The importance of understanding the experiences of patients

Patient perspectives are critical for the evaluation and development of mental health services. Insights from those with lived-experience can identify positive and negative aspects of care which cannot be detected by service users alone. These can inform better quality management decisions and open up new solutions for improving health outcomes and service (Gilbert, 2015)

Moreover, there is evidence that patients' satisfaction levels are linked to treatment outcomes. People who report higher levels of satisfaction are 3 times less likely to be readmitted (van der Post et al., 2014). Poorer patient views on treatment have been shown to predict subsequent civil detention and, for those involuntarily treated, longer admissions (van Der Post et al., 2014). Consistently, those who are involuntarily detained report lower levels of satisfaction (Hansson & Höglund, 1995; Smith et al., 2014).

User feedback can create an uncomfortable challenge for professionals as it often violates the expectations and assumed best practices of the traditional models of medicine (Debronkart, 2018). Therefore, while organisations often encourage greater patient involvement, they can remain resistant to the non-expert views they receive (Campbell, 2001). However, if the drivers behind patients' perceptions and ratings of their experience are welcomed, understood and considered, they can inform changes that lead to improved patient outcomes, which in turn ultimately secure greater value for money.

Patient feedback should therefore only be collected by service providers if it is intended to be used as an agent of change. This is captured in the challenged that Shields posed to mental health service providers in 1985:

> 'We must ask ourselves how much we actually do know about users' views of the services we provide. We must also ask whether we want to know, and whether we can be flexible enough to admit that the user may know better than the professional what is best for them'

> (Shields, as cited in Edwards, 2000)

What does the research suggest is important to patients?

A short review of the academic literature considering what is important to patients in psychiatric hospitals was undertaken. Figure 1 outlines the key themes and sub-themes, that were identified. Each is discussed in more detail below.
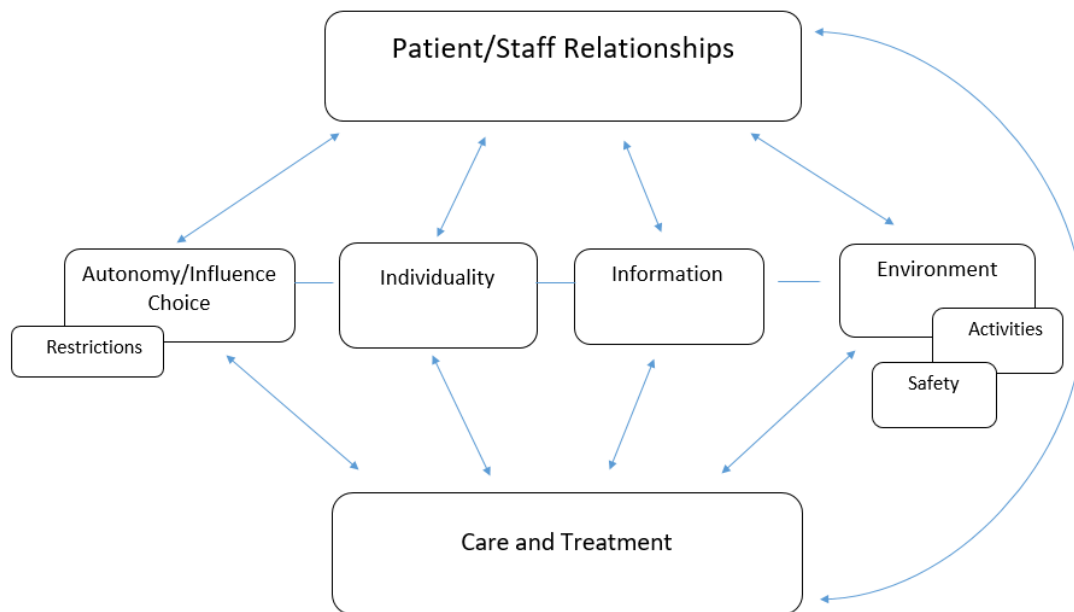

