The impact of interpersonal and intersubjective factors on engagement with psychological services in individuals who repeatedly display deliberate self-harm (DSH) behaviour

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

This thesis focuses on the relationship between individuals who repeatedly self-harm and healthcare services. It investigates potential barriers within this relationship that limit the access of service users to psychological therapies for self-harming behaviour available in the NHS.

As repeated self-harm has a substantial economic burden, Part 1 presents a review of economic evaluations of psychological treatments for people diagnosed with Emotionally Unstable Personality Disorder, who often use deliberate self-harm as coping mechanisms. Twenty studies were included following a systematic search of the literature. Overall, Dialectical Behavioural Therapy has the highest chance to be considered as cost-effective, followed by Schema Focus Therapy and Mentalisation Based Therapy.

Part 2 presents a qualitative study where semi-structured interviews were conducted with service users who repeatedly self-harm, and mental health professionals working in Accident and Emergency (A&E) department. Additionally, one focus group took place with mental health professionals working in the community. All data were analysed using Framework Analysis. Results suggest current clinical care and service structures do not meet the needs of some individuals who repeatedly self-harm. Clinical and organisational changes were suggested to increase the use of psychological interventions.

Part 3 of this thesis is a critical appraisal that reflects on some of the issues that arose during working on the project. It focuses on three topics: difficulties with conducting research with individuals who do not engage with health services, personal difficulties involved in the interviewing process, and the relevance of health-economic knowledge among clinical

psychologists. This is a joint thesis, carried out with Daniel Harris (DClinPsy, 2019); a summary of the contributions of each author to this study is given in Appendix A.

Impact Statement

The project has numerous implications in the field of academic research and clinical practice. The implications apply to both the literature review and empirical paper. In the academic domain, the impact of the empirical study emphasises the importance of investigating repeated self-harming behaviour from a systemic point of view. By adopting this perspective, the study locates psychopathology within the relationships between service users and their environment, focusing especially on healthcare services. This meta-stance encourages researchers to pursue methodological practices that enable a more holistic perspective on mental health difficulties, and therefore hopefully allow a wider range of potential solutions for mental health challenges. The important methodological contribution of this study is the integration of both sides of the relationship by evaluating their unique contributions equally. Consequently, this study stands out from the majority of the available qualitative explorations in the field, which adopt an explorative stance focusing solely on one side of this relationship.

Outside of academia, the empirical paper encourages policy and decision makers to reflect on the unique needs not only of service-users but also of healthcare professionals who are in charge of delivering treatments. It therefore provides a comprehensive examination of how health policies are being translated into practices, and points out limitations that can now be addressed with a better understanding. Particularly, the study illustrates how non-medical needs are being met by repeatedly attending A&E departments, consequently increasing the workload and economic burden of these facilities. Therefore, the impact of this study is that it enables future examination of alternative, possibly cost-effective,

interventions or treatment facilities, where individuals who repeatedly self-harm can have their psychological needs met.

In addition to the empirical paper, the literature review contributes as well to the academic domain. This impact is mainly with regards to how researchers can increase the relevance of their studies for policy-making processes, by collecting data that can be used by health-economic analyses. In the field of deliberate self-harming behaviour, the review suggests that understanding interventions better can be facilitated by prioritising outcome measures such as "the quality-adjusted life year", which allow health-economists and decision makers to estimate the value for money of psychological interventions. Unfortunately, many studies did not include outcome measures relevant for health economics, resulting in a need for rough estimations and therefore more ambiguous results. These, in turn, do not allow policymakers to make well-informed decisions about which interventions the system should prioritise.

Another impact of the literature review relates to the promotion of the discussion regarding whether or not clinical psychologists should be familiar with the subject of health economics. This study argues that influential leadership positions require a holistic understanding of how health organisation operate. This means that leaders should be familiar with the interaction between the economic and clinical fields. This project serves as evidence that there is value in clinical psychologists gaining experience and knowledge in health-economics, and it challenges possible current perceptions that clinical psychologists are limited to the clinical realm exclusively. I believe that this project can promote a discussion about the potential benefits of including health-economics studies in the curriculum of DClinPsy training

Table of contents

Index of Tables and Figures

Part 1: Literature Review

Part 2: Empirical Paper

Acknowledgments

> "אדם רודף את שחסר לו. לא חסר לו, לא רודף..."
> *רבי מאיר בעל הנס*

Part 1: Literature Review

Economic evaluations of three leading treatments for Emotionally

Unstable Personality Disorder (EUPD): A systematic review

Abstract

Aims. Emotionally Unstable Personality Disorder (EUPD) is a common psychological disorder that is associated with heavy utilisation of primary and secondary health services, posing a high economic burden on public health sectors. In a budget restricted system, there is a continued need to assess the costs as well as the effectiveness of psychological interventions. The study provides a review of the literature on health economic studies of three evidence-based treatments for EUPD: Dialectical Behavioural Therapy (DBT), Mentalisation-Based Therapy (MBT) and Schema Focused Therapy SFT.

Method. A systematic literature search was conducted in PsycINFO, Embase, Web of Science, Cochrane Colloquium, Econlit, Medline, NHS EED and ISPOR for economic evaluations of DBT, MBT and SFT. Quality assessments were conducted by using the Consensus on Health Economic Criteria checklist and the Cochrane Collaboration's tool for assessing the risk of bias. All costs were inflated to the year of 2016, and converted into Great British Pound (GBP) to allow comparisons between studies.

Results. Ten full and ten partial economic evaluations were identified. The methodological quality was moderate, with average fulfilled criteria of 80% for full economic evaluations and 73% for partial economic evaluations. DBT has the most substantial evidence of being cost-effective, yet with a considerable degree of uncertainty. More ambiguous results were obtained for SFT followed by MBT.

Conclusion. DBT has the highest chance of being cost-effective, although it depends on the type of effectiveness measures used. For MBT and SFT, the economic evidence failed to provide robust conclusions due to methodological limitations. Areas for further research are outlined.

1. Introduction

Among all psychological treatments for personality disorders, the vast majority of effectiveness studies are comprised primarily of participants with a diagnosis of Emotionally Unstable Personality Disorder (EUPD), also known as Borderline Personality Disorder (BPD) (NCCMH, 2009). However, there is limited evidence that these treatments are financially beneficial for the society that funds them (Brettschneider et al., 2014). This review investigates whether the available treatments provide a satisfactory clinical value for the amount of money invested in them.

1.1 Emotionally Unstable Personality Disorder and its economic impact

EUPD is defined by the *International Classification of Diseases 11th Revision* as a personality disorder characterised by a combination of instability of affect regulation together with a tendency to act impulsively with limited consideration of the consequences (World Health Organization, 2018). It is usually accompanied by an unstable sense of self, difficulties in relationships with others and self-harming behaviour. It is commonly associated with other mental health difficulties, such as depression, anxiety, substance misuse, and eating disorders (NICE, 2009).

The characteristics of BPD are linked with a high burden of illness, manifested by low levels of functioning, a struggle to maintain employment, and a high level of service utilisation, including outpatient appointments and repeated admissions to A&E and psychiatric hospitals (Sansone, Farukhi, & Wiederman, 2011; Torgersen, Kringlen, & Cramer, 2001). As the prevalence of EUPD in the UK is estimated to be between 0.7-4.6%, it imposes a significant economic burden on public health services (Brazier et al., 2006;

McCrone, Dhanasiri, Patel, Knapp, & Lawton-Smith, 2008; Trull, Jahng, Tomko, Wood, & Sher, 2010).

In a budget-constrained healthcare system, a high economic burden poses a challenge to stakeholders and decision makers of public health services (Razzouk, 2017). As health systems operate within a limited resource framework, this leads stakeholders to choose treatments that maximise clinical achievements in terms of better health outcomes within the available financial resources, in other words, choosing treatments based on their effectiveness (Luyten & Knapp, 2017). According to the National Institute for Health and Care Excellence guidelines manual (2012), health economics focuses on resource efficiency in promoting public health, and it is the responsibility of the Public Health Advisory Committee (PHAC) to ensure an appropriate decision-making process is implemented based on the available information on costs and effectiveness.

1.2 Health economics: aims and relevant terms

1.2.1 Full vs partial economic evaluations.

One of the main goals of a health economic analysis is to assist and support decision-making processes, which are both clinically and economically informed (Razzouk, 2017). It is usually done by conducting two types of investigations: partial and full economic evaluations.

Partial economic evaluations, also known as cost analyses, compare the costs of two or more alternatives (van Mastrigt et al., 2016). Costs are usually separated into two categories, namely, direct and indirect costs. Direct costs include the expenses of medical and psychological care that are given directly to the individual, and these usually include inpatient care, outpatient care, medication, or A&E treatment. Indirect costs, on the other

hand, are characterised by a loss of productivity as a consequence of disease and mostly refer to sick leave and early retirement (Tarricone, 2006).

Full economic evaluations assess not only the costs of interventions but also their effectiveness/outcomes (Phelps, 2016). There are a number of ways to assess the effects of treatment in health economic studies. Effects can be measured by natural units (e.g., number of parasuicidal events), utility units (e.g., quality-adjusted life years = QALYs; see below) or monetary units, which are usually measured by the actual amount that was paid or by other techniques, such as "willingness to pay" (WTP) estimations. Based on the measurement methods, full economic evaluations are subdivided into three categories: cost-effectiveness analyses (CEA) using natural units, cost-utility analyses (CUA) using utility units, and cost-benefit analyses (CBA) using monetary units as measures of effect (Bassi & Lau, 2013; Gafni, 2006; Rascati, 2013).

Since 2012, NICE guidelines officially advise using CUA, which use QALYs, to measure utility (NICE, 2012). QALYs measure the state of health of an individual or a group in terms of both quality and length of life. In other words, they estimate the number of years remaining to an individual after they have undergone a particular intervention; this is calculated by evaluating their ability to complete activities of daily life while free from excessive physical or mental pain. Therefore, one year of life in "perfect health" is equivalent to one QALY (Knapp & Mangalore, 2007)

1.2.2 Main outcomes of economic evaluations

To assess which intervention is preferable in terms of cost compared to clinical outcome, decision makers use a statistic called the incremental cost-effectiveness ratio

(ICER). The ICER is calculated by dividing the difference in the costs of two competitive interventions by the differences in the chosen measure of effect (for example, choosing QALY for cost utility analyse or other natural units as parasuicidal events avoided for cost effectiveness analyse). It provides a ratio of additional costs per unit of health effect (Razzouk, 2017).

$$ICER = \frac{Cost\ of\ treatment\ 1 - Costs\ of\ treatment\ 2}{Effects\ of\ treatment\ 1 - Effects\ of\ treatment\ 2}$$

Healthcare systems vary in the amount they are willing to invest for improved health outcomes. This is called the "willingness to pay threshold" (WTP threshold). If an intervention obtains the desired health outcome, and the monetary investment was lower than the WTP threshold, the intervention isconsidered to be "cost-effective" (Knapp, McDaid, & Mossialos, 2006). Consequently, the probability of an intervention being considered cost-effective is influenced by its WTP threshold. To assess this probability, health economists use a graph-based method called a Cost-Effectiveness Acceptability Curve (CEAC). It demonstrates the likelihood that an intervention will be cost-effective in relation to different pre-determined thresholds (Fenwick, Marshall, Levy, & Nichol, 2006). Therefore, the higher the threshold, the more likely it is that the treatment will be accepted as cost-effective.

1.2.3 The role of perspectives

Economic evaluations adopt different points of view or "perspectives" for evaluating costs and outcomes (Phelps, 2016). Narrow perspectives focus on the costs and outcomes of individuals or health services. These are called the "patient perspective" and "third payer perspective" respectively (Shemilt et al., 2006). They usually calculate the direct medical

costs that are associated with the examined intervention (e.g., medication, GP visits, outpatient or inpatient psychological services, etc.).

Wider perspectives examine costs that extend beyond the focus of health services or individuals. They take into account productivity losses and other non-health sector costs, for example, the utilisation of social services. These wider points of view, the "societal perspective", are recommended by the NICE guidelines (2012) when health economists assess the implementation of new healthcare treatments. Therefore, a societal perspective was used in this review to evaluate cost-effectiveness evidence for EUPD treatments.

1.3 Which treatments for EUPD are considered effective?

This review examines three treatments that have significant evidence of effectiveness and are available within the NHS. Based on numerous RCTs and meta-analyses (Kliem, Kröger, & Kosfelder, 2010; Panos, Jackson, Hasan, & Panos, 2014; Stoffers et al., 2012), NICE guidelines for personality disorders recommend Dialectical Behavioural Therapy (DBT) as a treatment of choice for EUPD (NICE, 2009; Snowden & Kane, 2003). Furthermore, the guidelines mention two additional interventions, namely, Mentalisation Based therapy (MBT) and Schema-Focused Therapy (SFT), both of which are supported by empirical evidence (NICE, 2009).

1.3.1 Dialectical Behavioural Therapy

DBT is an evidence-based intervention designed to help people with EUPD and chronically suicidal individuals (Long & Witterholt, 2013). DBT comprises four main modules: mindfulness, interpersonal effectiveness, distress tolerance, and emotion regulation (Linehan, 1993). Additionally, DBT involves four stages: obtaining behavioural control

(mostly self-harming behaviour) and promoting motivation to stay in therapy; increasing emotional experiencing to reduce traumatic stress; problem-solving of daily living challenges; and achieving transcendence and building capacity for joy (Linehan & Kerher, 1993). NHS services deliver stages one and two, while the remainder form part of self-actualisation, and so are outside the focus of the delivered intervention.

