

# **Patients' experiences of emergency hospital care following self-harm:**

## **Systematic review and thematic synthesis of qualitative research**

### **Abstract**

Rates of hospital presentation for self-harm have increased in recent years and although clinical practice guidelines on clinical provision prioritise positive patient experiences, the quality of provision remains variable. This systematic review provides an updated and extended synthesis of qualitative research on: i) patients' experiences of treatment following presentation to hospital; and ii) patients' perceptions of the impact of treatment on recurrent self-harm and/or suicidal ideation, and future help-seeking. 26 studies were identified for inclusion in the final synthesis. Three meta-themes emerged: i) individuals undertake extensive identity work when presenting with self-harm, navigating the process of becoming a patient and negotiating the type of patient they want to be; ii) care ranges from gentle to hostile, with care at admission and discharge being particularly disorientating and iii) negative experiences of clinical treatment may increase future self-harm. Emerging research gaps include the need for further theoretically-informed qualitative research in this area.

### **Background**

Self-harm is a significant public health concern. Rates of hospital presentation have increased in recent years, with concern that routine data underestimates actual presentation rates (Clements et al., 2016). There remains debate whether this trend reflects a rise in self-harm, increased help-seeking or is an artefact of changes in

clinical practice and administrative coding (McGill et al., 2018). Clinical management of patients within emergency department settings is a priority across international suicide prevention strategies (Australian Government Department of Health and Ageing, 2007; HM Government Department of Health, 2015; New Zealand Associate Minister of Health, 2006; Scottish Government, 2018; U.S. Department of Health and Human Services (HHS) Office of the Surgeon General and National Action Alliance for Suicide Prevention, 2012; Welsh Government, 2015; World Health Organization, 2014). Guidelines, including NICE clinical practice guidelines on the short-term management and prevention of recurrent self-harm (National Institute for Health and Care Excellence, 2004), prescribe evidence-informed treatment provision and standards for care quality. Effective treatment can prevent recurrent presentation to services and reduce future health care costs (Kapur, Steeg, et al., 2013; Sinclair, Gray, Rivero-Arias, Saunders, & Hawton, 2011).

Despite issuing of international clinical practice guidelines, extant evidence reports variability in both the delivery and quality of clinical care (Arensman et al., 2018; Cooper et al., 2010). Management related to psychosocial assessment is only delivered in 22% to 88% of cases across UK hospitals, with no significant increase since 2001 (Cooper et al., 2013). Recent data has demonstrated inconsistency in clinical management according to the socio-demographic characteristics of patients, potentially exacerbating health inequalities (Morgan et al., 2017). However, there was a 26% improvement in quality of care across UK hospitals between 2001 and 2011 (Cooper et al., 2013).

Patients' experiences remain a central priority in ensuring continued improvement in clinical provision. The most recent systematic review of patients' attitudes towards services presents largely negative perceptions, with studies reporting that staff foster

poor communication strategies with patients, possess limited knowledge of self-harm and occasionally provide punitive treatment (T. Taylor, Hawton, Fortune, & Kapur, 2009). Syntheses of clinicians' attitudes are largely consistent with such experiences, indicating negative perceptions of this patient group, particularly towards those presenting with repeat self-harm (Saunders, Hawton, Fortune, & Farrell, 2012).

The present systematic review builds on previous syntheses to provide an updated and comprehensive understanding of patient experiences of short-term management and prevention of recurrent self-harm treatment following presentation to hospital for self-harm. It incorporates a range of research published since the most recent review in this area (T. Taylor et al., 2009) permitting the exploration of longer-term changes or continuities in experiences since the issuing of guidelines. It also responds to the increasing number of studies that disaggregate the discrete if inter-related aspects of treatment (e.g. psychosocial assessment) (Hunter, Chantler, Kapur, & Cooper, 2013), attempting to ascertain if experiences differ according to different provision rather than reporting global assessments of clinical treatment. Operating within a social constructionist epistemology, the review further aims to provide a more interpretive and relativist account of experiences, with a particular focus on understanding the interactional aspect of hospital-based clinical treatment. This extends to consider how such interactions may impact upon future self-harm, disclosure or help-seeking.

The review systematically synthesizes qualitative evidence to address the following questions:

1. What are patients' experiences of short-term management and prevention treatment following presentation for self-harm (irrespective of the level of suicidal intent) and/or suicidal ideation?

2. What are patients' perceptions of the impact of short-term management and prevention treatment on recurrent self-harm, (irrespective of the level of suicidal intent) and/or suicidal ideation, future disclosure and help-seeking?

For the purposes of this study we define self-harm as the infliction of damage to the external surface of the body and self-poisoning (National Institute for Health and Care Excellence, 2013). In accordance with the UK tradition, we do not differentiate self-harm with or without suicidal intent (Kapur, Cooper, O'Connor, & Hawton, 2013). As such, our definition includes non-suicidal self-injury, suicide attempts, self-harm with an undetermined intent, or self-harm with ambivalence. Where possible we retain the nomenclature used within included studies, and reflect upon differences in the phenomena where significant to patients' experiences.

## **Methodology**

The methodology for this systematic review is reported in accordance with the PRISMA checklist (Moher, Liberati, Tetzlaff, Altman, & The, 2009; Moher, Stewart, & Shekelle, 2016).

### ***Protocol and Registration***

The systematic review protocol is registered with PROSPERO (CRD42017079371).

### ***Eligibility Criteria***

For a study to be included in the review it had to meet the following criteria i) study participants could be of any age, gender or other socio-demographic characteristic; ii) participants had experienced self-harm (irrespective of the level of suicidal intent) and/or suicidal ideation. Self or clinician classification of outcomes were relevant. All methods of harm were included; iii) participants had received short term management

and prevention of recurrent self-harm treatment, as fits within the scope of NICE guidelines (National Institute for Health and Care Excellence, 2004). This primarily involved treatment delivered in the immediate period following presentation to an emergency department. It could include but was not limited to medical treatment for physical injury, psychosocial assessment and referral to community based provision; iv) studies reported data on participants' experiences of short term management and prevention treatment. All qualitative study designs were included. The search terms were in English and while all languages were included, only those that were indexed in English or had an English translation of the title and abstract were retrieved. At the screening stage the majority of non-English retrievals were bi-lingual (with a translated English abstract) and this enabled screening. Where an English abstract was not provided, expertise within the team and wider University was utilised to translate. No non-English articles progressed to full text.

