation: Some patients recognised that medication was important for the inpatient care pathway [20, 39, 41]. Some trusted staff to decide on appropriate sedation [32, 52] while others felt empowered to decide on timing and dose of medication when administered on an 'as needed' basis [32]. However, concerns were also voiced by patients that included lack of communication about consent, information about medication and advanced wishes [39, 52]; lack of confidentiality regarding medication [32, 42]; perceived overmedication [32, 39, 41, 46, 47, 52, 69] (including overlooked or ignored reports of side effects) [28,41]; and fear of harm during forced medication [32,20, 39, 54, 60, 78] for example patients in crisis reported a fear of being raped by staff, or dying [20, 41, 78, 88].

Seclusion: Some patients reported seclusion as helpful or necessary [79, 24, 88, 57], and feeling safe as staff were nearby [24, 57, 88, 90]. Patient concerns included having insufficient information about the reasons for seclusion [23, 24, 46, 57, 88] before or after the event [24, 57]. Seclusion was perceived as a punishment [79] and associated with limited contact [57, 88], lack of concern by staff [89], degradation and humiliation e.g. lack of facilities [24, 57, 89] or being stripped of clothing in front of staff members [61, 79, 89, 91], and violation of rights [88] and dignity [61].

Restraint: Described as forcible manual or mechanical restraint and typically involving several staff, mostly nurses [23, 60, 78, 88, 92] but occasionally security staff [78, 92]. Restraint was described negatively [25, 78, 33] and fear of restraint prevented patients from seeking help earlier [33]. There was a risk of harm if mechanical restraints were used [87], although these

were not used in all countries. Talking with staff following restraint or being allowed to examine records of the event was considered helpful [33].

In addition to the use of coercive measures, patients also described perceived punishment by staff [19, 35, 41, 80, 91] in the form of the removal of leave entitlements [35], removal of furniture and personal items [41, 91] and being able to stay up in the evening [19, 80]. Patients described this as a violation of their rights [23, 57, 58, 88].

A healthy, safe and enabling physical environment and ward milieu

The third main theme focused on a healthy, safe and enabling environment. This contributed to how relatives felt when visiting [92], how patients felt about themselves [39], and how they reacted [36, 39, 42]. Johansson et al (2003) [63] argued that the physical environment was as important to patients as receiving satisfactory care.   A number of studies reported that patients saw hospital as a 'sanctuary' [80] or a 'safe space' [62], where they could have time to reflect away from day to day stressors [38, 50], be kept safe [19, 39, 48, 54] and experience a caring, therapeutic environment [80].

Patients felt that their inpatient care pathway was aided by connection to the 'real world' [61] and that being made to feel 'normal' [24, 28, 51, 77] was important. This included being allowed to walk around hospital grounds [80, 39]. Older establishments often had extensive grounds and patients reported that access to these spaces resulted in less need for medication [32]. Access to a place of worship was comforting [68, 51], as was freedom to make small decisions [31, 41] such as making snacks [62] or hot drinks [36]. Private bedrooms were important [80] and being near windows enabled ward-bound patients to enjoy the outside and fresh air [83], while

appropriate use of colour was described as conducive to recovery [80]. An environment where staff and patients mixed together reduced feelings of stigma [51] and encouraged favourable interactions [63].

Patients reported several environmental problems that were not conducive to recovery-focused care. Some of these were associated with arguments and violence between patients [36, 39, 48]. Other environmental problems included noise from door bells, alarms and telephones [82]. Poor positioning of the nurses' stations often created physical divisions between patients and staff, and reduced interaction [61, 80, 92]. Communal spaces sometimes lacked privacy for visiting relatives or opportunities for physical activity [49], especially for those under close observation [92].

There were also contradictory reports. In several studies, some patients described hospital as a place of confinement rather than therapy [19, 29, 36, 37, 39, 42, 80]. There were analogies with prison [29, 36, 39, 42, 80] and punishment [37, 39]. This was particularly so in secure units with a lack of outside space [39] and where more patients were admitted compulsorily [29].