DBT consists of a weekly 2-hour psychoeducational skills training group over a year and a weekly 1-hour session of individual therapy. Additionally, the intervention includes phone-based and other in-vivo coaching to support the generalisation of the learned skills. Furthermore, it includes consultation meetings for therapists to help them maintain their fidelity to the treatment (Linehan, 1993).

DBT uses a number of therapeutic elements from cognitive behavioural therapies, such as behavioural analysis, contingency management, exposure, and psychoeducation (Van Dijk, 2013). DBT incorporates many other unique strategies, for example, chain and solution analyses to increase problem-solving abilities; validation strategies, such as radical genuineness; and dialectical strategies that promote shared perspectives with the client (Feigenbaum, 2007; Linehan, 1993).

The clinical effectiveness of DBT has been repeatedly demonstrated. A Cochrane review (Stoffers et al., 2012) investigated the effectiveness of psychotherapies for people with EUPD and confirmed that DBT is effective in increasing emotion regulation skills, reducing self-harming behaviour, and improving general functioning. Other studies have shown that the implementation of DBT skills in daily life is a mediator in treatment effectiveness (Barnicot, Gonzalez, McCabe, & Priebe, 2010; Koons et al., 2006; Lynch, Chapman, Rosenthal, Kuo, & Linehan, 2006; Neacsiu, Rizvi & Linehan, 2010;;).

21

1.3.2 Mentalisation Based Therapy

Mentalisation-Based Therapy (MBT), also called psychoanalytically orientated partial hospitalisation, conceptualises psychopathology as a consequence of a failure in the process of mentalisation - the ability of individuals to interpret the actions of others and themselves as valuable in terms of subjective and intentional mental states (Bateman & Fonagy, 2004).

By increasing self-reflective capacity, the intervention aims to alleviate problematic behaviours and help service users to make sense of their feelings, beliefs, wishes, and thoughts about themselves and others (Fonagy & Allison, 2014). MBT has two variations: day hospital programmes and outpatient programmes. The first programme includes up to 18-24 months of five times a week individual therapy session. The second programme involves 18 months of weekly individual therapy (50 min) and weekly group therapy (90 min). The group therapist is different from the individual therapist (Bateman, 2006).

Similar to DBT, the clinical effectiveness of MBT has been repeatedly tested. In a recent systematic review (Vogt & Norman, 2018), service users with EUPD showed a significant improvement in functioning, as well as a reduction in personality disorder-specific symptoms and their associated distress. Other studies (Bateman & Fonagy, 2001; Bateman & Fonagy, 1999; Jørgensen et al., 2013) have shown an improvement in quality of life and reduction in the comorbidity of anxiety and depression.

1.3.3 Schema Focused Therapy

Primarily aimed at treating individuals with entrenched interpersonal difficulties associated with personality disorders, SFT is an integrative approach that adopts elements from CBT, psychodynamic psychotherapy, attachment theory, and Gestalt theory (Young,

Jeffrey, Klosko & Weishaar, 2003). SFT, which is structured and systematic, aims to modify service users' schema, a blueprint for understanding self and others (Leahy, 2018). However, the length and pace of treatment may vary according to the service user's needs. In contrast to DBT and MBT, SFT does not include group-based interventions, and it can last up to three years. It does not require the therapist to follow a specific protocol or session structure (Young, 2014).

There is growing empirical support for SFT as an evidence-based treatment for personality disorders. Several publications, including one meta-analysis (Jacob & Arntz, 2013), have demonstrated that SFT is an effective treatment for people with personality disorders. Studies have found a reduction in BPD-specific symptoms (van Asselt et al., 2008) and general psychiatric symptoms, such as depression and anxiety (Bamelis, Evers, Spinhoven, & Arntz, 2014), as well as improvements in quality of life (Giesen-Bloo et al., 2006). These results have led to an increase in the use of SFT in NHS services, especially in personality disorder, forensic, and primary care services (Camden and Islington NHS Foundation Trust-2019; Southern Health NHS Foundation Trust, 2016; The British Association for Behavioural and Cognitive Psychotherapies, 2019).

1.4 Past evidence

In 2006, Brazier and colleagues published an extensive economic review of psychotherapies for people with EUPD. Additionally, Brettschneider and colleagues (2014) evaluated 15 economic evaluations of psychotherapies for people with EUPD until the year 2012. Both evaluations focused on treatments for adults with EUPD and did not reveal robust conclusions. Brazier's report did not find DBT to be cost-effective, mainly due to the study being based on a small number of RCTs that yielded mixed results and the high variations in

methodological quality of the examined studies. Yet, it suggests that of the treatments considered, DBT has the highest potential to be cost-effective.

Similarly, the review by Brettschneider (2006) identified DBT as the treatment with the highest probability of being cost-effective yet with a significant discrepancy in incremental costs, which ranged between cost-saving treatments and ones that required a large amount of extra costs. This was reflected in the heterogeneity of the ICERs, which ranged between treatments that were found to be dominant (both more effective and with fewer costs) and ones that were not cost-effective. Together with a high variety of different comparators, it was difficult to obtain robust conclusions.

The most recent economic review was conducted by Meuldijk et al (2017). It is important to note that the authors investigated only partial economic evaluations, and compared treatments for EUPD in terms of costs alone. Additionally, apart from DBT, MBT and SFT, they included treatments that are not mentioned by NICE guidelines.

1.5 The focus of this review

This review examines three of the treatments for EUPD: DBT, MBT and SFT. It improves upon former reviews by including a higher number of reviews (n=20) and focusing only on treatments mentioned by the NICE guidelines for EUPD (2009). Furthermore, this review includes populations that were excluded in past reviews by including studies with suicidal adolescents and individuals who have additional psychopathologies besides EUPD (e.g. MBT for eating disorders).

Specifically, the current review aimed to achieve the following:

A. provide a comparative analysis between DBT, MBT, and SFT in terms of cost-effectiveness

B. provide decision makers and services with synthesised data regarding the implementation of each therapy in terms of both costs and clinical effectiveness

C. identify remaining uncertainties and suggest possible action plans to allow more informed decision-making process in the future

2. Method

2.1 Search strategy

A systematic literature search was conducted in two steps. First, the following databases (PsycINFO, Embase, Web of Science, Cochrane Colloquium, Econlit, Medline, NHS EED and ISPOR.) were searched up to the cut-off of October 2018. These databases were recommended by the *Expert Review of Pharmacoeconomics & Outcomes Research* (Mastrigt et al., 2016). Additionally, authors were contacted to gain valuable information that was not included in the published version of their studies.

Second, key search terms were gathered and organised according to the "PICO" framework (Population, Intervention, Comparator and Outcome) (Huang, Lin, & Demner-Fushman, 2006). Decisions regarding which terms to use were based on the need to maximise inclusiveness. Therefore, the terms for "Borderline Personality Disorder" and its different varieties were chosen under the category of "Population". Similarly, a variety of relevant terms for the treatments DBT, SFT, and MBT were included under the category of "Intervention". Based on the need to identify all relevant papers, the "Comparator'" category was left blank, while under the "Outcome" category, terms related to "Cost studies'" were chosen according to the *Expert Review of Pharmacoeconomics & Outcomes Research* guidelines (Mastrigt et al., 2016). Variations of terms and the different uses of the operators "OR" and "AND" are available in Table 1.

Table 1

Search strategy

Population		Intervention		Comparator		Outcome
Mental health OR Healthy population		DBT, MBT, SFT		N.A.		Economic evaluation
"Personality disorder" OR "PD" OR "BPD" OR "borderline personality disorder" OR "Emotionally Unstable Personality Disorder" OR "EUPD" OR "DSH" OR "deliberate self harm" OR "Adult*" OR "Adolescent*" OR "Natural*" OR "Healthy" OR "pathologic*" OR" Young*"	AND	"dialectical behavioral therapy" OR "dialectical behavioural therapy" OR "dialectical behavior therapy" OR "dialectical behaviour therapy" OR "DBT" OR "dialectical behavioral treatment" OR "dialectical behavioural treatment" OR "dialectical behavior t treatment" OR "dialectical behaviour treatment"	AND	N.A..	AND	Cost* OR "cost-effectiveness" OR "cost-utility" OR "Cost-Benefit Analysis" OR "Cost-Benefit" OR "cost" OR "costs" OR "economic evaluation" OR "economic analysis" OR "Health Care Costs" OR "Health Care Costs" OR "Quality-Adjusted Life Years" OR "Quality-Adjusted Life Years" OR "Quality-Adjusted Life Year" OR "QALY" OR "QALYs" OR "cost-consequence" OR "cost-consequences" OR "cost-minimization" OR "cost-minimisation" OR "cost-outcome" OR "cost-outcomes" OR "efficiency" OR "Value for money" OR "Health economic*"

Table 1 *(continued)*

As noted above	**AND**	"mentalization based therapy" OR "mentalization based therapy" OR "MBT" OR "mentalization base treatment" OR mentalization base treatment" OR "mentalization base therapy" OR "mentalization base therapy" OR "MBT" OR "mentalization base treatment" OR mentalization base treatment"	**AND**	N.A.	**AND**	As noted above
As noted above	**AND**	"Schema focused therapy" OR "SFT" OR "Schema therapy" OR "Schema treatment" OR "schema focused treatment" OR "Schema focus therapy" OR "Schema therapy" OR "schema focus treatment"	**AND**	N.A.	**AND**	As noted above

*AND, OR = Boolean operators; *= truncation; BPD= Borderline Personality Disorder; PD= Personality Disorder; EUPD= Emotionally Unstable Personality Disorder; DSH= Deliberate Self Harm; DBT= Dialectical Behavioural Therapy; MBT= Mentalisation based Therapy; SFT= Schema Focused Therapy; QALY= Quality Adjusted Life Year*

2.2 Study pool

A flow diagram of the systematic literature search is presented in Figure 1. Results were derived from varied data bases including MEDLINE, Ecolit, Web of Science, ISPOR, EMBASE, PsycINFO, and NHSEED. Additionally, articles were also obtained through the Cochrane library and by contacting experts in the field. Non-relevant articles and duplicates were removed following abstract screening. Full text screening excluded qualitative and case studies, study protocols, audits, studies that were not in English, and studies that were not economic evaluations.
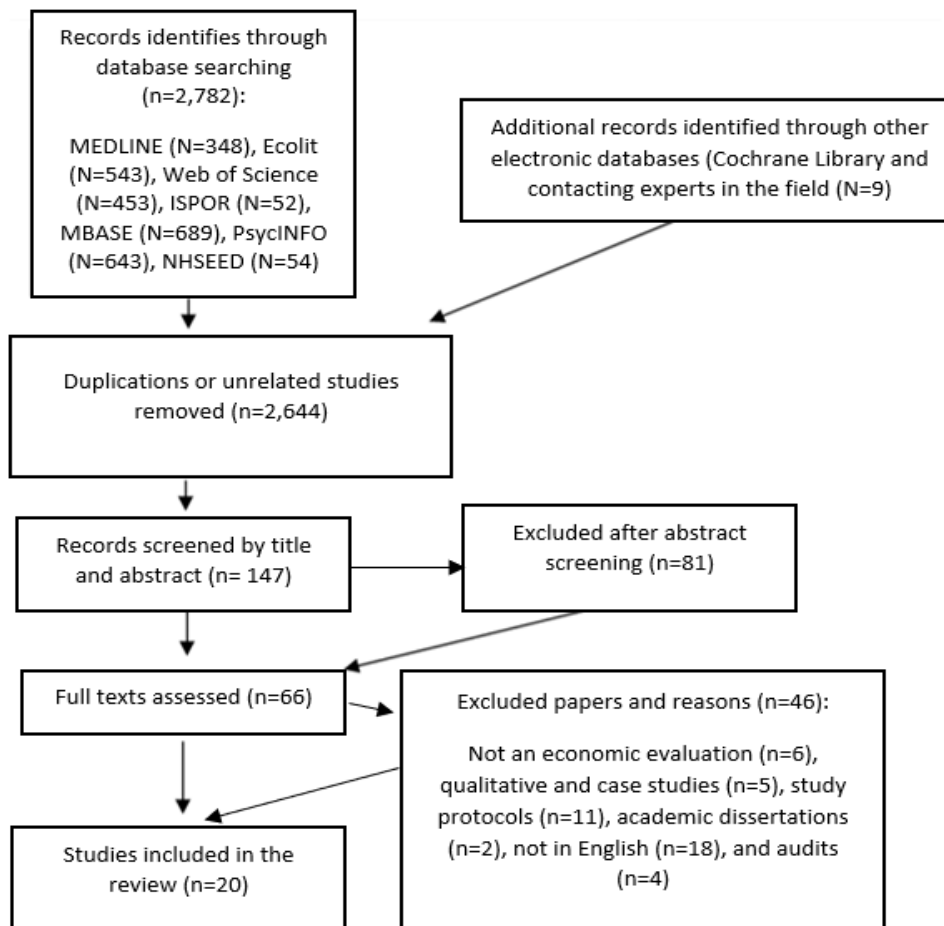
Figure 1

Search flowchart

2.3 Inclusion and exclusion criteria

Economic evaluations of DBT, MBT, and SFT were included in this review. The inclusion criteria specified that suitable papers for review must:

- include a description of costs
- be conducted with participants who meet the EUPD or BPD diagnostic criteria according to one of the following manuals:

   a. the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; American Psychiatric Association, 2013)

   b. the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-4; American Psychiatric Association, 2000)

   c. the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition* (DSM-3; American Psychiatric Association, 1987)

   d. the *International Classification of Diseases, Eleventh Edition* (ICD-11; World Health Organization, 2018)

   e. *the International Classification of Diseases, Tenth Edition* (ICD-10; World Health Organization, 1992)

- be published in English and between November 1990 and November 2018
- be empirical quantitative studies

Studies that did not document the method of cost assessment, case studies, conference abstracts, editorial letters, dissertations, non-English, qualitative studies, and books were excluded.