### ***Information Sources***

Eleven bibliographic databases were searched for published or unpublished studies: ASSIA; Social Services Abstracts; CINAHL; Embase; HMIC; Medline; Medline in process; Opengrey; PsycINFO; Social Care Online; and Scopus. Thirty-one relevant national and international websites focused on self-harm prevention and intervention were searched. Searches were conducted from database inception until the date of searching (November-December 2017). An international panel of experts were contacted to identify studies for inclusion, and forward and backward citation tracking of included studies was undertaken.

### ***Search Strategy and Study Selection***

A search strategy was developed using an adapted version of a Health Technology Assessment qualitative methodological filter (DeJean, Giacomini, Simeonov, & Smith, 2016). The extant academic literature and search strategies from related systematic reviews informed the substantive topic search terms (T. Taylor et al., 2009). The search strategy was developed, piloted and refined in Medline before being adapted to the functionality of each database. The search strategy is presented in Appendix A.

Search records were exported into Endnote software and de-duplicated. One reviewer screened study titles to exclude clearly irrelevant retrievals (for example, clinical trials of pharmacological treatments). These were verified by a second reviewer. Remaining studies were exported to the Rayyan QCRI online systematic review platform. Two reviewers independently assessed abstracts. Disagreements were resolved by progressing the study to full text screening. Full texts were independently screened in duplicate against the a priori inclusion criteria, with disagreements being resolved by consensus or recourse to a third reviewer. Exclusion reasons were coded as: study design; outcome; population; setting; and evaluation. Where full texts were unavailable, the authors were contacted to request the articles.

### ***Data Extraction***

Included studies were exported to the propriety qualitative software package N-Vivo for inductive coding. A subset of studies was indexed to develop and refine a coding tree before being applied to the whole corpus of data. Two reviewers independently conducted inductive coding of studies. Disagreements in coding were recorded and resolved through discussion, with additional coding being undertaken where required.

Memos were recorded and discussed through the coding process to ensure researcher reflexivity. Study and participant demographic characteristics were extracted into an excel spreadsheet.

### ***Thematic Synthesis***

A thematic synthesis was then conducted (Melendez-Torres, Grant, & Bonell, 2015; Thomas & Harden, 2008). Meta-ethnography was considered but there was an inadequate number of studies that included conceptually rich second order constructs (Toye et al., 2013). We purposefully sampled eligible studies for inclusion in the final thematic synthesis. Purposeful sampling is used in reviews as a way of conducting a detailed synthesis of a selected number of studies instead of a more cursory synthesis of a larger number of studies (Harsh, 2011). Articles were selected according to their extent of interpretation (that is, the participant or author presented some conceptual development around the experience of treatment). For quality assurance, results of unselected studies were considered in relation to the final synthesis to ensure that the synthesis would not have been significantly different if they had been included.

Inductive coding was conducted, with coding undertaken of primary data, in addition to study background and discussion in order to provide contextualisation and understand authors' interpretations. Codes were subjected to the constant comparative method in order to generate a set of descriptive themes characterizing the data.

Descriptive themes progressed to analytical themes by seeking understanding of their causes and context, and how discontinuities in experiences might be explained. We further explored how themes related to any second-order interpretative concepts presented within included studies, while also drawing upon the wider extant literature to support the development of our own conceptual understanding (for example, the authenticity of the patient). Resulting analytical themes (for example, identity work)

were further categorised into three overarching meta-themes: construction and negotiation of the patient identity; the nature and quality of treatment; and perceived impact of care provision on future self-harm, disclosure and help-seeking.

### *Quality Appraisal*

Appraisal of study quality utilized the assessment criteria developed by Rees et al (2011). Studies were allocated a weight of evidence (low, medium, high) across two domains. First, the reliability and rigour of the findings were appraised in terms of sampling; data collection; analysis; and whether results were grounded in data. This domain included: whether personal biases had been taken into account when conducting the study; how they ensured consistent and transparent data analysis; and whether verbatim narratives were included to support findings

Second, the relevance of findings to the review were appraised which included assessing the richness and complexity of description and analysis; and the privileging of participants' perspectives. Appraisal was independently assessed by two reviewers, with disagreement resolved through consensus or recourse to a third member of the research team. While there are debates over the assessment of qualitative research in systematic reviews (Noble & Smith, 2015; Ring, Jepson, & Ritchie, 2011), it had utility in supporting decision-making with regard to the type of synthesis employed. Studies were not included on the basis of quality and the resultant themes reflect a spread of high, medium and low quality articles. Appraisal of included studies is summarised in Table 3.

## **Results**

### ***Study Inclusion and Characteristics***

The process of study screening and retrieval is presented in Figure 1. A total of 8053 unique articles were identified. Following the screening of titles and abstracts, 239 articles remained, with 7814 not being relevant. Of these articles, 39 met the eligibility criteria.

Following purposeful sampling, a subset of 26 articles (representing 26 studies) were included in the final synthesis. Thirteen articles did not progress to the final synthesis as they only provided rudimentary, global assessments of care provision (for example, positive or negative) and did not include any interpretation.<sup>1</sup> These articles represented ten studies. Two articles related to the same study (Bergmans et al., 2009; Spence et al., 2008) and two articles were related to studies included in the final synthesis (Holliday & Vandermause, 2015; Vatne & Nåden, 2016). The articles that reported directly relevant data were included in the final synthesis (Holliday, 2012; Vatne & Nåden, 2014). Articles that included more limited relevant data were not included in the final synthesis (Holliday & Vandermause, 2015; Vatne & Nåden, 2016).