Figure 1: Key themes and sub themes of importance to patients

Patient-Staff Relationship

Patients stress the importance of person-to-person interactions; the centrality of the relationship they have with the nurses; and, the need to have a fellow human being to talk and rely on (Lilja & Hellzén, 2008; Thibeault et al., 2010). As such, patients rate their experience to be better when they get more one-to-one time with staff (Csipke et al., 2014). What is often experienced, however, is a gap between what patients feels they need and expect from staff and the reality they encounter (Edwards, 2000; Thibeault et al., 2010). While patients are looking for a deeper connection with staff, they perceive that staff value ward routines or an atmosphere of control over patient need and that talking to patients is a secondary concern (Edwards, 2000; A. Faulkner, 2005; Johansson et al., 2009; Thibeault et al., 2010; Walsh & Boyle, 2009). Patients want more time with staff (Lelliott & Quirk, 2004).

They arrive with expectations that staff will initiate contact and demonstrate care for them (Gilburt et al., 2008). However, more often they are told it is up to them to 'come and find' staff, only to then find them to be too busy (Stenhouse, 2011). Failed attempts to access support from staff fosters anxiety as well a sense of guilt about being ill which can continue long after a patient has left hospital (Coatsworth-Puspoky et al., 2006).

Patients place a high value on staff who are approachable, available and spend time listening to, and problem solving with, them (Bowers et al., 2008; Coatsworth-Puspoky et al., 2006; Edwards, 2000). They wish to be reassured and given assistance, appreciating nurses who are insightful, friendly, non-judgemental, non-threatening and trustworthy (Biering & Jensen, 2017; Cleary, 1999; Dickens et al., 2011; Moreno-Poyato et al., 2016). They also consider relationships with their key worker to be central to their recovery (Faulkner, 2017).

While patients appreciate many nurses are doing the best they can, staff that are unable or unwilling to prioritise time with patients are perceived as uncaring or disinterested. This can leave patients feeling isolated, vulnerable, dehumanised, punished, not accepted and uncared for (Coatsworth-Puspoky et al., 2006; Katsakou & Priebe, 2007; Moreno-Poyato et al., 2016; Rose et al., 2015). Such perceptions do not describe an atmosphere that is conducive to recovery and in the absence of receiving a caring approach, some patients find this support in other patients (A. Faulkner, 2005; Lelliott & Quirk, 2004; Shattell et al., 2008).

Care and Treatment

Patients want to be involved in decisions about their care and treatment but consistently report that they are not (Faulkner, 2017; Walsh & Boyle, 2009). Collaborative care-planning is seen to facilitate recovery however it requires meaningful information exchange between staff and patients and, in practice, there are insufficient opportunities for negotiation over treatment (Bee et al., 2015; Bowers et al., 2005). Patients experience poor levels of involvement and a lack of information on their medication, treatment and care (Stenhouse, 2011). They can also feel that there is a pressure for them to accept that they are ill, a stance that they come to understand will bring about their discharge sooner (Lelliott & Quirk, 2004).

Patients are looking for a regime in which medications are minimal and based on patient wishes and needs, and are combined with conversations from non-paternalistic and respectful staff (Lilja & Hellzén, 2008; Valenti et al., 2014). What they can experience, however, is an omniscient psychiatrist who gives them prescriptions rather than listens. They resent doctors taking decisions for them and such an approach erodes their sense of self and leaves them feeling steam-rollered, discounted and worthless (Lilja & Hellzén, 2008). They dislike the primacy of the medical model at the expense of psychological approaches, and while they wish and expect addiction and psychological support, such therapies are not routinely offered (Lelliott & Quirk, 2004; Sharac et al., 2010; Walsh & Boyle, 2009). They also wish education about their illness (Cleary, 1999).

Patients are not asking for extravagant therapies but for support that is relevant to their needs and provided in a compassionate manner (Coulter, 2012; Edwards, 2000). They wish to be told about different options and have their preferences taken into account (Coulter, 2012; Csipke et al., 2014). They want help to solve their problems but by being guided rather than directed and such an approach would be in keeping with three key care philosophies: person-centred care; shared decision-making; and, patient empowerment. (Shattell et al., 2007).