Following the removal of duplicates, data extraction was performed by the author (IC). Title and abstract screening were conducted by the author \. When the abstract did not

provide a clear description of the study, the full text was examined to assess eligibility. The literature review includes full and partial economic evaluations utilising a wide range of study designs including RCTs; quasi-experimental designs and pre-post comparisons were included to present a wide perspective on the existing literature.

2.4 Data extraction

A number of steps were taken to extract relevant data. These steps included the identification of studies' characteristics followed by the documentation and extraction of the relevant costs and effects (Appendix B). As a significant number of studies were conducted outside the UK, costs were converted to GBP-£ using Purchasing Power Parties (GBP-£ PPP) and inflated to the year 2016[1]. This was done by using a cost converter created by the Campbell and Cochrane Economics Methods Group (CCEMG, 2016), which automatically adjusts for costs and price year (Shemilt, Khan, Park, & Thomas, 2016). Additionally, when costs were related to groups, a transformation was made to obtain costs per patient.

When analysing full economic evaluations, ICERs were extracted as well as CEACs. It is important to note that different studies chose different cost thresholds for each different effectiveness outcome (based on the fact that studies vary across different countries with different health systems). It yielded varied probabilities for the values by which an intervention is considered cost-effective.

Regarding effectiveness outcomes, this review extracted the QALY, Parasuicidal Event Avoided (PSEA) and general functioning data. Unfortunately, NICE guidelines provide specific WTP thresholds only for QALYs (which stands currently at between £20,000-£30,000 for an increase of one point of QALY). In other words, for general

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[1] The year of 2016 was chosen as it allowed costs to be converted most accurately.

functioning or PSEA, there is no agreed WTP threshold that can be used to assess whether an intervention is cost-effective. Therefore, the majority of studies that have used general functioning or PSEA set the WTP threshold as £0.

2.5 Quality and Risk of Bias (RoB) assessment

Quality and Risk of Bias (RoB) assessments of economic evaluations were applied by using the Consensus Health Economic Criteria list (the CHEC; Evers, Goossens, de Vet H, van Tulder & Ament, 2005) and the Cochrane Collaboration's tool for assessing the risk of bias (Higgins et al., 2011) (Appendix C). It is crucial to use both tools in the field of economic evaluation because they allow policiy-makers to assess the reliability as well as validity of data and to rate evidence respectively (Feliu-Soler et al., 2018).

According to Evers (2005), the CHEC list was developed by using a Delphi method (three Delphi rounds; 23 international experts). It comprises 19 items focused on health economics, where the results are displayed as a percentage of fulfilled criteria. This checklist has been recommended by the NICE technology appraisal guidance (NICE, 2015).

Additionally, the Cochrane Collaboration risk-of-bias assessment tool (Higgins et al., 2011) was used to assess the validity and quality of the RCTs (Table 6). It assesses RoB in six different domains: (1) selection bias, (2) performance bias, (3) detection bias, (4) attrition bias, (5) reporting bias, and (6) other bias (e.g., conflict of interest, therapist's qualification, etc.).

3. Results

3.1 Characteristics of chosen studies

20 articles were considered in this review: 10 evaluations were full economic evaluations, and 10 were partial economic evaluations. Furthermore, 11 evaluations were

based on clinical trials, five on decision analytical models where the author synthesises information from numerous sources by applying wide variety of mathematical techniques (Petrou & Gray, 2011), and four on secondary data analyses.

As presented in Tables 2 and 3, ten evaluations were conducted in the United Kingdom, three in the Netherlands, two in Germany, two in the USA, one in Australia, and one in Norway. The most recent evaluation dated back to 2018, and the least recent dated back to 1991. In addition, 16 evaluations adopted a societal perspective, three adopted a service-oriented perspective, and one adopted a payer perspective. Regarding the full economic evaluations, the time horizon ranged from one to four years. The time horizon for the partial economic evaluations ranged from six months to four years. The majority of the studies included more than 60 service users, while a small number of studies recruited fewer than 30. In 19 studies, the majority of the service users were females, with a percentage ranging from 58% to 100%, and the mean age of participants ranged from 15 to 47 years.

Table 2

Full economic evaluations – Characteristics

Study	Country	Type of study	N	Perspective	Time horizon (years)	Proportion of females	Average age	Original currency
Bamelis et al. (2015)	Netherlands	RCT	250	Societal perspective	3	n.s.	n.s.	Euro
Bateman and Fonagy (1999) (Brazier, 2006)	UK	Model based RCT	44	Societal perspective	1	58%	31.8	GBP
Haga et al. (2018)	Norway	RCT	77	Societal perspective	4	88.3%	15.6 years	NOK
Koons et al. (2001) (Brazier, 2006)	UK	Model based RCT	28	Societal perspective	1	100%	35	GBP
Linehan et al. (1991) (Brazier, 2006)	UK	Model based RCT	44	Societal perspective	1	n.s.	n.s.	GBP
Priebe at al, (2012)	UK	RCT	80	Societal perspective	1	88%	32.2	GBP

Table 2 (continued)

Sinnaeve et al. (2018)	Netherland	RCT	84	Societal perspective	2	95%	26	Euro
Turner et al. (2000) (Brazier, 2006)	UK	Model based RCT	33	Societal perspective	1	77%	22	GBP
Van Asselt et al. (2008a)	Netherlands	RCT	86	Societal perspective	5	93%	30.6	Euro
Van den Bosch et al. (2002) (Brazier, 2006)	UK	Model based RCT	58	Societal perspective	1	100%	37.5 years	GBP

RCT=Randomised Control Trial; NOK= Norway Krone; GBP = Great British Pound; n.s.= not stated

Table 3

Partial economic evaluations – Characteristics

Study	Country	Type of study	N	Perspective	Time horizon (years)	Proportion of female	Average age	Original currency
Amner (2012)	UK	Pre-post no control	27	Service perspective	3	86%	35	GBP
Bateman and Fonagy (2003)	UK	RCT	41	Service perspective	3	58%	31.8	GBP
Heard (2000)	USA	RCT	63	Societal perspective	1	100%	18-40	US dollar
Pasieczny and Connor (2011)	Australia	RCT	90	Societal perspective	3	93%	33.58	AUS
Meyers et al. (2014)	USA	Retrospective cost analysis study	44	Service perspective	4	46%	47.1	US dollar

Table 3 (continued)

Okamura et al. (2018)	USA	Cost analysis	34,507	Service perspective	1	53.4%	29.9	US dollar
Robinson et al. (2015)	UK	RCT	68	Societal perspective	3	92.7 %	31.1	GBP
Van Asslet (2008b)	Netherlands	RCT	86	Societal perspective	5	93%	30.6	Euro
Wagner et al. (2014)	Germany	Controlled study	64	Societal perspective	3	91.5%	30.1	Euro
Wunsch et al. (2014)	Germany	Population-based cost-saving analysis	0.7% of the population was assumed to have BPD	Societal perspective	1	n.s.	n.s.	Euro

RCT=Randomised Control Trial; GBP = Great British Pound; AUS= Australian dollar; n.s.= not stated

3.2 Methodological quality of identified studies

Tables 4 and 5 present the methodological quality of economic evaluations according to the CHEC-list (for the full description of the CHEC-list fulfilled criteria, see appendix C). Differentiating between full and partial studies is important. Among the full economic evaluations, all the studies obtained a high degree of methodological quality of 80% on average (ranging between 73% and 89%). Yet, the partial economic evaluations included more varied results of methodological quality with an average of 73% (ranging between 53% and 86%).

Some criteria were not fulfilled, which affects the validity of the results. Four studies did not take into consideration the societal perspective, which according to NICE guidelines, is the minimum requirement for decision making within the NHS. Eight studies did not include all relevant costs, even though five of them reported adopting a societal perspective. The majority did not report costs concerning productivity and employment loss even though the population included individuals of employment age. Five studies did not include discounting[2] when the study lasted more than one year, and five did not cover all the relevant outcomes. Additionally, among the full economic evaluations, three studies used PSEA as the only effective measure. This can serve as an obstacle when considering the generalizability of the findings, as NICE guidelines have no agreed consensus on cost thresholds in relation to PSEA.

It is important to note that only two studies discussed how treatments should address the unique characteristics of EUPD; for example, how interventions for EUPD address self-

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[2] As public healthcare interventions are usually long-term, and future costs are usually valued less than present costs (Hutton, 2012), NICE guidelines (2015) recommend applying a discount factor of 3.5% per year in health economic studies.

harming behaviour that might occur during treatment. Elaborating on the ethical elements of proposed treatments is particularly important when conducting research with a population that is considered "at-risk" (Biddle et al., 2013). Even though this does not affect the methodological quality of the study, it is important for decision and policy making to receive a holistic picture before allocating financial resources.

Table 4

Quality Assessment – Full economic evaluations

Criteria	Haga et al. (2018)	Sinnaeve et al. (2018)	Priebe et al. (2012)	Koons et al. (2001) (Brazier, 2006)	Linehan et al. (1991) (Brazier, 2006)	Van den Bosch et al. (2002) (Brazier, 2006)	Turner (2000) (Brazier, 2006)	Bateman and Fonagy., (1999) (Brazier, 2006)	Bamelis et al. (2015)	Van Asselt (2008a)
Proportion of criteria fulfilled by the study	89%	74%	78%	78%	74%	78%	73%	78%	89%	89%

Table 5

Quality Assessment – Partial economic evaluations

Criteria	Okamura et al. (2018)	Wagner et al. (2014)	Meyers et al. (2011)	Wunsch et al. (2014)	Pasieczny and Connor (2011)	Amner, (2012)	Robinson et al. (2015)	Bateman and Fonagy (2003)	Van Asselt (2008b)	Heard (2000)
Proportion of criteria fulfilled by the study	73%	86%	66%	80%	53%	73%	53%	73%	86%	80%

3.3 Risk-of-Bias (RoB) Assessment:

Each domain was independently assessed for each RCT by the reviewer (IC). Each study was scored between 1 and 6 and was classified as high risk of bias (if at least one domain was rated as high), low risk of bias (if all individual domains were rated as low) and unclear risk of bias (if at least one domain was rated as unclear and the other domains were rated as low); this is in accordance with the Cochrane Handbook guidelines for the RoB process (Higgins & Altman, 2008).

Overall, the results show that none of the studies applied a double-blind procedure. However, this is understandable, as in psychological therapies, both participants and therapists are aware that therapy is taking place. Furthermore, only seven studies provided a sufficient amount of data regarding either the allocation process or the randomisation process. Yet, the majority of the studies had a low risk attrition biases and reporting biases. Additionally, other risks included small sample size (Bateman & Fonagy, 1999; 2003; Koons et al., 2001, Linehan et al., 1991; Priebe et al., 2012; Turner, 2000), missing important economic data (Haga et al., 2018; Heard, 2000; Koons et al., 2001; Linehan et al., 1991; Priebe et al., 2012; Sinnaeve et al., 2018) and lack of follow-up (Heard, 2000; Van Asselt 2008a).

Table 6

ROB assessment

Study	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding (performance bias and detection bias	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias	Rating
Haga et al. (2018)	+	?	-	+	?	-	2 H
Sinnaeve et al. (2018)	?	+	-	?	+	-	2 H
Priebe et al. (2012)	+	?	-	+	+	-	2 H
Koons et al. (2001) (Brazier, 2006)	?	?	-	+	?	-	2 H
Linehan et al. (1991) (Brazier, 2006)	?	?	-	+	?	-	2 H
Van den Bosch et al. (2002) (Brazier, 2006)	+	-	-	+	+	?	2 H

Table 6 (continued)

Turner (2000) (Brazier, 2006)	?	?	-	+	+	-	2 H
Bateman and Fonagy, (1999)	?	+	-	+	+	-	2 H
Bamelis et al. (2015)	+	+	-	-	?	?	2 H
Van Asselt (2008a)	+	+	-	-	+	-	3 H
Pasieczny and Connor (2011)	-	?	-	+	+	?	2 H
Robinson et al. (2015)	+	?	-	+	+	?	1 H
Bateman and Fonagy (2003)	?	+	-	+	+	-	2 H
Van Asselt (2008b)	+	+	-	-	+	-	3 H
Heard (2000)	?	+	-	-	?	+	2 H

"+" indicates a low risk of bias, "– "indicates a high risk of bias, and "?" Indicates an unclear risk of bias.;H: High risk; 1-6: number of high risks items ("- ")

3.4 Cost categories

Tables 7-9 summarise the calculation of costs in the reviewed studies. The majority of the studies (n=12) included calculation of costs for psychiatric inpatient admission, A&E admission, and outpatient treatments. Eight studies provided information regarding indirect costs, which included early retirement, absence and sickness, productivity losses, and work disability.

Four studies did not report the exact price of the examined intervention or its comparator but included it as part of the total direct costs. One study (Okamura et al., 2018) provided the costs associated with providing and implementing DBT in services, including tariffs of tuition, consultation, training certification, revenue loss, and indirect labour costs. Four studies did not provide costs data regarding inpatient admissions. However, these costs can be estimated by using Brazier's (2006) applied regression cost model to deduce relevant costs from the number of parasuicide events and the length of inpatient psychiatric stay.