Details on study characteristic are presented in Table 1 (Characteristics of Studies Included in the Thematic Synthesis) and Table 2 (Characteristics of Studies Not Included in the Thematic Synthesis).

Studies were conducted in: the UK (n=12), USA (n=5), Canada (n=2), South Africa (n=2), Italy (n=1), Norway (n=1) and Sweden (n=1). One study drew on international data and one did not specify the location. Phenomena of interest, as specified by the studies, were: self-harm (n=9); self-injury (n=2); self-injurious behaviour (n=1); self-wounding (n=1); suicide attempt (n=11); and a combination of self-harm and suicide

(n=2). The gender profiles of study participants included all females (n=5), all males (n=2), mixed (including male, female, other, trans, gender fluid and none) (n=17) and unspecified (n=2). Of studies including both males and females, six had a sample where more than three quarters were female. Thirteen studies reported adult experiences (aged from 18 years), seven reported data from children and adolescents (aged 10-25 years), and one looked at children through to adults. Four did not specify participant age, and one employed the generic term 'young people'. Seventeen studies did not report participants' race or ethnicity. The remaining included either groups of mixed ethnicity or race (n=5) or white populations (n=4).

### ***Meta-themes and Sub-themes***

Three overarching meta-themes emerged from the review synthesis: i) the construction and negotiation of the patient identity; ii) the nature and quality of treatment received; and iii) the perceived impact of treatment experiences on future self-harm, disclosure and help-seeking. All meta-themes and corresponding sub-themes are detailed in Table 4.

### ***Meta-theme: Construction and Negotiation of the Patient Identity***

Presentation to hospital and receipt of clinical treatment entails complex identity work for patients, providing clarity but also ambivalence and disorientation about what it means to be an individual engaged in self-harm. Sub-themes consider the experience of becoming a patient, navigating different patient identities, and the emotional labour involved in this process.

*Sub-theme: Becoming the Patient*

Fifteen studies reported participant experiences of assuming, being ascribed or being denied the identity of 'patient' (Brown & Kimball, 2013; Chandler, 2016b; Donskoy, 2011; Ghio et al., 2011; Harris, 2000; Horrocks, Hughes, Martin, House, & Owens, 2005; Hunter et al., 2013; Kirkland, 2000; Mitten, Preyde, Lewis, Vanderkooy, & Heintzman, 2016; Nehls, 1999; Owens, Hansford, Sharkey, & Ford, 2016; Sinclair & Green, 2005; Spandler, 1996; Strike, Rhodes, Bergmans, & Links, 2006; B. Taylor, 2003).

Transition into the patient role was seen as positive on occasion, particularly as provision of a treatment plan can provide a sense of relief that needs are being acknowledged rather than dismissed (Hunter et al., 2013). Yet despite potential benefits, the majority of study participants felt clinicians precluded them from assuming the patient identity. Indeed, across the treatment pathway, from presentation to discharge, and irrespective of the level of suicidal intent, participants felt that their authenticity and legitimacy was in question (Brown & Kimball, 2013; Owens et al., 2016; Sinclair & Green, 2005; Hunter et al., 2013; Mitten et al., 2016; Strike et al., 2006). Denial of patienthood was often explained by the fact that wounds had been self-inflicted (Owens et al., 2016) or that the individual had not reached a pre-specified treatment threshold (Hunter et al., 2013).

Positioning outside of the patient identity, whether actual or perceived, could make individuals embarrassed at being a burden on hospital staff or believe that they were illegitimately making claims on clinicians' time (Hunter et al., 2013). Clinicians could heighten such feelings, for example by informing the individual they were taking the place of more deserving patients (Ghio et al., 2011; Harris, 2000; Horrocks et al., 2005). One study reported participants' sense of being de-prioritised and 'put in the

back of the line' for treatment (Brown & Kimball, 2013, p. 201). Importantly, feeling unworthy of care led to a perceived lack of agency to complain about receipt of 'bad treatment', which reinforced any sense of worthlessness (Owens et al., 2016, p. 288). Potential denial of patienthood was considered to encourage or even compel laborious identity work amongst presenting individuals, who felt they had to prove their authenticity and eligibility for care. This included continuing self-harm while in hospital or progressing to perceptibly more lethal methods:

. . . I ended up doing some damage to my wrist so that they'd admit me, because I knew that if I went home where I had knives . . . So it's kind of like you feel you've got to turn up the volume loud enough by doing stuff before they take you seriously (7: 22) (Strike et al., 2006, p. 363).

While narratives largely centred on the negative experience of not being permitted to become a patient, for some, ascription of such an identity was problematic due to the associated loss of control. This included physical withdrawal of freedoms, such as the right to smoke (Manning et al., 2015). Individuals presenting with non-suicidal self-harm also felt that becoming a patient rendered their self-harm pathological, serving to rupture their own carefully crafted identity where self-harm is a coping mechanism used to achieve control over their 'tensions' and 'anxieties' (Horrocks et al., 2005, p. 111). Some individuals felt that the process of constructing self-harm as a sickness reflected clinicians' fundamental misunderstanding of these behaviours (Nehls, 1999).

#### *Sub-theme: Patient (Mis)classification*

Beyond contestations over *becoming* a patient, six studies reported individuals' concerns about the *type* of patient they would become within short-term care provision (Bantjes et al., 2017; Brown & Kimball, 2013; Donskoy, 2011; Harris,

2000; Mitten et al., 2016; Sinclair & Green, 2005). Participants expressed frustration or fear at being wrongly classified by clinicians, firstly as an individual who had made a suicide attempt when they were presenting with non-suicidal self-harm (Brown & Kimball, 2013; Donskoy, 2011; Harris, 2000), and secondly as someone with an underlying mental health condition (Bantjes et al., 2017; Mitten et al., 2016; Sinclair & Green, 2005). Participant narratives often sought to reject medical professionals' misclassification by delineating differences between their own sense of identity, needs and motivations, and those of other patient groups. For example, this included the assertion that self-harm denotes a coping mechanism to ensure survival, which is the very antithesis of an intention to die (Harris, 2000).