Ward milieu

Related to environment was experience of ward milieu which was shaped by the conduct of staff. Staff provided structure, order and safety [82] and were responsible for creating a congenial atmosphere [54]. Feeling safe was a prime concern to patients [48, 65] who perceived wards to be safe when they viewed staff as trustworthy [35], caring and supportive [35, 38]. Wards were sometimes criticised as too busy [36, 49, 54], and reactive to events such as restraint [56, 79, 92], seclusion [91] or violence [23, 58, 80]. Patients felt vulnerable to the latter [23, 37, 39], fearful

of other patients [49, 78] and worried about security of belongings [36, 65, 80]. Fear contributed to withdrawing within the ward [49,81] or leaving hospital [37,80].

Ward routines also shaped patients' experiences. The day [51] was often structured to include individual and group therapies, and other activities e.g. puzzles, conversation, or listening to music [92]. Evenings were typically less structured [51]. Some patients relished the leisure time [38, 50, 54,24] and some took this as a time for personal reflection [38, 51, 57]. However, others were uneasy [38, 51] and reported insufficient [49,36] activity [39, 49 23, 24, 68]. The location of the hospital close to family was important to patients [79] and they appreciated the inclusion of, and support from, families [22, 38, 53].

Boredom

'Boredom' or having little to do was mentioned in several studies [23, 24, 27, 41, 51, 54, 59, 68, 80, 82, 83, 91]. Patients suggested that inactivity slowed the inpatient care pathway [59], reduced self efficacy [41], exacerbated symptoms[80] and was related to aggression and violence on the ward [23]. Some patients reported that inactivity encouraged poor health outcomes e.g. saying that they would eat, sleep or smoke but not exercise [24, 59, 80, 83].

Authentic experiences of patient-centred care
The final theme brought together a collection of sub-themes focused on authentic experiences of patient-centred care, which included shared decision making, sensitivity to gender and culture, and information-provision:

Shared decision making: Two studies reported that patients' involvement in treatment decisions was associated with positive experiences of care [50, 65].

Gender and Cultural Differences: Patients wanted to be understood and seen as individuals, and this was framed in respect of their gender, ethnicity and religion [33, 34, 68, 78]. Some patients described cultural differences in perceptions of privacy, and reported concern that staff had not recognised or responded to their discomfort in accepting care from differently gendered staff [68], for example during restraint and sedation [33], or for women with a history of sexual abuse by male perpetrators [78]. More positively, female patients tended to prefer single sex wards (where they felt safer [36]). Where this was not available, female patients were satisfied on mixed wards if they had access to a quiet room, if their privacy was respected and if had access to personal hygiene products [81]. Faith also mattered: prayer, rituals (e.g. hand washing) offered comfort to some patients [68] but were not always understood or accommodated by staff [34].

Information: There were several reports in which patients felt they had not received sufficient information about their diagnosis [23, 65, 69, 87], treatment [20], treatment plan [23, 60,23, 32, 52, 65, 69, 90,87,57, 88, 91], choices or rights [20, 46, 53, 64, 86]. Timing of information was also important as patients found it difficult to understand or remember this when unwell [45, 69].

Discussion

The aim of this review was to identify the most salient aspects of inpatient experience, to support improvements in care in ways that are conducive to recovery-focused care. To the best of our knowledge this is the largest review of its type in the UK and internationally,

with 72 included studies of which one-third were from the United Kingdom. The Review makes an important contribution to the field of mental health in-patient experiences through the identification of four key, interlinked themes: the importance of high quality relationships; averting negative experiences of coercion; a healthy and safe and enabling physical environment and ward milieu; and authentic experiences of patient-centred care. These themes and their associated sub-themes represent the active ingredients of a high quality mental health in-patient experience, as well as the common causes of very poor experiences. A strength of the review was the involvement of the Patient and Carer Reference Group who provided importance face and content validity checks and were able to identify additional areas of experience such as boredom which could be built into the main review. We summarise salient aspects of each theme.

The importance of high quality relationships was the most commonly reported theme, with staff-patient relationships representing the 'backbone' of a patient experience, with good experiences reported when staff were compassionate, caring, and respectful, engaging the patient in ways that helped them feel valued and understood. High quality relationships also had an important role in recovery-focused care and in reducing the use of coercive measures. As such, the role of staff in creating high quality environments and in enabling patient-centred care was key. In terms of enhancing future care, improving the initiation and the development of meaningful staff/patient relationships, particularly through conversation and listening to the patient, could have an important impact on care.