Nine studies calculated indirect costs as required when adopting a societal perspective. However, attention should be given to the study by Sinnaeve et al. (2018), which did not provide specific details on the type of indirect costs and how they were calculated.

Table 7

Cost categories - DBT

Study	Direct costs											Indirect costs		
	Outpatient care	Inpatient care	ET	PH	Medication	Community care	AT	Informal care	Assisted living facility	SV	other	Sickness/ disability	Absence from work	ER
Haga et al. (2018)	+	+	+	-	+	-	+	-	-	+	-	-	+	+
Sinnaeve et al. (2018)	+	+	-	-	-	-	-	-	-	-	-	+	-	-
Priebe et al. (2012)	+	-	-	-	-	-	-	-	-	+	+	-	-	-
Koons (2001)	+	+	+	E	+	E	E	E	E	E	-	E	E	E
Linehan et al. (1991)	+	E	+	+	+	-	-	-	-	E		-	-	-

Table 7. (continued)

Van den Bosch et al. (2002)	+	E	+	+	+	E	-	-	-	E	+	+	+	+
Turner et al. (2000)	+	E	+	+	+	-	+	-	-	E	+	-	-	-
Okamura et al. (2018)	+	+	+		+	-	-	-	-	+	+	-	-	-
Wagner et al. (2014)	+	+	+	+	-	+	-	-	-	-	-	-	-	-
Meyers et al. (2011)	+	-	-	-	+	-	-	-	-	+	+	-	-	-
Wunsch et al. (2014)	+	-	-	-	+	-	-	-	-	+	+	-	-	-

Table 7. (continued)

Pasieczny and Connor (2011)	+	+	-	+	+	+	+	-	-	-	-	-	-	-
Amner (2012)	+	+	+	+	+	-	-	-	-	-	-	-	-	-
Heard (2000)	+	+	+	+	+	+	+	-	-	+	-	-	+	-

"+" = Costs mentioned; "-" = Costs not mentioned; E= Estimation of costs based on regression models; ET= Emergency; PH = Partial hospitalisation; AT= Alternative therapy; Treatment SV= Supervision; ER= Early retirement

Table 8

Cost categories - MBT

Study	Direct costs											Indirect costs		
	Outpatient care	Inpatient care	ER	PH	Medication	Community care	AT	Informal care	Assisted living facility	SV	other	Sickness/ disability	Absence from work	ER
Bateman and Fonagy (1999)	+	+	+	+	+	+	-	-	E	+	-	+	+	-
Robinson et al. (2015)	+	+	-	+	+	+	+	-	-	-	-	-	-	-
Bateman and Fonagy (2003)	+	+	-	+	+	-	-	-	-	-	+	+	+	+

"+" = Costs mentioned; "-" = Costs not mentioned; E= Estimation of costs derived by regression models. ET= Emergency; PH = Partial hospitalisation; AT= Alternative therapy; Treatment SV= Supervision; ER= Early retirement

Table 9

Cost categories - SFT

Study	Direct costs											Indirect costs		
	Outpatient care	Inpatient care	ER	PH	Medication	Community care	AT	Informal care	Assisted living facility	SV	other	Sickness/ disability	Absence from work	ER
Bamelis et al. (2015)	+	+	+	+	+	+	+	-	-	+	+	-	-	-
Van Asselt (2008a)	+	+	-	+	+	+	+	+	-	+	+	+	+	+
Van Asselt (2008b)	-	-	-	-	-	-	-	-	-	-	-	+	+	+

"+" = Costs mentioned; "-" = Costs not mentioned; E= Estimation of costs derived by regression models. ET= Emergency; PH = Partial hospitalisation; AT=

Alternative therapy; Treatment SV= Supervision; ER= Early retirement

3.5 Outcome measures

Among the full economic evaluations, eight different effectiveness measures were used. Three evaluations (Bamelis et al., 2015; Sinnaeve et al., 2018; Van Asselt, 2008a) used the EQ-5D to measure QALYs. In three additional studies (; Bateman & Fonagy, 1999; Koons, 2001; Turner et al., 2000), QALYs were measured via the Beck Depression Inventory (BDI; Beck, Steer, & Carbin, 1988) scores. This was done by the conversion method "mapping" also known as "cross-walking" (Round & Hawton, 2017). This conversion was achieved by applying an existing algorithm that converts the scale scores into EQ-5D scores (Brazier, Yang, Tsuchiya, & Rowen, 2010).

Seven studies examined effectiveness by focusing on PSEA, which is defined as an act the patient performed with intention and which caused physical damage, or as acts which include attempted suicide, overdosing, or self-mutilation. These events were measured by five different measures, specifically, the Lifetime Parasuicide Count (LPC; Comtois & Linehan, 1999), the Parasuicidal History Interview (PHI; Linehan, Wagner & Cox, 1989), the Suicide and Self-Harm Inventory (Gratz, 2001), and self-report logs (Turner et al., 2000), which ask the patient to report self-harming behaviour. Moreover, one study measured effectiveness assessing global functioning by the self-harm and global functioning scale (CGAS; Shaffer et al., 1983).

3.6 Analysis results

Table 10

DBT: Description of full economic evaluations, ICER and CEAC

Study	Model based on	T vs Comparable	Outcome measures	Direct costs	Indirect costs	Intervention cost (per patient)	Effect	ICER	Chance for cost-effectiveness
Haga et al. (2018)	n.a.	DBT-A	PSE avoided (LPC)	£19,467 (SD-£11,763)	n.a.	£18,683	15.0 (SD=17.5) 10.4 (SD=13.4)	Parasuicidal: £305 per per event avoided	At £0/ PSEA: 89.8%.
		EUC	Global Functioning (CGAS)	£26,340 (SD-£35,381)	n.a.	£19,504	37.5 (SD=52.9) 6.3 (SD=14.9)	CGAS: £1676 per one-point Improvement	At At £1408/ CGAS: 94.9%

Table 10. (continued)

Sinnaeve et al. (2018)	n.a.	Step-down dialectical behaviour therapy (DBT)	QALY (EQ-5D)	£17,543 (SD = £12,607)	£798	Measured as part of direct costs	0.65 (SD =.33)	£24,5151 per QALY	At £70,530/QALY: 21%
		Outpatient DBT		£ 10995 (SD = £12527)	£849	Measured as part of direct costs	0.62 (SD=28)		
Priebe et al. (2012)	n.a.	DBT	Parasuicidal event (interview)	£6,369	£1,240	Measured as part of direct costs	Incremental Effect: 9% reduction (2 months period)	£40 per event avoided	Not provided
		TAU		£4,206	£1,156	Measured as part of direct costs			

Table 10. (continued)

Koons et al. (2001) (Brazier, 2006)	Brazier 2006	DBT	Parasuicidal events (PHI) QALY (EQ-5D - BDI converted)	DBT= £30,510	n.a.	£14,880	4 events 4.2 events	Parasuicidal : £56,129 per event avoided QALY: £374,195 per QALY	At £0 /PSEA: 5% At £36,769 /QALY: 5%
		TAU		TAU= 19284£	n.a.	£7,223	0.07 QALY 0.04 QALY		
Linehan et al. (1991) (Brazier, 2006)	Brazier 2006	DBT	Parasuicidal events (PHI)	£20,425	n.a.	£19,618	6.82 events	Parasuicidal : £58 per event avoided	At £0/PSEA: 53%
		TAU		£21,996	n.a.	£11,978	33.54 events		
Van den Bosch et al. (2002) (Brazier, 2006)	Brazier 2006	DBT	Parasuicidal events (LPC)	£22,688	n.a.	£101,44	16 events	£52 per event avoided	At £0/PSEA: 65%
		TAU		£21,746	n.a.	£5,124	34,1 events		

53

Table 10. (continued)

Turner (2000) (Brazier, 2006)	Brazier 2006	DBT	Parasuicide Events (Self-report)	£20,492	n.a.	£10,364	2.92, 12.33 events	Parasuicidal event: £720 per event avoided	At £6,462/PSEA: 85%. At £25,848/QALY: 90%
		CCT	QALY: (EQ-5D - BDI converted)	£27,316	n.a.	£9,313	QALYS: 0.17, 0.05	QALY: £56,455 per QALY	

PHI = Parasuicide History Interview; QALY = Quality Adjusted Life Years; MBT = Mentalisation Based Therapy; DBT= Dialectical Behavioural Therapy;

SFT = Schema Focused Therapy; EUC - Enhanced Usual Care; TAU= Treatment as Usual; BDI – Beck Depression Inventory; CCT - Client-Centred Therapy;

CEAC = Cost-effectiveness acceptability curve; CGAS = Children's Global Assessment Scale

Mean QALY gain (or loss) has been calculated to be the area under the curve (AUC);

All Costs were converted to GBP-£ using Purchasing Power Parties (GBP-£ PPP) and inflated to the year 2016.

Table 11

MBT and SFT: Description of full economic evaluations, ICER and CEAC

Bateman and Fonagy (1999)	Brazier 2006	MBT	Parasuicide events (Suicide and Self-Harm Inventory) QALY: (EQ-5D - BDI converted by the AUC)	£23,488 (Range £20,678 - £27,140)	n.a.	Measured as part of direct costs	6.1 (2.3 to 10) events. 0.04 QALYS	Parasuicidal event - ICER= £558. Cost per event avoided £49.11	At a £6,462/PSEA: 80%. At £25,848/QALY: 45%
		TAU		£22,931 (Range £18,093 - £28,432)	n.a.	Measured as part of direct costs	17.5 (10.7 to 24.2) events. 0.01 QALY	QALY: ICER =£558 Cost per QALY £9,359	

Table 11. (continued)

Study		Intervention	QALY measure				QALY	ICER	Probability
Bamelis et al. (2015)	N/A	SFT	QALY: measured by EQ-5D	£22,267	Indirect and direct costs were calculated together.	-	QALY - 2.34	£34,610/QALY	At £0/QALY: 75%
		TAU		£24,632		-	QALY - 2.23		
Van Asslet et al. (2008a)	Brazier 2006	SFT	QALY: measured by EQ-5D	£7,905	£3,105	£1,991	2.15 QALY	£133,758 /QALY	At £36,769 / QALY: 75%
		TFP		£10,320	£3,334	Measured as part of direct costs	2.27 QALY		

PHI = Parasuicide History Interview; QALY = Quality Adjusted Life Years; MBT = Mentalisation Based Therapy; DBT= Dialectical Behavioural Therapy; SFT = Schema Focused Therapy; TFP; Transference Focused Psychotherapy; EUC - Enhanced Usual Care; BDI – Beck Depression Inventory; CCT - Client-Centred Therapy; CEAC = Cost-effectiveness acceptability curve; CGAS = Children's Global Assessment Scale

Mean QALY gain (or loss) has been calculated to be the area under the curve (AUC);

All Costs were converted to GBP-£ using Purchasing Power Parties (GBP-£ PPP) and inflated to the year 2016.

Table 12

DBT- Description of partial economic evaluations and cost differences

Study	T vs Comparable	Direct costs	Indirect costs	Indirect costs were measured by	Cost Offset	Cost Offset T vs. comparator	Intervention costs
							£13,459
Okamura (2018)	DBT	n.a.	n.a.	n.a.	n.a.	£7,472	
	PCIT	n.a.	n.a.	n.a.			£5,987
Wagner et al. (2014)	DBT: Pre	£26,928	£8,739	Human Capital Approach	£13,352	n.a.	
	DBT Post	£14,341	£7,973	Human Capital Approach			£5,378

Table 12. (continued)

Meyers et al. (2015)	DBT Pre	MED: £15,080 MENT: £6,328	n.a.	n.a.	£6,860	n.a.	£6,010
	DBT Post	MED: £10,832 (£7,350) MENT: £3,715 (£3,383)	n.a.	n.a.			
Wunsch et al. (2014)	DBT Pre	Direct benefits: £432 million to £795 million	Indirect benefit: £524 million to £655 million	-	Each £0.95 invested, £1.44 can be gain.	n.a.	£2,860 gain
	DBT Post			-			
Pasieczny and Connor (2011)	DBT	£6,670	n.a.	n.a.	n.a.	£3,241 (£129,678 after 3 years)	-
	TAU	£9,912	n.a.	n.a.			
Amner (2012)	DBT Pre	£190,710	n.a.	n.a.	£40,033	n.a.	£9,495
	DBT Post	£150,677	n.a.	n.a.			

Table 12. (continued)

Heard (2000)	DBT	£9,670	n.a.	n.a.	n.a.		
						£9,702	-
	TAU	£19,373	n.a.	n.a.	n.a.		

MBT = Mentalisation Based Therapy; DBT= Dialectical Behavioural Therapy; SFT = Schema Focused Therapy; PCIT – Parent/Child Interaction Therapy;

LGCA - Limited Human Capital Approach: A method evaluates changes in the employment status of service users who are employed at baseline and after treatment (Van den Hout, 2010).

EHCA - Extended Human Capital Approach: A method evaluates changes in employment status between all service users (independently their employment status at baseline). (Van den Hout, 2010).

FCA - Friction Cost Approach: A method evaluates productivity loss from the employer perspective, measuring the time which takes to replace an employee who is unable to work due to illness (Van den Hout, 2010).

All costs were converted to GBP-£ using Purchasing Power Parties (GBP-£ PPP) and inflated to the year 2016.