The work involved in ensuring an accurate classification was linked to concerns about being ascribed a stigmatised patient identity (Bantjes et al., 2017; Mitten et al., 2016), such as that of a 'mad person' (Bantjes et al., 2017, p. 1439). Close physical proximity to and interactions with other patients, particularly those in the midst of a mental health crisis, arguably allowed such stigmatising labels to reify and scare participants (Mitten et al., 2016). Studies reported anxiety about receiving inappropriate or unnecessarily excessive treatment as a consequence of misclassification, such as having freedoms curtailed due to being wrongly assessed as being at a high risk of suicide or being admitted to a psychiatric facility (Bantjes et al., 2017). Fear was expressed that transitioning into psychiatric care would further expose individuals to stigma, especially amongst their own family (Bantjes et al., 2017; Donskoy, 2011). There was also concern that clinicians' misunderstandings could lead to a focus on the wrong issues, which may be counterproductive and even lead to a patient dying by suicide in future if the underlying causes of self-harm were ignored or overlooked (Donskoy, 2011).

Study participants were also troubled that their assigned patient identity would become intractable, with the wider medical profession, family and friends using this classification to describe and relate to them beyond the immediate period of acute treatment. They felt they had limited control to contest this process of labelling and were powerless in halting or changing the treatment pathways once set in motion by clinicians (Bantjes et al., 2017).

*Sub-theme: Identity Work, Revealing and Hiding*

Ten studies explored the extensive and often challenging biographical work associated with the process of identity formation. Such work was reported when presenting for self-harm (Donskoy, 2011; Horrocks et al., 2005; Kirkland, 2000; Owens et al., 2016; Reece, 2005) and following a suicide attempt (Bantjes et al., 2017; Crockwell & Burford, 1995; Hausmann-Stabile, Gulbas, & Zayas, 2017; Strike et al., 2006; Wiklander, Samuelsson, & Åsberg, 2003). Biographical work primarily encompasses patients conducting a complex set of micro-practices within interactions with clinicians, where they negotiate the revelation or hiding of their self-harm. It was done in order for participants to manage the ascription of patient identity or negotiate the type of patient they may become. Strategies for hiding largely related to the physical coverage of scars or wounds (Wiklander et al., 2003), but also encompassed efforts to conceal emotions and mental health status (Horrocks et al., 2005), or attempts to minimize or excuse the true nature of their injuries (Donskoy, 2011; Owens et al., 2016). Conversely, some study participants discussed the need to share, with one individual describing the importance of showing the feelings and battles that were pictorially displayed on their body (Reece, 2005).

Decisions to draw upon these various strategies were dynamic, oscillating between reaching out and retracting depending on patients' perceived agency and the potential

response received from others. Motivations for hiding included preventing family from discovering what had happened (Donskoy, 2011) and the associated fear of rejection (Crockwell & Burford, 1995). Individuals further discussed wanting to avoid the feelings of shame associated with asking for help, with some seeking to lie about the origin of their injury so staff would not think them ‘stupid’ (Owens et al., 2016, p. 288).

Concealment was also discussed as a strategy for managing transitions throughout the care pathway. Study participants discussed holding back on full disclosure and ‘bottling up’ emotions in order to avoid admission (Bantjes et al., 2017, p. 1441) or hasten discharge (Horrocks et al., 2005). Studies also reported perceived positive consequences of hiding emotions and stories, with patients claiming it offered control in the midst of a rather exposing and disempowering experience, whilst disclosure would be associated with a loss of control (Donskoy, 2011).

Revelation of self-harm was considered as an alternative approach within interactions (Owens et al., 2016; Wiklander et al., 2003). Study participants expressed their relief at being able to take off their ‘mask’, following non-judgemental treatment by clinicians (Wiklander et al., 2003, p. 297). Patients also found meaning in helping medical professionals understand their self-harm and its underlying causes, and being asked why they had engaged in such practices was important in their decision to open up further (Owens et al., 2016). However, patients’ decisions to share their narratives for the first time could be a sudden and shocking process, where they were forced to come to terms with what had happened. In some instances, there was expressed regret at having disclosed too much, especially if they received negative staff responses (Wiklander et al., 2003).

Executing strategies to reveal and hide was considered to have significant impacts on patients, with the continual decisions involved in choosing to share histories, or create new narratives through interactions with clinicians, consuming extensive energy, concentration and emotion (Hausmann-Stabile et al., 2017). The perpetual effort and vulnerability involved in this process was reflected in one study's account of a patient:

In this instance she allowed herself to trust this nurse and “completely broke down” to reveal, to a complete stranger, the vulnerable individual inside, the one in distress, and go beyond the physical evidence offered by the wounds and for which she had gone to A&E. The nurse offered the right space for Jane to open up. In so doing, Jane also took the risk of not being in control of the situation. (Donskoy, 2011, p. 143).

Encountering numerous medical professionals during treatment at hospital merely serves to increase the number of decisions patients have to make about enacting their strategies and risking the potential detrimental consequences of making an incorrect choice.

### ***Meta-theme: Nature and Quality of Treatment***

Studies explored various aspects of care received on presentation to a hospital for self-harm. Sub-themes included the specific experience of transitions at the point of presentation and discharge, and the quality of treatment received from clinicians. They further explored how patients perceive care to be over-standardised, often overlooking the emotional aspect of events.

*Sub-theme: Transitioning into and Out of Treatment*

While studies predominantly reported general experiences of short-term management and prevention provision, appraisals of specific points along the care pathway tended to focus on initial presentation (Chandler, 2016b; Ghio et al., 2011; Hausmann-Stabile et al., 2017; Holliday, 2012; Horrocks et al., 2005; Manning et al., 2015; Mitten et al., 2016; Owens et al., 2016; Strike et al., 2006) and/or discharge (Crockwell & Burford, 1995; Horrocks et al., 2005; Hunter et al., 2013; Owens et al., 2016). Patients often recounted experiencing these transition periods as disorientating and abrupt (Chandler, 2016b; Crockwell & Burford, 1995; Horrocks et al., 2005; Hunter et al., 2013; Manning et al., 2015), with such feelings being particularly frequent amongst young people (Hausmann-Stabile et al., 2017; Manning et al., 2015; Mitten et al., 2016).