Individualisation

Early research identified that factors causing patients to feel most dissatisfied were feelings of isolation and loneliness and the failure to be treated as an individual (Macdonald et al., 1988). Subsequent studies confirm, that patients wish to be treated with the respect and dignity that is afforded to non-patients (Carlsson et al., 2006; Katsakou & Priebe, 2007), but are often faced with discrimination and rejection (Lilja & Hellzén, 2008). They can feel stripped of their pre-patient identity in a process of depersonalisation (Lelliott & Quirk, 2004) which transforms them from a unique individual into part of a collective (Lilja & Hellzén, 2008). They report rarely being asked how they are feeling, with opinions about them being based more frequently on observations of their behaviours by staff (Walsh & Boyle, 2009).

Therefore, patients express the wish to be treated 'as a human being', 'on the same level', or 'equally', and to be known as a person rather than as a patient, a diagnosis or a number (Coatsworth-Puspoky et al., 2006; Edwards, 2000; Gilburt et al., 2008;

Thibeault et al., 2010). They look for indications that confirm their identity that are as simple as being called by their name (Thibeault et al., 2010) and as fundamental as receiving support that is sensitive to their individual needs (Edwards, 2000). The impact of being treated inconsiderately, without respect or care, or as problems to be solved rather than individuals leaves patients feeling dehumanised (Moreno-Poyato et al., 2016).

Autonomy/Choice/Influence

Linked to feelings of dehumanisation, is the degree to which patients feel they have any control over their situation. Patients feel that just because they needed help at a vulnerable time, this did not mean that they had forfeited their rights and responsibilities as adult (Edwards, 2000).

The desire to be treated as autonomous individuals is key to both adolescents (Biering & Jensen, 2017) and adults (Katsakou & Priebe, 2007) and is linked to satisfaction levels (Macdonald et al., 1988) . Those involuntarily detained experience a loss of autonomy (McKenna et al., 1999) and so value having freedom of choice (Valenti et al., 2014) and participation in decisions (Katsakou & Priebe, 2007). The need to feel in control is shared by voluntary and involuntarily patients, with freedom being viewed as a basic human right – and a lack of freedoms felt to contribute to mental ill-health (Gilburt et al., 2008). Patients feel their suffering is contributed to by experiencing a lack of influence and the associated feelings of dependence and feeling trapped – but this can be alleviated by being provided with choices and being allowed to take responsibility for their own care (Johansson et al., 2009). Enhancing agency and respecting the autonomy of patients is not only ethical, but can improve treatment adherence and outcomes (Grande et al., 2014).

The presence or removal of power and control for patients can take a number of forms: from having little say in when they can talk to staff or being denied access to information, to being subject to powers of compulsion (Grande et al., 2014; Thibeault et al., 2010). The inherent power differential between staff and patients can be experienced as oppressive and traumatic (Thibeault et al., 2010). Patients see staff using coercion to get patients to behave as they wish them to. They describe the breaking of any ward rules being met with medication, intimidation or overpowering,

eventually forcing patients to succumb to repressive care ((Bowers et al., 2005; Lilja & Hellzén, 2008)

> *Restrictions* – For those involuntarily detained, they literally experience a loss of their liberty, rights and control, playing no part in the decisions made about them and leading them to feel devalued (Katsakou & Priebe, 2007). The use of seclusion is experienced as abandonment by patients. By being 'shut away', they feel less human and as if they are being punished for who they are (Thibeault et al., 2010). The use of powers of compulsion is acknowledged by nurses as being in conflict with establishing effective therapeutic relationships with patients (Bigwood & Crowe, 2008).