Table 13

MBT and SFT- Description of partial economic evaluations and cost differences

Study	T vs Comparable	Direct costs	Indirect costs	Indirect costs were measured by	Cost Offset	Cost Offset T vs. comparator	Intervention costs
Robinson et al. (2016)	MBT-ED	Full descriptions of costs were not provided by author	-	-	-	£3,000	Full descriptions of costs were not provided by author
	SSCM-ED	Full descriptions of costs were not provided by author	-	-			
Bateman and Fonagy (2003)	MBT	£7,072	n.a.	n.a.	n.a.	£3,707	£1,175
	TAU	£10,779	n.a.	n.a.			

Table 13. (continued)

Van Asselt et al.(2008b)	SFT	n.a.	LHCA= £1,566; EHCA = £6,638; FCA = £720	FCA		LHCA=£306		
				EHCA	n.a.	EHCA=£325		-
	TFP	n.a.	LHCA=£1873 ; EHUA= £6313; FCA= £1037	LHCA		FCA= £316		

MBT = Mentalisation Based Therapy; DBT= Dialectical Behavioural Therapy; SFT = Schema Focused Therapy; PCIT – Parent/Child Interaction Therapy;

LGCA - Limited Human Capital Approach: A method evaluates changes in the employment status of service users who are employed at baseline and after treatment (Van den Hout, 2010); EHCA - Extended Human Capital Approach: A method evaluates changes in employment status between all service users (independently their employment status at baseline). (Van den Hout, 2010); FCA - Friction Cost Approach: A method evaluates productivity loss from the employer perspective, measuring the time which takes to replace an employee who is unable to work due to illness (Van den Hout, 2010).

All costs were converted to GBP-£ using Purchasing Power Parties (GBP-£ PPP) and inflated to the year 2016.

3.7 Narrative summary

According to Mastrigt et al. (2016), there is currently no consensus over quantitative methods for pooling combined health economics estimates (incremental cost-effectiveness, cost–utility, or cost-benefit ratios) that have been gathered from multiple evaluations. In addition to the various sources of heterogeneity (e.g., different countries with distinctive differences in healthcare systems and policies), the pooling of different economic evaluations is not recommended (Mastrigt et al., 2016), Therefore, this review adopted both graphic (Tables 10-13) and narrative presentations. The following narrative summary is subdivided according to the three examined interventions. For each intervention, the results were grouped by the comparator, country of origin, and similarities of economic analysis.

3.7.1 DBT

3.7.1.1 DBT vs TAU

Four full economic evaluations compared DBT to TAU (Koons et al., 2001; Linehan et al., 1991; Priebe et al., 2012; Van den Bosch et al., 2002;). All four used PSEA as the outcome variable, which allowed CEA to be performed. There was a large discrepancy between the study by Koons et al. (2001) and the rest. While Koons et al. (2001) found an ICER of £56,129 per PSEA, the mean ICERs of the rest was £50. Consequently, the possibility of the intervention being cost-effective ranged from 5% to 65% when the WTP threshold was £0 per one PSEA. According to Brazier (2006), the reason for this discrepancy was the need to estimate costs based on missing data (see Table 7). Different regression models were applied to different studies. The model that was used in Koons et al's (2001) study did not reduce inpatient admissions, and therefore, a high amount of service utilisation was calculated for all of the participants (Brazier, 2006), resulting in the inflation of costs affecting the ICER and the CEAC.

Only one full economic evaluation compared DBT to TAU when QALYs served as the outcome measure. Brazier et al. (2006) extracted participants' BDI scores from the study by Koons et al (2001) and converted them into QALYs. This allowed them to conduct a cost-utility analysis (CUA). The ICER was £374,195 per one-point increase of QALY, with only 5% chance of being more cost effective than TAU when the WTP threshold for one-point increase in QALY was set at £36,769. However, this result should be treated with extreme caution due to the choice to use the over-generalising cost regression model mentioned above. Moreover, RoB assessment revealed significant shortcomings due to a small sample size (n=28), as well as an unclear allocation and randomisation process.

Three studies compared the costs of DBT and TAU, AND did not collect information about the clinical effectiveness. Therefore, these were considered as partial economic evaluations. This made it possible to perform cost-saving analyses to examine the question of whether investing money in DBT may reduce costs somewhere else in the health system (Knapp, McDaid & Parsonage, 2011). Both Pasieczny and Connor (2011) and Heard (2000) found DBT cost savings ranging from £3,241 to £9,702 per patient receiving DBT. However, there were significant methodological differences between these two studies. Both took place in different countries and different healthcare systems (the USA and Australia respectively). Moreover, the results of the quality assessment of the study by Pasieczny and Connor (2011) revealed significant shortcomings, fulfilling only 53% of the CHEC list requirements.

Okamura et al. (2018), on the other hand, focused on costs associated with the implementation of DBT in services and compared this to other evidence-based behavioural interventions such as CBT, trauma focused CBT and cognitive processing therapy. By calculating the fees for tuition, consultation, training, certification, and revenue loss, they found that DBT is

the most expensive intervention to implement (£13,459 per service user), with a cost that is almost double that of the next most expensive intervention. However, the study did not calculate the potential monetary benefits which might make the implementation a wise investment (e.g., reduction in the utilisation of other healthcare services as inpatient admission, A&E facilities, etc.)

3.7.1.2 DBT vs other interventions

Three full economic evaluations compared DBT and its modifications to different therapies. Turner (2000) conducted both CUA and CEA, comparing DBT to Client-Centred Therapy (CCT). The results indicate DBT to be cheaper and more effective than CCT, with an ICER of £720 for an increase of one point of PSEA, and of £56,455 for an increase of one QALY. These results suggest an 85% chance of DBT being considered cost-effective when the WTP thresholds are above £0 (for PSEA) and £26,000 (for QALYs).

Similar results can be found in the study by Sinnaeve et al. (2018), which compared outpatient DBT to a residential programme of DBT namely, "step-down DBT". The latter includes, in addition to the outpatient DBT, daily mindfulness classes, weekly drama therapy, and a fortnightly network training session together with family and friends, all of which are provided by DBT-trained inpatient staff. Outpatient DBT was found to be equal to step-down DBT when the effectiveness outcomes were measured by QALYs. However, step-down DBT costs significantly more. Consequently, the results suggested only a 25% chance of the intervention being cost-effective when the WTP threshold is above that recommended by NICE guidelines (£30,000).

Haga et al. (2018) compared DBT for adolescents (DBT-A) to enhanced usual care (EUC). EUC is a non-manualised psychodynamic- or CBT-oriented therapy. It is important to note that DBT-A is different from standardised DBT in two main aspects. Firstly, the duration of DBT-A is

significantly shorter and lasts between 16 and 20 weeks (compared to a year or more for adult DBT). Secondly, it involves conducting the skills training group in a multifamily format.

There were no significant differences in the overall costs between the two conditions, but DBT-A was found to be more effective in both PRSE and global functioning, yielding an ICER of £27 for one PSEA and £153 for a one-point improvement in global functioning. Consequently, the chance of DBT-A being cost-effective was 89.8% (WTP=£0) and 94.9% (WTP=£129) respectively.

3.7.1.3 Pre-post DBT

Four partial economic evaluations examined whether DBT is cost saving and evaluated costs before and after treatment was received. Wunsch et al. (2014) and Wagner et al. (2014) adopted a societal perspective. The two studies found a reduction in costs post-DBT treatment, and therefore concluded it to be cost saving.

The study by Wunsch et al. (2014), conducted in Germany, calculated that for each £0.95 invested in providing DBT, £1.44 could be saved. From a governmental point of view, providing DBT can potentially save annually up to £524 million and £432 million of direct and indirect costs respectively. When calculating the potential savings per individual, Wagner et al. (2014) found that DBT saved £12,908 per person receiving DBT. However, unlike Wunsch et al. (2014), they did not find a significant reduction in relation to indirect costs. From a health economic point of view, the CHEC list provided good support for both studies. Yet, lack of randomisation and the fact that they took place outside the UK healthcare system reduced the validity of the findings for the UK.

Both Meyers et al. (2015) and Amner (2012) found that DBT was cost saving. However, they focused on a narrow perspective, evaluating costs for healthcare services alone. Meyers et al.

(2015) found DBT to be cost saving, with a reduction of £6,860 per patient per year. Amner (2012) also found a reduction in costs, but those were not statistically significant. The reduction in both studies was mainly due to the lower number of hospitalisations and lower A&E utilisation. It is important to note that the methodological value of these two studies is relatively low, as both suffered from crucial shortcomings, including no randomisation procedures, small sample size (N=44 and N=27 respectively), and lack of indirect costs calculations.

3.7.2. MBT

Bateman and Fonagy (1999) conducted one CUA and one CEA, comparing an MBT day hospital programme to TAU. The two interventions did not differ in terms of costs (£23,488 and £22,931 respectively) when TAU included regular psychiatric review, inpatient admissions when needed, and twice weekly outpatient and community follow-ups.

However, MBT was found to be more effective in both outcomes (QALY and PSEA). Therefore, the ICERs were £50 per one PSEA, and £6,462 per QALY. When the WTP for one PSEA was £6,462, MBT was considered 80% cost-effective. However, when QALYs were the outcome measure, and the WTP threshold was set at £25,000, the chance for MBT to be considered as cost-effective decreased to 45%.

Two methodological shortcomings were identified by the RoB and CHEC-list assessments: small sample size (N=44) and missing data about indirect costs. This might have minimised the power of the study, thereby weakening the significance of MBT as a cost-effective intervention.

In a consecutive study, Batman and Fonagy (2003) performed a partial economic evaluation and found MBT to be cost-saving compared to TAU (TAU comprised psychiatric

reviews, inpatient admissions, and non-psychoanalytic intervention post-discharge). Indirect costs were not evaluated. MBT was found to save health services £3,707 per patient over the 18 months of the study period. This study had one significant methodological limitation concerning the small sample size (N=41).

3.7.3 SFT

Both Bamelis (2015) and Van Asslet (2008a) conducted CUAs with QALY as the effectiveness outcome. Bamelis compared SFT with TAU (which included CBT, an insight-oriented treatment, EMDR, supportive therapy, or no treatment at all), while Van Asslet compared SFT to Transference Focused Psychotherapy (TFP). SFT was found to be dominant over both TAU and TFP, with ICERs of £34,610 and £133,758 per QALY respectively. The chances of SFT being considered as cost-effective were 75% in both studies, but with different WTP thresholds, when these were set at £0 (Bamelis, 2015) and £36,769 (Van Asselt, 2008a). As the two studies took place in the same healthcare system (the Netherlands), calculated similar direct and indirect costs and covered equal periods, the gap between the two costs raises questions. Other non-methodological explanations should be taken into consideration, such as the possible changes in the labour market[3] at different years of the two examinations (2008 and 2015).

One partial economic evaluation (Van Asselt, 2008b) focused on indirect costs only, which were calculated according to three different methods (see Table 13). SFT was found to be cost-saving when the Friction Cost Approach and the Limited Human Capital Approach were applied. Results suggest a benefit of £306-£316 per service user receiving SFT. However, when the

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[3] Changes in labor market include trends and variations in rates of employment and unemployment, salaries of health workers and costs of educational programmes (Walton, Kim & Weiner, 2017).

Extended Human Capital Approach was applied, the comparative intervention (TFP) was found to be cost saving with the benefit of £325 per service user receiving the intervention. It is important to note that even though the study received a relatively high rating by the CHEC list (80%), it is vulnerable to attrition and detection biases (see Tables 4-6) and therefore should be considered with caution.

4.Discussion

4.1 Overview of the (systematic review) findings

This review examined three psychological interventions for people with EUPD: DBT, MBT, and SFT. The results of the systematic search revealed that DBT is the most investigated treatment (seven full and seven partial economic evaluations), followed by SFT (two full and one partial economic evaluations), and MBT (one full and two partial economic evaluations).

All full economic evaluations found that DBT is more effective, whether effectiveness was measured by PSEA, QALY, or global functioning. Yet, the wide range of the ICER and of the CEAC raises questions regarding DBT as a cost-effective intervention. This range was found to be dependent on two parameters: the chosen threshold, and the type of effectiveness outcome. Results range from DBT as dominant (Haga et al., 2018;Turner, 2000; Van den Bosch et al., 2002) to not cost effective (Koons et al., 2001). Unlike DBT, the evidence for SFT and MBT is relatively scarce. SFT was found to be cost-effective in two full economic evaluations (Bamelis et al., 2015; Van Asselt, 2008a), while one study found MBT to be more effective but with slightly higher costs (Bateman & Fonagy, 1999).

4.2 In-depth examination of the evidence

4.2.1 DBT

Examination of the full economic evaluations revealed a wide range of incremental costs. There are two possible reasons for this. First, four out of the seven studies were model-based (Koons et al., 2001; Linehan., 1991; Turner, 2000; van den Bosch, 2002). Brazier et al. (2006) mentioned that the process of modelling included using costs regressions, which might have led to an overestimation and inflation of the incremental costs. The second reason might involve the underestimation of the lower values of costs due to the process of transformation from different countries (e.g. Linehan et al., 1991) to the UK healthcare system (Brazier et al., 2006).

Examination of the partial economic evaluations revealed a number of methodological shortcomings, thus limiting the ability to draw robust conclusions. Four out of the seven studies can be characterised as quasi-experimental in the form of one group pre-post design, which has a significant impact on the ability to determine causation. Additionally, the majority of studies did not adopt a societal perspective as recommended by NICE guidelines, thus excluding essential costs, which are required to assess the economic value of providing DBT beyond the healthcare sector accurately. Furthermore, excluding data regarding indirect costs has significant implications, as it ignores valuable evidence, which has suggested that the major portion of the economic burden may be attributed to productivity loss (Soeteman, Roijen, Verheul, & Busschbach, 2008; Van Asselt, Dirksen, Arntz, & Severens, 2007).