At the point of admission, study participants often cited a lack of control, which occasionally, due to the individual's physical state of intoxication, had led others to take ownership of the process (Chandler, 2016b). Patients reported feelings of trepidation about what would happen to them, and in one case this manifested in an attempt to halt or disrupt admission through 'screaming' and 'yelling' (Hausmann-Stabile et al., 2017, p. 168). Fears were expressed about suddenly entering a new and unfamiliar environment, which included meeting new people (Mitten et al., 2016) and being exposed to other patients who were experiencing trauma (Manning et al., 2015). Some of these feelings were potentially exacerbated by transitioning between multiple wards (Manning et al., 2015).

Participants also reported feelings of shame and embarrassment, particularly at being subjected to the gaze of others:

Well I had to walk in through the lobby. Like they- to the emergency room. And we couldn't go through the gateway-like the back way into the place. So we had to go in through the emergency department. And I had everybody looking at me, and everybody knows I was there because I tried to commit suicide. And that was like really embarrassing both times, so it was really, really embarrassing. And it just made me feel really upset (l. 307-312). (Holliday, 2012, p. 82).

Descriptions of leaving clinical care resonated with experiences of entering. It was often sudden, with similar feelings of confusion and disorientation:

you're out the next morning walking to the bus stop thinking "what the hell's gone on?" (Horrocks et al., 2005, p. 20)

Abandonment was a predominant feeling among participants. Some felt let down and in shock that they were at the end of the process, reporting being 'sent off' and 'just left hanging' (Crockwell & Burford, 1995, p. 9). Others described how follow-on help had been promised but had not been forthcoming (Horrocks et al., 2005; Hunter et al., 2013). Negative consequences of this included loneliness (Horrocks et al., 2005), fear about being unable to cope (Horrocks et al., 2005) and feelings of hopelessness about the future (Hunter et al., 2013).

#### *Sub-theme: Quality of Treatment*

Studies explored the range of ways in which clinicians treated patients, with the quality of care experiences tending to fall somewhere along the continuum of hostility and gentility. Seventeen of the 26 studies negatively characterised care quality when presenting to hospital for self-harm (Brown & Kimball, 2013; Chandler, 2016b; Donskoy, 2011; Harris, 2000; Horrocks et al., 2005; Kirkland, 2000; Mitten et al.,

2016; Owens et al., 2016; Reece, 2005; B. Taylor, 2003), a suicide attempt more explicitly (Aspaslan, 2003; Bantjes et al., 2017; Hausmann-Stabile et al., 2017; Strike et al., 2006; Wiklander et al., 2003), or both (Nehls, 1999; Spandler, 1996). The physical space of emergency departments was likened to an asylum or prison (Hausmann-Stabile et al., 2017; Mitten et al., 2016), with perceptions being amplified by the presence of security guards (Mitten et al., 2016) and restrictions on access to personal belongings (Bantjes et al., 2017). A range of hostile encounters with clinicians was reported, including but not limited to: professionals' lack of care or sensitivity when dealing with wounds (Chandler, 2016b; Harris, 2000; Horrocks et al., 2005; Nehls, 1999); being left to tend to their own wounds (Kirkland, 2000); being made to wait in a dirty cubicle (Brown & Kimball, 2013); verbal abuse (Horrocks et al., 2005; Reece, 2005); and being denied pain relief (Chandler, 2016b; Kirkland, 2000; Owens et al., 2016). Narratives frequently drew upon violent metaphors to recount these events, often evoking images of clinicians wrestling or aggressively fighting with injuries (Chandler, 2016b).

Hostility was also experienced through clinicians' failure to communicate with patients (Bantjes et al., 2017). This left some patients having high levels of anxiety about what harm they have caused themselves (Horrocks et al., 2005). Elsewhere, the absence of any rationale for treatment contributed to feelings of stress and confusion (Bantjes et al., 2017). For example, in one instance a patient had refused medication following an almost fatal suicide attempt as they felt clinicians had not sufficiently provided an explanation of the potential side effects (Bantjes et al., 2017).

Some study participants felt that clinicians' hostility was because they were presenting with self-inflicted harm. For example, one patient thought they were refused treatment due to a history of self-harm, even though on this occasion they

were presenting with an unrelated injury (Owens et al., 2016). A different adult patient asserted that anaesthesia was withheld due to the reason for presentation:

I have been discriminated against, cos I, I turned up, I'd cut my arm, and my stomach ... and [...] taken myself up to A&E and, er, [pause] they, ... I had to get 11 staples, em, to, to sort of patch it up, and em, they didn't bother giving me anaesthetic or anything they just went, 'Well, you're a self-harmer', click. You know, it was, ... I was just lying there going, 'You're not gonna give me anaesthetic' they went 'Nah, you're a self-harmer – you did this to yourself so, ... don't really care' and I'm like, 'But – but you're just stapling me up with nothing!' (Chandler, 2016b, pp. 125-126).

Patients further thought that such treatment stemmed from clinicians' belief that they had a high pain tolerance because they had been able to inflict injuries on their own body (Nehls, 1999), whilst others felt it was an attempt punish them in order to prevent further behaviour (Spandler, 1996; Wiklander et al., 2003).