> Restraint is often used in response to incidents of aggression on the wards. Research suggests that while staff tend to consider incidents of patient aggression to be related to factors internal to the patient, patients consider them to be extreme behaviours driven by external factors on the ward, including relational issues with nurses (Irwin, 2006; Rose et al., 2015). Interpersonal violence between patients and staff requires at least two parties and both these parties influence the interaction (Whittington & Richter, 2006). It has been argued that if the environmental context is considered, patient aggression can be viewed more as a normal interaction response to the responses of staff (Haugvaldstad & Husum, 2016). Patients view incidents of restraint as punitive rather than therapeutic, but, if used, debriefing is recommended and can lessen negative views (Alexander, 2006)

Provision of Information

The participation in decision-making can lessen feelings patient have of coercion related to their care (McKenna et al., 1999). However, patients across all health domains require the necessary support and information to allow them to participate effectively, make appropriate decisions and state their informed preferences (Coulter, 2012). If service providers allow a degree of participation in treatment care, this can reduce negative views and increases patients sense of self-value (Katsakou & Priebe, 2007). Patients feel stressed when they do not have enough information (Johansson et al., 2009) and can experience increased levels of anxiety or anger if they cannot, for example: gain clarity on their length of stay; if ward rules are not

clearly defined; or, as a result of not knowing information about other patients (Alexander, 2006; Stenhouse, 2013). They also report not having enough information on admission or discharge (Walsh & Boyle, 2009).

Patients wish to retain or reclaim a sense of control over their lives and the provision of sufficient information is essential to this. Part of a process of empowering patients, this can feel threatening to professionals, but it helps patients; to use the service better; to manage their condition; make choices and move from passivity and dependency to active functioning (Edwards, 2000).

Environment

The environment of psychiatric hospitals has been linked to the frequency and rate of patient progression (Coatsworth-Puspoky et al., 2006). Aspects of in-patient psychiatric care can be unconducive to well-being (e.g. locked doors, unchanging routines and lack of routine and personal space) (Katsakou & Priebe, 2007). Both patients and nurses can feel confined in a 'prison-like' world, but while time passes quickly for nurses who are busy, the day drags for patients who are bored (Cleary, 1999; Shattell et al., 2008). However, the environment is not consistently brought up spontaneously by patients when asked about their experiences (Evans et al., 2012; Hansson & Höglund, 1995; Thibeault et al., 2010)

Patients can find ward life boring, with a sense that there is no goal and they are simply 'waiting' (Lelliott & Quirk, 2004; Lilja & Hellzén, 2008). Activities, therefore, are valued, and the participation in therapeutic activities relates to more positive patient experiences (Csipke et al., 2014). Patients feel that the best therapeutic interventions are ones that offer practical solutions and occupy them usefully (Edwards, 2000). One study suggests that replacing observations with individualised, structured activity improved patient and staff outcomes (Dodds & Bowles, 2001). However, nurses acknowledge that when the ward becomes busy, it is activities that are first to go (Bowers et al., 2008).

Patients have expectations of safety – both physical and psychological - in the hospital (Gilburt et al., 2008; R. Stenhouse, 2013). They are looking for a place of sanctuary, security, rest and refuge from self-destructiveness (Lelliott & Quirk, 2004; Walsh & Boyle, 2009). They view hospital as a place to turn when home is too

stressful, and even those detained involuntarily, can retrospectively report the benefits of being protected from harm (Katsakou & Priebe, 2007). Patients do, however, report experiencing feelings of fear, threat or vulnerability and have an expectation that staff will keep them safe and de-escalate rather than contribute to incidents of aggression (Gilburt et al., 2008; Macdonald et al., 1988; Stenhouse, 2013). Experiencing fear is associated with higher levels of dissatisfaction (Macdonald et al., 1988).

Patients express a need for private territory where they can withdraw (Lilja & Hellzén, 2008). A lack of privacy or personal facilities adds to feelings of dehumanisation and so, steps like, open access to drinks and refreshments can lessen feelings of depersonalisation (Alexander, 2006). They also value communication with the outside world confirming the need for family friendly rooms (Walsh & Boyle, 2009)

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