Wunsch et al. (2014) did assess appropriate indirect costs at a societal level. Yet, the presented model poses two significant difficulties. First, it is heavily country-specific, relying on country-specific data sources (e.g., German insurance companies, regional accounts, etc.). The

ability to translate cost-benefits ratios from the German healthcare system to the British healthcare system requires the implementation of models which are beyond the scope of this review. Second, the study was based on the estimated number of individuals who had EUPD in the Netherlands. The authors stated that this method of estimation is vulnerable to cumulative errors, especially in relation to indirect benefits, which are at risk of overestimation.

4.2.2 MBT

The analysis revealed mixed outcomes in relation to MBT. One full economic evaluation (Batman & Fonagy, 1999) revealed MBT to be cost-effective compared to TAU. However, there were substantial differences between the types of effectiveness measures. When PSEA was used as the effectiveness outcome, the chance of the intervention to be cost-effective was more than 80%, but when QALYs were used, the chance dropped to below 50%.

Similarly, two partial economic evaluations revealed mixed results. One partial economic evaluation (Bateman & Fonagy, 2003) provided evidence for MBT as cost-saving for the healthcare sector. However, these results should be examined carefully, as they did not include data regarding indirect costs.

The second study examined a modified version of MBT for the treatment of both EUPD and eating disorders (Robinson et al., 2016). This modified version included a group based intervention in addition to the standard delivery of MBT. The treatment proved to be effective in relation to EUPD symptoms (Robinson, 2014), but was found not to be cost saving for the healthcare sector. These mixed outcomes, together with the low number of available RCTs, increase the uncertainty regarding the question of whether MBT is a cost-effective intervention.

4.2.3 SFT

SFT was found to be cost-effective in two full economic evaluations (Bamelis et al., 2015; Van Asselt, 2008a; 2008b), and cost-saving for both the healthcare and non-healthcare sectors. Although both studies obtained a high methodological quality and a low RoB, it is still difficult to conclude cost-effectiveness for two main reasons. The first is the insufficient number of available RCTs, while the second is the fact that all three studies took place in a distinct healthcare system, outside of the UK. The latter poses a transferability challenge due to differences in healthcare policies and budget concerns.

4.3 Between treatments analysis

Overall, DBT was found to be associated with cost reduction and had the highest chance to be cost-effective when using PSEA as the effectiveness measure. However, there is no consensus regarding the WTP thresholds for PSEAs whereby stakeholders can decide whether the intervention has an economic benefit. Unlike QAYLs, where there is a consensus over WTP thresholds, PSEA is a less preferred outcome measure (Brettschneide, 2014). When examining DBT in the light of QAYLs, the evidence was not sufficient to conclude cost-effectiveness. WTP thresholds play another important role regarding the ability to draw conclusions and assimilate them into the UK healthcare system. Most of the thresholds for QAYLs that are mentioned by the reviewed studies were above the upper threshold of costs recommended by NICE guidelines (£30,000). Therefore, the chances for the intervention to be cost-effective are likely to decrease even more. One exception was the study by Turner (2000), where DBT was found to have a high chance (above 85%) of being cost-effective when the threshold was £25,000.

SFT seemed to be second to DBT regarding the chance to be cost-effective when taking PSEA as the effectiveness outcome. Even with QALYs as the effectiveness measure, van

Asselt et al. (2008) showed a high chance for SFT to be cost-effective, with a 75% chance of being cost-effective when the threshold was £36,000 (only £6,000 more expensive than the upper WTP threshold recommended by NICE guidelines). Yet, these results are based on a significantly lower number of studies than these that investigated DBT. Similarly, the results provided limited evidence that MBT is cost-effective, with significantly fewer RCTs or full economic evaluations.

4.4 Strengths

The main strength of this narrative review is the adoption of relatively wide and flexible inclusion criteria. Given that health economic studies of DBT, MBT, and SFT are relatively scarce (Meuldijk, 2017), the inclusion of studies across a number of different designs, healthcare systems, and perspectives allowed an examination of whether current treatment policies justify the use of economic resources.

Another strength of this review is that it addresses two of the main limitations of past reviews: the balance between the number of studies and the percentage of evidenced-based treatments examined. Three reviews adopted different health economic methods and modalities to examine the cost-effectiveness of DBT, MBT, and SFT. Brazier et al. (2006) summarised the available evidence of both clinical effectiveness and cost of psychological therapies including DBT and MBT. This extensive work included useful information for decision-making agencies within the UK by using advanced methodologies such as estimated cost-regression models for studies that did not provide financial data. However, it contained a relatively low number of studies (10), some of which had poor methodological quality. Moreover, due to the date it was written, some evidence-based treatments (i.e., SFT) were not included.

Brettschneider (2014) conducted a more up-to-date review of treatments for Borderline Personality Disorder (also known as EUPD). It was based on a higher number of studies (15), including SFT, but also on other treatments with evidence of low effectiveness. Therefore, not all of them are recommended by NICE guidelines. The same criticism applies to the review by Meuldijk et al. (2017), which included 30 studies. However, not all of them were evidence-based treatments. Additionally, the latter adopted a cost-offset approach, which does not provide important data regarding ICERs. Therefore, this review promoted a balanced stance between the two important required conditions – a high number of studies and focusing on evidence-based treatments only.

4.5 Limitations

Firstly, even though 20 studies were investigated, the majority (14) focused on DBT. The systematic search identified only one full economic evaluation for MBT and only two full economic evaluations for SFT. It consequently limited the ability to draw robust conclusions and required that the results be examined from a preliminary perspective.

Secondly, as the majority of studies identified high costs per QALY, which are above the WTP thresholds recommended by NICE guidelines, it is important to stress that there is a growing criticism regarding the use of QALY as a sufficiently sensitive outcome for personality disorders (Knapp& Mangalore, 2007). The distinct advantage of the QALY as a generic and unidimensional measure of impact (which permits comparisons to be made across different diagnostic or clinical groups due to it being unidimensional and generic) is also a source of debate. The use of generic instruments of QALYs (e.g., the EQ-5D, which was adopted by the reviewed studies) is not sufficiently sensitive to assess trends of relevant symptoms, functioning, and quality of life of

individuals with EUPD (Razzouk, 2017). Being insensitive to the outcomes of interest might lead to effective treatment not being funded.

Third, due to the flexible inclusion criteria, the review included quasi-experimental studies, some with a low number of participants or with insufficient data in relation to costs. This might affect both the internal and external validity of the review negatively.

The fourth limitation is concerned with the difficulties of drawing conclusions from studies conducted outside the UK, as each study was conducted in a different health system policy, facilities, and WTP thresholds for mental health related clinical benefits (e.g., paying for healthcare insurance is mandatory for each citizen in the Netherlands, according to Schafer et al., 2010). Although this review has adopted technical procedures to provide a match between currencies and yearly costs, adopting a model-based analysis was beyond the scope of this review. Decision makers should be aware that this raises questions regarding the generalisability of some of the studies and requires further investigation before implementation by UK services.

4.6 Implications for policies and further research

The review identified two main implications for an adequate decision-making process. First, stake holders should take into account the challenge of transferability, that is, the ability to generalise results attained from one framework or context to another (Currie & Manns, 2002). As mentioned above, this review included studies from different countries, with different financial systems and public health policies. Therefore, extending further research according to the following three suggestions is recommended: first, there is a need for further UK-based pragmatic RCTs comparing treatments, which this review found to have the highest chances of being cost-effective (DBT to SFT); second, in order to increase transferability,and conducting further economic evaluations on the existing studies is recommended, preferably by applying more

advanced techniques (e.g., formal modelling for long-term effects of associated indirect costs, which were unfortunately beyond the scope of this review); and third, there is a need for additional up-to-date full economic evaluations focusing on MBT.

A further potential benefit is identification of the crucial need for available and well-defined WTP thresholds for the effectiveness measures of PSEA. The current situation restricts researchers to use the lowest threshold (£0 for one PSAE), and consequently overly increases the probabilities of treatments being cost-effective. Therefore, agreeing on a specific threshold has the potential to increase the ability to use and draw practical implications from the available studies.

4.7 Conclusions

The results suggest that DBT has the highest chance of being cost-effective, specifically when PSEA is the effectiveness measure. However, after taking into account all the effectiveness measures, the results are more ambiguous.

For MBT and SFT, the economic evidence failed to provide robust conclusions regarding these therapies being considered as cost-effective. Both showed evidence of being cost-effective, but the low number of studies leads to a significant degree of uncertainty.

It is important to note that the heterogeneity of cost assessments was evident, and there was a risk of biases influenced by the transferability between different countries. The decision-making process would benefit from achieving a consensus on a cost and effectiveness measurement.

Given the available evidence, this review suggests that policy makers should prioritise DBT over SFT and MBT. Further head to head research, preferably applying advanced health economic models, is needed in order to increase levels of certainty of the suggested treatments.

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Part two: Empirical paper

The impact of interpersonal and intersubjective factors on engagement with

psychological services in individuals who repeatedly display deliberate self-

harm (DSH) behaviour

Abstract

Aims: This study aims to explore the interpersonal factors that lead individuals who repeatedly self-harm not to utilise psychological services in the community, and instead rely on frequent attendance in Accident and Emergency services (A&E).

Method: Semi-structured interviews were conducted with eight service users who repeatedly self-harm, and seven primary care mental health staff members. An additional focus group was conducted with 17 mental health professionals who work in secondary care psychological services. Data were transcribed and analysed using Framework Analysis to identify main themes and extract clinical implications.

Results: Service users described experiencing negative encounters with primary and secondary health services, that had led to negative perceptions, sense of mistrust in care providers, and fear of being involved in mental health interventions. Staff members echoed the occurrence of such negative interactions and their negative impact. They also added that limited available resources maintain and even contribute to the current situation, where psychological therapies are out of reach for some individuals who repeatedly self-harm. Both service users and staff members identified numerous possible solutions, in clinical and administrative aspects, that could modify the way services operate, allowing more service users to access an improved care pathway.

Conclusions: The accounts of both service users and staff members provided a valuable contribution that has yet to be recognised in earlier studies. It seems that current clinical care and service structures are not synchronised with the unique characteristics and needs of individual who repeatedly self-harm. This desynchronization serves to maintain the insufficient use of preventative psychological interventions. These findings suggest that there is a need for future

research on alternative clinical interventions and organisational modifications, that will bypass the

barriers identified in this study.

1. Introduction

1.1 Deliberate self-harm

Deliberate self-harm (DSH) refers to a broad spectrum of actions of self-injury executed by an individual, regardless of their motivation (Hawton et al., 2003), and is one of the most substantial risk factors for death by suicide (Bergen et al., 2012; Cooper et al., 2007). Also known as self-injury, it takes many forms – cutting one's own skin, burning or striking body parts, self-poisoning by ingesting tablets or toxic chemicals, deliberate starvation, excessive exercise, among others (National Institute for Health and Care Excellence [NICE], 2012).

DSH is highly prevalent, and research has identified high-risk groups, including women, adolescents, individuals with a low socio-economic status, and individuals lacking social support (Meltzer et al., 2002). Other risk factors include having a family history of DSH (Hawton et al., 2002), having experienced physical, emotional or sexual abuse (Fliege et al., 2009; O'Connor et al., 2009a), and struggling with substance dependency (Gunnell et al., 2008;Horrocks et al., 2003).

Estimations of DSH vary significantly. In their cross-national study examining the prevalence of DSH among 17 different countries, Nock et al. (2008) found that 0.5–5% of people reported an episode of DSH. Moreover, according to the Adult Psychiatric Morbidity Survey (2014), the percentage of the population who have reportedly self-harmed in the UK has increased significantly from 3.8% in 2007 to 6.4% in 2014. It is important to note that the reported prevalence fails to reflect the true extent of the phenomenon. It has been estimated that the majority of the acts are never reported to healthcare services (Geulayov et al., 2016) because they do not require urgent medical treatment or can be managed with assistance from non-specialist mental health services (McManus et al., 2016).

1.2 Repeated DSH

Unfortunately, DSH is often repeated (Sakinofsky, 2000). Owens et al. (2002) identified that about a sixth of people attending Accident and Emergency services (A&E) following acts of self-harm will self-harm once more in the next year. Similarly, Geulayov et al. (2016) indicated that more than a fifth of individuals who presented at A&E as a result of DSH, attended A&E again the following year.

The element of repetition of DSH carries a significant risk, including further and more severe forms of physical damage, as well as a higher chance of death by suicide (Ribeiro et al., 2016). Among those with repeated presentations in A&E, the risk for a more severe act is 2.24 times greater than that of those with a single presentation (Zahl & Hawton, 2004), and the risk of death by suicide is 20% higher for those who have been admitted to A&E (Bergen et al., 2010a; Da Cruz et al., 2010).

Repeated DSH affects more than just the physical and emotional state of individuals and their families. It has a noteworthy social impact, mostly due to the associated heavy economic burden. This burden is composed of two main components. The direct costs of DSH include direct medical contact with healthcare services through the utilisation of A&E services, engaging with psychological therapies, or the price of medications (Tsiachristas et al., 2017). Indirect costs mostly refer to productivity loss, including increased sick leave, early retirement and unemployment (Kinchin & Doran, 2017; Mitchell & Bates, 2011).

NICE guidelines (2012) state that the cumulative direct and indirect costs of DSH are unknown and difficult to estimate because the healthcare system is not aware of the majority of

DSH acts (Sinclair et al., 2011; Tsiachristas et al., 2017). However, they clearly state that the economic burden is likely to be substantial, given the high prevalence of repeated DSH in the UK (Nice, 2012). This has led decision makers to recognise the repetition element as a profound public health issue (Haq, Subramanyam & Agius, 2010).