In contrast, some studies also explored examples of gentle and compassionate care (Chandler, 2016b; Ghio et al., 2011; Holliday, 2012; Horrocks et al., 2005; Manning et al., 2015; Mitten et al., 2016; Owens et al., 2016; Vatne & Nåden, 2014; Wiklander et al., 2003). This entailed instances of medical professionals putting patients at ease, making them feel safe, and treating their emotions with respect and consideration (Horrocks et al., 2005). Young people in particular highlighted the value of staff lightening the mood by telling jokes or making small talk (Holliday, 2012). With respect to physical injuries, patients mentioned the importance of clinicians' gently handling and treating their wounds (Chandler, 2016b) and recognising that they may not want any scars on display (Owens et al., 2016). Assessments of care also extended to the physical space, with participants discussing the importance of safety and

comfort (Holliday, 2012; Horrocks et al., 2005). For young people this could mean having colourful pictures on the walls (Manning et al., 2015) or providing alternatives for those who needed to engage in self-harm, although these alternatives were not expanded on (Mitten et al., 2016). Gentle care was seen as important in alleviating patients' feelings of shame and making it easier to acknowledge their difficulties (Wiklander et al., 2003). When reflecting on their treatment needs and approaches to improve care, participants said that they had no expectation of special provision. Rather they wanted 'treatment as usual', with care encompassing the 'openness, warmth and respect' that would be offered to anyone (Owens et al., 2016, p. 289).

While the experiences of hostile and gentle care demonstrate the varied and contrasting experiences available to patients, they do not exist as a binary. Many patients reported to have negative and positive experiences simultaneously (Brown & Kimball, 2013; Nehls, 1999; Spandler, 1996; Strike et al., 2006). Importantly, as Chandler (2016b) highlights, accounts of gentle care can actually serve to reinforce and even magnify negative clinical encounters, being used 'to underline the power of the 'horror stories'... as well as the enduring impact of poor instances of care' (Chandler, 2016b, p. 126).

#### *Sub-theme: Over-standardization of Treatment*

Eight included studies considered the entrenched rhythms and routines of emergency departments (Carrigan, 1994; Crockwell & Burford, 1995; Hausmann-Stabile et al., 2017; Horrocks et al., 2005; Hunter et al., 2013; Mitten et al., 2016; Sheehan, Corrigan, & Al-Khouja, 2017; Spandler, 1996), amidst participants' perceptions that treatment can be overly-standardized, irrespective of the presenting individuals' needs or history. Such standardization left patients feeling that they were moving along a 'production line' and were simply 'a lump of meat' (Horrocks et al., 2005, p. 11).

This experience was linked to clinician's prioritization of treating the immediate physical injury, administering medication, taking blood (Horrocks et al., 2005), ensuring stability (Hausmann-Stabile et al., 2017) or identifying the substances consumed in the event of an overdose (Crockwell & Burford, 1995). In one study, conduct of these routine tasks were seen as clinicians 'doing their job' (Horrocks et al., 2005, p. 13).

Through this focus on the physical, patients felt that the complex and specific emotional aspects of their self-harm were neglected which led to a lack of sensitive and personalized support. This included insufficient help in addressing the feelings and context associated with the event (Hausmann-Stabile et al., 2017; Sheehan et al., 2017), a failure to tackle the underlying causes (Carrigan, 1994; Spandler, 1996), and a dearth of time provided to 'open up' (Mitten et al., 2016, p. 13). Even in the case of psychosocial assessments, participants discussed their passivity in being assessed for risk, with clinical responses often comprising simple increases in medication (Horrocks et al., 2005). Where assessments were considered as part of the pre-discharge routine, patients felt constrained by the procedural and regimented aspects, feeling it was a mandatory task for staff (Hunter et al., 2013).

Contrasting accounts illustrated the benefits of treatment that was individualized and focused on the emotional experience of the self-harm event and subsequent help-seeking. Psychosocial assessment was considered beneficial when conducted sensitively to individual needs, (Horrocks et al., 2005), and when it went beyond the superficial checklist to provide space for emotions to be discussed (Hunter et al., 2013). This approach legitimized patients' experiences, helping to make them more hopeful about the future (Hunter et al., 2013). Opportunities to discuss emotions were also considered important in developing therapeutic relationships

with clinicians (Bantjes et al., 2017). Such positive relationships were seen as part of the road to recovery and overcoming future suicidal thoughts (Crockwell & Burford, 1995).

***Meta-theme: Perceived Impact of Care Provision on Future Self-harm, Disclosure and Help-seeking***

The impact of short-term management and prevention provision was not extensively explored across studies. Narratives predominantly ceased with participants' reflections on the experience of hospital discharge and transition to follow-on services.

***Sub-theme: Impact on Future Self-harm***

Five studies included patient reports of actual or intended self-harm or suicide attempts following a hospital presentation (Brown & Kimball, 2013; Harris, 2000; Hausmann-Stabile et al., 2017; Owens et al., 2016; Spandler, 1996). Participants' experiences of clinical care were often triggering due to the elevation of emotional distress and negative self-perception. For example, Owens et al. (2016) describe how one individual felt like going home and 'finishing the job' (that is, attempting suicide) because a hospital presentation had reinforced their sense of low self-worth. Imminent self-harm also served as an exercise in exerting control following a period in hospital where an individual felt their rights and freedom had been curtailed (Spandler, 1996). One study reported that care experiences could lead to patients being more resolute in future suicide attempts in order to avoid potential re-admission (Hausmann-Stabile et al., 2017).

*Sub-theme: Impact on Future Disclosure and Help-seeking*

Seven studies explored how individuals' negative encounters with clinicians made them less inclined to engage in future disclosure or help-seeking (Chandler, 2016b; Harris, 2000; Hausmann-Stabile et al., 2017; Hunter et al., 2013; Kirkland, 2000; Owens et al., 2016; Strike et al., 2006). Such encounters were equally evidenced across different age groups, genders and the presenting behaviours. Rationales were largely a response to the hostility of previous treatment received, with participants wanting to avoid past feelings of shame that had been induced by professionals' judgement and impatience (Owens et al., 2016), the erosion of pride from being 'locked up' (Strike et al., 2006, p. 36), or simply the 'horrendous' experience (Chandler, 2016b, p. 124). Patients further discussed the futility of seeking help, largely due to the inadequacy of previous care and being made to feel they were wasting clinician time (Kirkland, 2000). One study also referenced the repetitive cycles of help-seeking, to the point where the very repetitiveness of the act was a negative experience (Hunter et al., 2013). Patients described developing repertoires of self-care and pain management in order to support the avoidance of seeking help in future, including tending to their own wounds (Chandler, 2016b; Harris, 2000; Kirkland, 2000; Owens et al., 2016; Strike et al., 2006). In some instances, however, injuries were left unattended, which led to numerous infections (Owens et al., 2016).