The second theme focused on coercion and averting negative experiences of coercion. Experiences of coercion included sedation, seclusion and restraint. Some patients reported

very distressing experiences that overwhelmed them, particularly if they did not understand the reason why it was happening. Patients sometimes recognised a need for different forms of coercion, but still expected to be valued, to be understood, and treated professionally with their rights protected. The potential for intense distress caused by coercion creates particular challenges for collecting experiences data and highlights the need for the co-production of data collection systems that facilitate feedback in contexts where people are in-patients and fear reprisal.

A healthy, safe and enabling physical environment and ward milieu represented the third theme, which included the atmosphere, the culture, staff attitudes and the wider patient community. The milieu could be vital for nurturing a patient and provide a sense of safety and sanctuary, almost a therapeutic intervention in itself. Staff played a key role in creating this milieu, with structure, order and safety producing congenial atmosphere which made wards feel safe. Conversely when the milieu was perceived as unsafe, feared or violent, it would be to the detriment of the patient experience. In a similar way the physical environment complimented the milieu with a good environment contributing to a greater sense of well-being. Sometimes accessing other physical places extended the therapeutic environment, for example access to green spaces or places of worship, or through feeling connected to the outside world.

The fourth and final substantive theme was authentic experiences of patient-centred care which recognised the importance of treating patients as individuals, and accounting for their perspectives, previous experiences, preferences, gender, ethnicity and religion. Key components of patient-centred care included sufficient timely information about diagnosis,

treatment, plans and choices. Relationships were often the conduit of patient-centred care

which started at admission and continued until and sometimes past discharge.

A consistent thread across all four themes was the key role of staff in the providing high

quality patient experience. Staff were the facilitators of a good experience and conversely,

the creators of a poor experience. However, staff operate within the context of a wider

system that needs to support the delivery of care. It was not always possible to understand

this wider context from the studies reviewed, because many did not provide wider

contextual information. This would have been useful, particularly in understanding why

some studies reported very negative experiences, while others reported more positive

experiences. Future studies might consider reporting contextual information to aid

interpretation.

It is important to note that the findings of studies relating to discharge appeared to be

influenced by the research design, with questionnaires identifying high levels of satisfaction

while experiences captured using qualitative methods were described differently. Future

studies should pay careful attention to the way in which design might impact on the

reporting of experiences.

Limitations

A limitation of this review, common to all secondary research, is that it is reliant on the

conduct and content of primary studies which may have included biases that we could not

account for. Few studies mentioned the involvement of service users in data collection [20, 39,

46, 79], and research design [20, 27, 39, 46, 79], and the study authors' professional perspective is

often unreported, so it is unclear to what extent a study finding reflects the user voice or whether it predominantly reflects the researchers interpretation of their data. Ensuring greater clarity about whose voice is represented, as a means of minimising bias, represents an important methodological challenge for future research. The case might be made in future reviews for privileging studies where there is evidence of a strong user voice in the conduct and interpretation of the study.

Although we utilised data saturation as a concept to decide when to stop data extraction at the point where we judged no new themes were emerging, it is always possible that other papers contained nuances in themes that were unintentionally omitted. The risk of bias in this review may have been mitigated to some extent with our scoping review which identified key authors, a citation search of their papers of included papers and other literature reviews. In addition the PPIRG provided important assurance of face and content validity.

Our study relies on secondary analysis of qualitative data. The findings we have presented are drawn from the reported of participants in primary studies. Many of these claims (e.g. the perceived role of good relationships in reducing a range of unwanted outcomes; or the role of boredom in exacerbating those outcomes) are reported across multiple primary sources. An important limitation of secondary research is the gaps that exist in studies. A key one in this review was the experiences of minority ethnic groups which appears to be an under-researched. Future studies should ensure they build ethnicity into their design.

Conclusions

This systematic review represents the largest review of its type, identifying key salient aspects of patient experience. The key role of staff in delivering a high quality experience was the common thread. The identified themes can be used to design and deliver high quality services, provide content for the development of robust patient experience questionnaires, or inform qualitative methods that aim to evaluate salient aspects of patient experience. It provides key evidence for the development of practice guidance that supports the implementation of high quality services. The evaluation of future service developments, based on such evidence and guidance will further strengthen services. Collectively these elements will contribute to the development of high quality experiences for mental health in-patients.

All the authors made a substantia contribution to the paper, including the conception, design, acquisition, analysis or interpretation of data, drafting the work or revising it critically for important intellectual content; AND final approval of the version to be published; AND all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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