1.3 Treatment pathways in the NHS

In 2017, NICE published its recommendations for the psychosocial and physical treatment of individuals who engage in DSH. When DSH is reported to medical services, frontline medical care teams should provide both physiological and psychological assessments to evaluate potential risk (NICE, 2017). In urgent cases (especially in cases of self-poisoning), the individual should be referred to the nearest A&E department. If the emergency department is not considered, a referral should be made for secondary mental health services. This guideline also obligates primary care professionals (e.g. GPs) to follow up any type of self-harm.

Psychiatric liaison services, which are multidisciplinary teams comprised of mental health professionals working in general hospitals, are in charge of the provision of comprehensive assessments that include an evaluation of the individual's psychological, social and motivational risk factors for DSH and suicidal behaviours. As psychiatric liaison teams are concerned with the care of people presenting with both mental and physical health symptoms in primary medical settings, they serve as a link to non-emergency healthcare services. Therefore the outcomes of these assessments are communicated with the GP, as well as relevant mental health services, to enable follow-up (Aitken, Robens, & Emmens, 2014). Individuals who present with DSH should be offered a long-term treatment pathway, including an integrated assessment of risk and psychosocial needs. Three separate mental health interventions should be offered, comprised of

interventions for self-harm, for treating associated mental health conditions, and for harm reduction. NICE guidelines (2009) clearly state that possible interventions to reduce self-harm and the associated economic burden should take into consideration this repetitive nature of self-harm in both the short and long term.

1.4 Engagement with services and repeated self-harm

The extant literature shows that prevention programmes, including engaging with psychological therapies, can reduce both repetition rates and the severity of DSH (Aseltine et al., 2007; Hawton, Rodham, Evans & Weatherall, 2002;; Saunders & Smith, 2016; Wasserman, 2016). However, it seems that many people who self-harm are not receiving interventions from medical or psychological services. According to McManus et al. (2016), 66% of 16–34 year olds who self-harm reported never receiving any medical or psychological support. Therefore it is crucial to understand what factors stand between service users and the available support provided by the NHS. This question has led to a growing literature in the field of DSH and help-seeking behaviour (Fortune, Sinclair & Hawton, 2008; Lucassen et al., 2011; Nada-Raja, Morrison & Skegg, 2003; Rowe et al., 2016).

Disengagement with services can be a result of both intra-personal or inter-personal factors. For example, Michelmore and Hindley (2012) identified negative views of mental illnesses, low perception of risk and limited knowledge about the usefulness of psychological treatments as intra-personal factors. Other research focused on the possible underlying psychopathology impairing relationships with care providers, including personality disorders (Chiesa, Drahorad & Longo, 2000; Martino, Menchetti, Pozzi & Berardi, 2012), depression (Arnow et al., 2007) and Post

Traumatic Stress Disorder (PTSD) (Dyerwt al., 2009; Webermann, Myrick, Taylor, Chasson & Brand, 2016).

Other explanations are rooted in self-harming individuals' sociocultural background. Link et al. (1999) stressed that cultural conceptions of the phenomenon of DSH have a significant consequence in relation to help-seeking behaviour, as well as to the overall outcomes. For example, stigma and discrimination regarding mental health have been widely recognised as strong predictors for maladaptive help-seeking behaviour (Corrigan 2004; Hinshaw & Cicchetti 2000; Kane 2006). Other factors consist of family pressure (Arkoff, Thaver & Elkind, 1966), a cultural perception of mental health problems as an intrinsic phenomenon (Bhugra & Desai, 2002), a perception that a person's willpower alone is the primary mechanism of change (Mallinckrodt, Shigeoka & Suzuki, 2005), and the belief that individuals with mental health difficulties will bring shame upon their families (Jang, Chiriboga & Okazaki, 2009).

Other reasons for disengagement focus on the practicalities and procedures by which treatments are delivered by healthcare providers, mostly within primary care. For example, studies suggest that over 50% of service users who attend A&E for self-harm do not wait for, or are not offered, a psychosocial assessment, which prevents the necessary referrals (Cooper et al., 2013; Kapur et al., 2008; Lepping, Woodworth, Roberts & Turner, 2006;). Moreover, and in contrast to NICE guidelines, less than 50% receive an assessment by specialist services (Cooper et al., 2013). In addition, Owens, Horrocks and House (2002) identified that those who attend A&E with 'minor' self-injuries are much less likely to receive an adequate psychosocial assessment and follow-up, possibly due to the misconception of a perceived lower risk for suicide (Bennewith et al., 2005; Grandclerc et al., 2016). It is important to note that hospitals may vary noticeably in their management of self-harm (Cooper et al., 2013).

1.5 Current study

One of the well-researched factors in help-seeking behaviour is the quality of interpersonal relationships (Barker, 2007), often in relation to family, peer support or healthcare providers (Petraitis, Flay & Miller, 1995; Veselska, 2010). Because A&E is often the first and only 'port of call' for many individuals who repeatedly self-harm (Pearsall & Ryan, 2004), this research will focus on the interpersonal relationships with frontline healthcare providers.

Current research in the field has revealed a mixed picture and often has not explored whether the dynamics between this specific group of service users and healthcare providers affect an individual's choice not to engage with mental health services (Chapman, Specht & Cellucci, 2005; Hadfield, Brown, Pembroke & Hayward, 2009). For example, according to NICE guidelines (2004), service users often describe their interactions with healthcare services as unpleasant, as staff often convey inexperience and negative attitudes, and their behaviour is even punitive. This was mirrored by studies in which individuals who self-harmed were asked to rate the sources of support, with medical professionals usually rated as the most unsatisfactory and generally negative source (Owens, Hansford, Sharkey & Ford, 2016; Warm, Murray & Fox, 2002).

On the other hand, the literature suggests that service users also have positive experiences during their care in A&E and other mental health services (Nada-Raja, Morrison & Skegg, 2003), especially when their psychological state was acknowledged (NICE, 2004). Additionally, a number of studies identified a positive attitude of medical professionals towards people who display DSH; they characterised the contact with them as helpful and attentive and optimistic about their prognosis (Gibb, Beautrais & Surgenor, 2010; Kelley et al., 2014; Sidley & Renton, 1996;).

This exploratory study will examine interpersonal factors that lead some service users to repeatedly use A&E following acts of self-harm. Additionally, it will explore the interpersonal factors that make them choose not to utilise psychological services in the community. Currently, no attempts have been made to encapsulate the perspective of service users and mental health professionals in a single qualitative investigation. Focus groups and interviews with service users and healthcare professionals were conducted to explore the following questions:

1. What are the interpersonal factors affecting an individual's choice not to utilise psychological therapies?

2. What are the interpersonal factors affecting an individual's choice to repeatedly use A&E services?

3. What do services need to change to increase a service users' attendance of psychological therapies in the community?

2. Method

2.1 Design

The study utilised one-off one-to-one qualitative interviews with service users who have experienced the phenomenon being investigated. Additionally, it used consecutive interviews and a focus group with staff members from a secondary care psychological service (which provide evidence-based treatments for individuals who engage in high risk behaviour) and with the hospital psychiatric liaison team, who are often the only clinicians these service users encounter before potentially being referred for further outpatient psychological treatment.

The data were analysed using framework analysis, a qualitative method used for assessing the success, failures and efficiency of organisational policies and procedures (Srivastava &

Thomson, 2009). Framework analysis is particularly useful for applied policy research investigating a particular phenomenon in a limited time frame alongside a need to provide clear operative steps and highly structured outputs of the summarised data for decision-making processes (Gale et al., 2013). It can generate theories, but its prime goal is to provide an accurate interpretation of what is happening in a specific setting (Ritchie & Spencer, 1994).

2.2 Inclusion and Exclusion criteria

For service users, inclusion criteria included: individuals who had presented to A&E more than once with either DSH or a suicide attempt and were subsequently offered psychological or psychiatric support but did not take up the offer; and who were over 18 years of age. Exclusion criteria included a lack of capacity to consent to being involved in the research, in view of it being necessary for participants to understand any potential burdens or harms related to being involved in the study.

Additionally, service users who were unable to communicate in or understand conversational English were excluded; this was because the financial and time constraints of the study did not allow us to provide translation facilities. Moreover, participants who were under 18 years of age were excluded due to the researcher lacking the capacity and time to gain parental consent.

For staff members, the inclusion criteria included medical and healthcare staff in direct contact with individuals who had attended psychiatric liaison services and A&E for DSH. Interviews were conducted with medical professionals, including managers of the psychiatric liaison team, medical doctors and psychiatrists working in A&E/psychiatric liaison team, nurses

working in A&E/psychiatric liaison team, psychologists working in A&E/psychiatric liaison team, social workers working in A&E/psychiatric liaison team and mental health support workers.

Additionally, the staff members from the secondary mental health service included Clinical psychologists, Cognitive Behavioural therapists, Dialectical Behavioural therapists, trainee Clinical Psychologists, Counselling psychologists and other mental health professionals, all are trained in providing evidence-based psychological treatment for individuals who DSH. We did not include administration, reception or technical support staff in this study.

2.3 Recruitment

Participants were recruited according to the two different streams (service users who repeatedly self-harm and staff members from both secondary and primary services; see invitation letter in Appendix D). Service users who met the inclusion criteria were randomly assigned a participant number to ensure anonymity. Similarly, staff members who met the inclusion criteria were randomly assigned a serial number.

Both recruitment streams aimed to recruit 15–20 participants based on the guidelines of Srivastava and Thomson (2009) which recommended this number as an appropriate sample size for qualitative studies. The same sample size was also used in other studies investigating the phenomenon of DSH (Kenning et al., 2010; Sinclair & Green, 2005).

2.4 Participants

Of the 32 participants who took part in the study, eight service users and seven staff members were interviewed individually, in addition 17 mental health professionals participated in the focus group. Seven service users who were suitable to the study decided to decline after

reading the information sheet. All the service users were females, recruited from A&E and secondary care psychological services. It is important to note that due to the possible difficulties with the service users' engagement with mental health services, data in relation to age, ethnicity and other demographics were not collected. It was assumed that the more information was collected, the more service users would be reluctant to participate.

Table 1

Characteristics of participants – Staff Members working is psychiatric liaison team (N=7)

Participant number	Work Experience in the field (in years)
P1	23
P2	25
P3	3
P4	9
P5	7
P6	4
P7	1

Staff members included service managers, clinical psychologists, consultant psychiatrics, medical doctors, and psychiatric nurses. In order to protect privacy and confidentiality, the job title of each participant was omitted.

Table 2

Characteristics of participants – staff members working in secondary care psychological services

(N=17)

	Clinical Psychologists (n=6)	Dialectical Behavioural therapists and Cognitive Behavioural therapists (n=3)	Trainee Clinical Psychologists (n=4)	Other mental health professionals (nurse, couple therapist (n=4)
Gender	F=5 M=1	F=2 M=1	F=3 M=1	F=3 M=1
Age (in years)	R= 32-56	R=39-55	R= 26-39	R= 33-57
Ethnicity	White-British, Mixed, White-other	Caribbean, Asian other	White British, Nigerian British, White-other	Afro-Caribbean British, White British, White Irish
Current working hours	Full time= 5	Full time= 2	Full time= 0	Full time= 3
	Part time= 1	Part time=1	Part time= 4	Part time= 1
Work Experience in the field (in years)	R= 8-28	R= 19-28	R= 5-10	R= 7-30

2.5 Procedure

Staff members who participated in the individual interviews were presented with the relevant information about the study during one of the weekly team meetings. Staff members who were willing to participate were given an information sheet about the study (Appendix E) and were later contacted by the researcher to arrange a meeting. During these meetings, the researcher made sure that potential participants were aware of their right to withdraw from the study at any time or to refuse to answer questions; they were also made aware that participation was voluntary. Written consent was obtained for each staff member before the interview took place. Interviews were conducted during working hours and lasted approximately 45 minutes.

The focus group with staff members was organised with the service manager and conducted during one of the weekly team meetings. Notice of the right to withdraw at any time and general information about the study were given to participants before conducting the focus group. Participants who wished to participate signed a written consent form before the beginning of the team discussion. It was conducted during working hours and lasted approximately 75 minutes. All the participants contributed to the discussion, yet with some degree of variation between individuals (appendix M). Staff were interested in voicing their opinion, and were reflective to the extent of acknowledging both the needs of the service and service users, and the service's limitations. Moreover, they were able to create a fruitful discussion about possible solutions and system-level changes, by making use of each other's professional background and expertise.

In relation to service users, the first contact with participants was determined according to the different sites of the study: the psychiatric liaison unit of the hospital and the secondary care psychological service for personality disorder. Staff at the psychiatric liaison unit were asked to identify potential participants that they had frequent contact with based on the inclusion criteria.

Within the personality disorder service, staff identified service users who they knew had not engaged with mental health services offered after presenting at A&E for DSH. Staff at both sites provided brief details of the study to the service user, clarifying that participation was entirely optional and that they had the right not to answer questions and that it would not affect any care they are entitled to receive. Potential participants were then asked whether they consented to the researcher contacting them. If consent was given, service users received the participant information sheet (Appendix E) and their contact details were collected using the contact details collection form (Appendix F).

The researcher then contacted the participants by telephone or email after seven days, giving sufficient time to carefully read the information sheet and make an informed decision regarding whether to participate. An interview was scheduled with those participants who wished to proceed. The researcher reminded the participants that for the interview to take place it was mandatory to read the participant information sheet and consent form (Appendix G) before the interview appointment. Interviews took place during working hours and lasted approximately 45 minutes.