In juxtaposition to accounts of avoidance, two studies provided examples of preparedness to engage in future disclosure and help-seeking. For some patients, presenting to hospital denoted an important aspect of their recovery from self-harm (Sinclair & Green, 2005). While studies rarely disaggregated different aspects of care provision, in one study psychosocial assessments were cited as encouraging help-

seeking, as they potentially signposted patients to resources and gave confidence to obtain support (Hunter et al., 2013).

## **Discussion**

This review has explored the experiences of patients in receipt of short-term management and prevention treatment when presenting to hospital for self-harm. To date there has been a proliferation in guidelines to support clinical provision at this point in the care pathway (Australian Government Department of Health and Ageing, 2007; HM Government Department of Health, 2015; New Zealand Associate Minister of Health, 2006; Scottish Government, 2018; U.S. Department of Health and Human Services (HHS) Office of the Surgeon General and National Action Alliance for Suicide Prevention, 2012; Welsh Government, 2015; World Health Organization, 2014) but there has been limited systematic attempts to comprehend any specificity of experience within this context.

A central concept to emerge from the synthesis is identity work, and how presentation to an emergency department for self-harm can serve as a major source of biographical disruption (Bury, 1982; Reeve, Lloyd-Williams, Payne, & Dowrick, 2010; Trusson, Pilnick, & Roy, 2016; Wouters & De Wet, 2016). Originally examined within the context of chronic illness, ruptures of biographies within critical situations are seen as transformative, bringing into sharp relief the precarity of an individual's sense of self, their relation to others, and their framing within medical discourse. For individual's presenting with self-harm, a significant aspect of biographical disruption is that of assuming, being ascribed or being denied the patient identity. There is complication and ambiguity within this process, which can be amplified by the abrupt transitions into and out of treatment. For some, prevention of adopting the 'sick role' is inherently problematic (Parsons, 1951), as their eligibility for care is diminished.

Becoming a patient may then be desirable and can even be empowering where it affords legitimacy. Conversely, attribution of the patient identity can be challenging if it pathologizes self-harm. Regardless of the appeal of different patient identities, it is important to see emergency departments as liminal spaces, providing complex places of transition and transformation.

The importance of acknowledging the biographical disruptions experienced by those presenting with self-harm encourages recognition of the work involved by a patient in reconfiguring their identity. Presenting individuals are perpetually engaged in navigating and negotiating their sense of self throughout clinical interactions, making difficult decisions about what to disclose and what to hide (Goffman, 1963). The energy and emotion entailed by these micro-practices are rarely brought to the fore within the extant research literature, but demand consideration due to their impact on the patient, especially given that self-harm may already involve an extensive amount of emotion. It is also important to remember that this work is conducted within a context where the individual may feel stigmatized both by themselves and by others (Mitten et al., 2016; Rimkeviciene, Hawgood, O'Gorman, & De Leo, 2015).

The review further explored patients' experiences of being treated by clinicians and the adequacy of treatment. Variability in care was evident, resonating with the wider research in this area (T. Taylor et al., 2009). Gentility and hostility of care were considered as having potentially positive and negative impacts on future self-harm and help-seeking. A significant theme within experiences of treatment was the notion of feeling processed, in accordance with the strict rhythm and routines of hospitals. Such experiences may be linked to the aforementioned identity work, where perceptions of being reduced to a patient without an appreciation of complex and

individualized needs, may make individuals particularly sensitive to the feeling that their treatment is merely procedural.

The present systematic review builds on previous syntheses by incorporating a range of research published since the most recent review in this field (T. Taylor et al., 2009). Two of these more recent publications scored ‘high’ in terms of overall usefulness to the review (Donskoy, 2011; Owens et al., 2016). Four of the more recent publications included reference to how patients’ care experiences impacted on future self-harm and help-seeking, and therefore enabled more interpretive accounts (Chandler, 2016b; Hausmann-Stabile et al., 2017; Hunter et al., 2013; Owens et al., 2016).

### *Limitations of Studies*

The predominant limitation of included studies was the paucity of reporting on participants’ demographic data, making it difficult to assess the applicability of the synthesis to diverse populations. Study participants were primarily characterized by the outcome or behaviour for which they received treatment (for example, suicide attempt). Of the twenty-six included studies, two did not report gender, four did not specify participants’ age range and seventeen did not indicate race or ethnicity. Such data is important as demographic factors may influence the nature and quality of care received and impact upon future intentions to self-harm or seek help (Al-Sharifi, Krynicki, & Upthegrove, 2015; Cooper et al., 2010; Saunders et al., 2012). Medical history and co-morbidities were infrequently discussed and there was no systematic reporting on whether participants were first time or repeat presenters. As such, it was

not possible to interpret data within the wider historical context of patients' experiences of treatment.

Where demographic characteristics were reported, there was heterogeneity across participants in terms of age, gender and ethnicity, although white females are highly represented in the review. No studies were retrieved that explicitly looked at suicidal ideation. Given that participants problematized the prioritisation of treating medical injuries, it may be important to consider cases where individuals present without physical harm. Studies defining the focus as self-harm often did not specify if there was also suicidal intent, and it is difficult to ascertain the differences in experiences where individuals were suicidal or not.

With regard to treatment provision, only a small number of studies provided a comprehensive breakdown of the different aspects of the care pathway or specified the medical professionals encountered. Where studies disassembled care components, two considered psychosocial assessments (Horrocks et al., 2005; Hunter et al., 2013), nine referenced the point of admission (Chandler, 2016b; Ghio et al., 2011; Hausmann-Stabile et al., 2017; Holliday, 2012; Horrocks et al., 2005; Manning et al., 2015; Mitten et al., 2016; Owens et al., 2016; Strike et al., 2006) and nine reported on discharge and the continuity of care (Chandler, 2016b; Crockwell & Burford, 1995; Harris, 2000; Hausmann-Stabile et al., 2017; Horrocks et al., 2005; Hunter et al., 2013; Kirkland, 2000; Owens et al., 2016; Strike et al., 2006). Understanding of care experiences are further restricted by the number of countries in which studies were conducted (n=7), and further comparative research is required to assess the relevance of the synthesis to a wider range of health-care systems. A further limitation of the review is that only studies indexed in English were retrieved and hence there may be relevant non-English studies that were missed.

Quality appraisal ascertained the methodological strength of studies and indicated a number of limitations that might be redressed in future research. These included: a lack of rigour in the approach to sampling; absent or poorly described approaches to analysis; decontextualized presentation of findings; and limited conceptual development. The usefulness of findings assessment, which evaluated conceptual richness, explanatory power and depth of findings (Rees et al., 2011), reported only two articles as having a high degree of utility (Donskoy, 2011; Owens et al., 2016). This suggests a need for further development of theoretically-informed qualitative research in this subject area. Studies would also benefit from longitudinally tracing changes in patients' lived experiences over time. At present, it is difficult trying to disentangle genuine trends in care provision from changes in the theory and methods employed to examine them.

### ***Implications***

The review has a number of important implications, both for research and practice. Most fundamentally, is the need to rethink our construction and discussion of the patient. From this review it is evident that patients are active, engaged and affected by their interactions with professionals. The effort and emotion involved in this activity needs to be acknowledged and measures taken to appropriately support the presenting individual. For example, an important consideration is the extent to which patients are required to re-tell their narratives to multiple professionals as they move through the care process. Increases in the number of clinicians encountered and limited communication between professionals may only exacerbate the emotional energy expended.

Secondly, we need to continue to problematize and progress our understanding of the causes and nature of self-harm, moving beyond the bio-medical discourses that have historically dominated the field. This shift has arguably commenced within the domain of research, with increased advocacy of models that integrate socio-cultural factors (Chandler, 2016a; Chandler, Myers, & Platt, 2011; Hjelmeland, 2016; J. D. Taylor & Ibañez, 2015). It is imperative that this progression continues within clinical treatment as the application of stringent medicalized models can feel inaccurate, reductionist and alienating to patients. From the review, it was apparent that patients' felt the complex emotional aspects of their situation were overlooked. To this end, medical professionals should seek to engage with the full complexity of self-harm. They must also understand that for the presenting individual, self-harm may not be symptomatic of sickness. Rather it may have been assimilated into their sense of self, forming part of a rational and carefully crafted set of coping and control mechanisms (Adler & Adler, 2011; Brossard, 2014; Chandler, 2016b; Harris, 2000). There have been recommendations within the extant literature to provide training to clinical staff to address their knowledge and understanding of self-harm (Saunders et al., 2012), and based on the findings of this review, it should incorporate a sociocultural lens.

Thirdly, the review also encourages us to reflect on current approaches to the short-term management and prevention of recurrent self-harm, as specified within clinical practice guidelines such as those issued by NICE in the UK (National Institute for Health and Care Excellence, 2004). Although included studies are reported across different healthcare systems, and thus notions of best practice may look different in different contexts, it is possible to draw out some generic recommendations to enhance provision. First, while standards of care are recommended to ensure consistency in high-quality treatment (Saunders et al., 2012), it is important not to risk

over standardization to the point that care feels too stringent and procedural to patients. Treatment plans need to encompass sufficient flexibility to ensure that patients feel that care is individualized and sensitive to their personal preferences (T. Taylor et al., 2009). It means that engagement with patients' emotional experiences need to be prioritized alongside physical treatment of injuries, and that clear communication is required to help individuals understand the rationale for their particular provision. For example, variation in the experiences and perceived utility of psychosocial assessment is linked to the extent to which clinicians explain its purpose, assess underlying contexts and support patients in identifying future support, rather than merely assessing medical and psychosocial risk (Horrocks et al., 2005; Hunter et al., 2013).

Fourthly, and relatedly, is the need to address the quality of care provided by clinicians. NICE standards mandate that patients who self-harm are cared for with compassion, respect and dignity (National Institute for Health and Care Excellence, 2013), and the review illustrates the importance of these values. Gentle as opposed to hostile treatment may encourage future disclosure and help seeking, while reducing the risk of recurrent self-harm. Drawing on the discussion from one study (Owens et al., 2016), we might assure clinicians that patients presenting with self-harm are not seeking exceptional treatment, but just to be cared for in the same manner as everyone else. There is a further need to ensure quality in the continuity of care across the pathway, whilst attempting to reduce the sense of abruptness and disorientation experienced at the point of transition.

Finally, work needs to be undertaken in monitoring the implementation of national clinical practice guidelines. Included studies often focused on the immediate, micro-level aspects of care, appraising individual interactions with clinicians. As such, there

was limited insight into the application of clinical practice guidelines within the specific context. Given reported variability in the provision prescribed by clinical practice guidelines (Cooper et al., 2013), it is not clear whether negative experiences in particular were the consequences of inadequate implementation or the complete absence of guideline enforcement. Further research is required to understand variation in experiences according to differences in implementation. Additionally, progress is required to capture this patient experience and translate it into the direct improvement of treatment. Previous recommendations have included the development of standardized service user interview schedules that can be used for routine auditing purposes (T. Taylor et al., 2009).

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<sup>i</sup> Thirteen articles did not progress to the final synthesis: (Balcombe, Jones, & Phillips, 2011; Bergmans et al., 2009; Bolger, O'Connor, Malone, & Fitzpatrick, 2004; Buykx, Ritter, Loxley, & Dietze, 2012; Chi et al., 2014; Holliday & Vandermause, 2015; Hume & Platt, 2007; Long, Manktelow, & Tracey, 2015; Pavulans, Bolmsjö, Edberg, & Öjehagen, 2012; Samuelsson, Wiklander, Åsberg, & Saveman, 2000; Spence et al., 2008; Vatne & Nåden, 2016; Yazdani, 1998).