The interview questions, whether for staff or service users, were open ended and based on a semi-structured schedule (Appendix H). Questions were focused on the factors affecting an individual's decision not to utilise psychological services following repeated DSH. Yet, it is important to note that some questions were more focused and directed. This is due to the intent to try and explore particular known challenges (e.g. reasons for disengagement) and ways to overcome them (e.g. procedures of healthcare provision that can be changed).

After each interview a full debriefing of the study was provided. Interviews and focus groups were digitally recorded and transcribed verbatim for future analysis. All identifiable data were securely stored in accordance with the Data Protection Act 2018 and General Data Protection Regulation (GDPR).

2.6 Ethics

Ethical approval was obtained by the West of Scotland Research Ethics Committee (REC reference: 18/WS/0198) on 18th December 2018 (Appendix I).

2.7 Measures

Participants were interviewed using semi-structured interview schedules that were developed by the researchers in collaboration with the primary investigator. Schedules were based as well on the existing literature and research guidelines, focused specifically on studies conducting framework analyses (Srivastava & Thomson, 2009).

This study used two different scheduled interviews, one for service users and one for staff members. Service users were initially asked to reflect on their experiences of being offered support from mental health services during or following A&E attendance for DSH, their expectations and what factors affected their decision to engage in psychological therapies . The subsequent part of the interview was focused on potential changes that service users would like to see in the system to make psychological therapies for DSH more appealing. Service users were asked what features they imagined a more attractive treatment would have, as well as more practical aspects such as possible locations, time of day and type of intervention.

Interviews and focus groups with staff members focused on the need to elicit information that is informed by their own clinical experiences, theoretical background and current practices.

Participants were initially asked to share their hypotheses about the phenomenon of repeated DSH and the decision not to utilise psychological services. Later, members of staff were asked to share their perspectives about the effects of cultural factors and possible stigma and were encouraged to think about potential ways to overcome them. Finally, staff members were questioned about the practical issues that need to be addressed as part of a potential new approach to increase the engagement of individuals who display repeated DSH, in addition to possible ways to motivate future participation.

The interview schedule was used to direct the structure of the conversation, yet the interviewer maintained a flexible stance and responded to the flow of the interview to ensure the opinion of the individual would be reflected accurately. All interviews were audio recorded, transcribed verbatim and all identifying details were removed.

2.8 Analysis

Framework analysis was the chosen qualitative methodology for this study. It was preferred over other qualitative methods for a number of reasons. First, it allowed the analysis of three participant groups. This was particularly relevant to this study as it required the synthesis of two separate data sources originating from two distinct populations (service users and staff members).

Second, it is highly structured, and therefore provides the researcher the opportunity to work according to clear step-by-step guidelines. This was particularly relevant to this study as it required the synthesis of two separate interviewing procedures (individual interviews and focus groups).

Third, framework analysis enables a more objectified decision-making process. It has been suggested that other qualitative approaches, for example thematic analysis, tend to provide a more

subjective picture of the investigated phenomenon, and have less literature available regarding outlining the pragmatic processes necessary for applied research (Nowell, Norris, White, & Moules, 2017). Framework analysis offers a more structured, systematic, transparent and explicit picture of the investigated research questions, thus helping decision makers to more accurately assess the rigorousness of the findings (Maggs-Rapport, 2001; Smith & Firth, 2011).

According to the guidelines written by Ritchie and Spencer (1994), data were analysed using the five phases approach. These phases include:

(1) Data management and familiarisation, a process where the researcher becomes familiar with the collected data by repeatedly listening to the recordings, transcribing them and reading the transcripts. In Framework analysis, unlike other qualitative approaches, reviewing all interviews can be done at different time points. It allows the researcher to manage large amounts of data, and begin the analysis before all data are gathered (Appendix J). It was particularly valuable for this study, as due to the nature of the two distinct populations, data gathered from staff members were completed first, perhaps due to the difficulties of service users to engage in the interviewing process.

 (2) Identifying a thematic framework, the process where the emerging themes are recognised or the hypotheses are strengthened by the newly collected data. Ritchie and Spenser (1994) stressed that the process is continual and can be revised at subsequent stages of the analysis. A list of the initial themes was generated during phases 1 and 2 to create the initial index framework (Appendix K). It is important to stress that most of the staff interviews were completed prior to the service user interviews, which could risk biases, as it could lead to an analysis that is influenced more by the account that has been obtained earlier. In order to minimise this risk, the process of identifying the thematic framework needs to be under rigorous supervision. By

continuously referring back to the raw data, themes were modified to correspond to the new data, which were revealed by reading the rest of the transcribed materials.

(3) Indexing the data appearing in the transcribed interviews and focus groups that correspond to a particular theme. This process was applied to all interviews and focus groups, in addition to key phrases that were summarised using participants' own words. This broadened and enriched the indexed themes and allowed new themes to be included.

(4) Charting is the process by which the indexed data are organised according to charts of themes, also known as a coding matrix. This matrix was created using Microsoft Office Excel and included the main themes, sub-themes and central extracts. The index categories were represented in rows, with each participant represented by a separate column. This charting facilitated comparisons, as well as the examination of which themes remained true to the raw data concepts (Smith & Frith, 2011).

(5) Mapping and interpretation included an analysis of the key characteristics and provided a schematic diagram of the research questions. The coded data were synthesised and summarised using the descriptive accounts. Additionally, a final matrix of data (Appendix L) was created to allow a transparent examination of the ways the codes, categories and themes were interlinked (Ritchie & Lewis, 2003).

2.9 Researcher's perspective

Personal assumptions, past experiences and personal values are known to influence the process of research. Good qualitative practice guidelines stress that researchers should explicitly state their assumptions and theoretical orientation prior to data collection, as well as any other

potential influencing factors that emerge during the process of research (Srivastava & Thomson, 2009; Welch, 2018).

My interest in this field of research derived from my experience of working with adolescents involved in prostitution, often presenting with severe self-harming behaviour and other inter-personal difficulties. The work was guided mainly by systemic principles, often trying to work collaboratively with their nuclear family, extended family and the educational system.

Exploring mental health difficulties in light of a theory that sees mental health difficulties as a systemic phenomenon influenced my choice to explore the research question in a way that focused on the interpersonal dynamic between service users and healthcare systems. In addition, I was aware of the need for practical modifications of the way treatment is delivered and therefore I chose to adopt a method that would facilitate a critical appraisal of current practices.

My wish to include a more rigorous and objective research method was also influenced by a growing sense of frustration when the service I worked in failed to minimise the rates of DSH. Although I witnessed some positive outcomes, I was aware that prioritising a subjective-based exploration alone was not sufficient to decrease rates of DSH with the adolescents we worked with. It was hard to extract practical steps from the information gathered, which left me feeling somewhat dissatisfied with the service.

Additionally, as a trainee who had acquired pre-training experience outside of the UK, I had no experience working with DSH individuals within the NHS. I believe that due to my lack of knowledge of the way NHS services deal with DSH, I was inclined to locate the problem within the services alone. This required me to discuss and reflect upon this in supervision, team meetings and with my colleagues, especially during the phases of data collection and interpreting the

findings. I needed to be reminded of the theoretical orientation I first approached this topic with in order to maintain a meta-perspective stance that would be sensitive to the views of both sides.

3.Results

Following the guidelines for framework analysis by Ritchie and Spencer (1994), the following results are the mapped key characteristics extracted from 15 interviews and one focus group with 17 mental health professionals working in a secondary care psychological service.

3.1 Overview and context

Both service users and staff members described the phenomenon of repeated DSH, not utilising psychological services and re-attending emergency services as a treatment of choice. They described the reason for the existence of this phenomenon, its consequences and potential solutions that allow services and service users to increase participation in psychological therapies. All interviewed service users were struggling with repeated DSH at the time of the interviews.

3.2 Themes

Thirteen themes were assembled into four superordinate themes: '*All rivers run to A&E'*, '*Expecting more of each other', 'Negative past experience with health services'* and *'What can be done differently*'. Tables 4 and 5 provide a summary of the themes and provide information about the number of participants who endorsed each one. In the following section, each theme illustrated with extracts taken directly from the interviews.

Table 3

Summary of themes

Superordinate themes	Subordinate themes
1. "All rivers run to A&E" (SU. 4)	*1.1: 'Hot potatoes' (SU. 3)* *1.2: Practically falling between the chairs* *1.3: Reinforcing environment* *1.4: 'A quick fix' (SU. 8)*
2. Expecting more of each other	*2.1: 'They ask me to change, but how?' (SU. 1)* *2.2: Mutual misconceptions* *2.3: Fear of treatments*
3. Negative past experience with health services	*3.1: First encounter with emergency services* *3.2: Painful experiences with other healthcare services*
4. What can be done differently	*4.1: Being instead of changing* *4.2: Centralised services* *4.3: Chain of services* *4.4: Being in touch*

Table 4

Number of service users and staff members endorsing each theme

	"All rivers run to A&E" (SU. 4)				Expecting more of each other			Negative past experiences		What can be done differently?			
	"Hot potatoes" (SU. 3)	Practically falling between the chairs	Reinforcing environment	"A quick fix" (SU. 8)	"They ask me to change, but how?" (SU. 1)	Mutual misconceptions	Fear of treatments	First encounter with emergency services	Painful experiences with other healthcare services	Being instead of changing	Centralised services	Chain of services	Being in touch
Service Users	7/8	8/8	4/8	6/8	5/8	6/8	5/8	7/8	8/8	7/8	6/8	6/8	6/8
Staff Member[4]	6/8	7/8	7/8	7/8	5/8	5/8	5/8	5/8	5/8	3/8	7/8	8/8	6/8
Overall	13/16	15/16	11/16	13/16	10/16	11/16	10/16	12/16	13/16	10/16	13/16	14/16	12/16

[4]This table regards the focus-group as a whole single unit

1. 'All rivers run to A&E' (SU.4)

The following four themes concern the dynamics between individuals who display DSH and staff members in A&E, along with the part these dynamics play concerning future engagement with secondary mental health services.

Theme 1.1. 'Hot potatoes' (SU.3)

Seven service users, six individual staff interviewees and seven focus group participants identified that individuals who engage in DSH are often transferred between multiple services and professionals, which creates a situation where A&E becomes the place where service users and staff members know they will definitely be attended to. However, this increases the tension in facilities that are already stressed and under-resourced. One staff member illustrated the malpractice caused by this:

> *We get the 'go fix it' attitude. The idea of fixing actually means 'take it away from me' which again is really unhelpful. They (service users) do need a less stressed environment.* (P.5)

One of the service users described how this attitude looks from the perspective of the patient:

> *"My mom rang 101, and they were like 'well if you think there's a problem go to A+E'. She was like 'I don't think you understand. I need help'… They didn't want to help. They didn't want any part of it. They just wanted to pass me on to the next person."* (SU.4)

Psychologists and other mental health professionals in secondary care services identified that there is a tendency to refer service users to A&E as an automatic default: *"A&E*

might resent that. Why does everybody say, 'I don't have time for you' or 'it is out of hours,

it is too much, it is high risk. Go to A&E.' A&E became the answer to anyone's problems."

(Focus Group)

> *"It is a relief for professionals to know that they took care of the situation by sending*
>
> *them to A&E. I am afraid we are reinforcing this behaviour because we have no*
>
> *resources, and we don't know what else to offer."* (Focus Group)

Seeing A&E as a 'backup plan' is possibly influenced by underestimating the amount

of stress present in emergency units and the negative effects of the potential stress on the

emotional state of staff members:

> *"We need to be careful and understand their perspective. They are trying their best*
>
> *to keep people alive, and then someone coming drunk and high overdosing, which*
>
> *services already offer him/her something. You lose your ability to be compassionate."*
>
> (Focus Group)

Theme 1.2. Practically falling between the chairs

All individual staff interviewees, seven focus group participants, and seven service

users described a situation where not everyone who attends A&E with DSH receives

information about the availability of secondary mental health services. Even though every

DSH patient attending A&E has to be seen by a mental health professional for assessment,

some decide to leave before the psychiatric liaison team reviews them, often a result of the

long waiting times in A&E due to presentations being prioritised according to severity:

"We need to assess them within one hour. We usually do it much quicker. But patients can wait maybe five hours in A&E until the medical staff can let us know about it. Some leave before we get the chance to assess them." (P.3)

Additionally, for less severe presentations of DSH, primary care services cannot follow up referrals they have made with the intention of facilitating communication between the individual and secondary care psychological service. All staff members from the psychiatric liaison team stressed that following up non-life-risking presentations is rare and highly dependent on the motivation of the referrer:

"But if service users don't engage with the process, nobody is going to follow it up unless they are very worried. I mean when the risk is high." (P.1)

One service user described how not being followed up by primary services left her feeling confused and continuing to injure herself:

"I didn't know if I could actually seek any help. I wasn't entirely sure what I should be doing. I'm a little bit upset where I had to start cutting myself and trying to take things, because I think it could have been nipped in the bud before anything actually happened." (SU.7)

Theme 1.3. Reinforcing environment

Seven individual staff interviewees, six focus group participants and four service users identified that the routine of attending A&E might trigger certain elements that have a reinforcing nature. Some of these are concerned with psychological needs that are not being answered in their personal life:

"Our service users are usually bored, lonely and scared to be alone. When they get to A&E, it's interesting. There are lots of people around, sitting around and talking. You don't feel as lonely or scared. And you get touched as well. which is, unfortunately, missing in some of our service users' life." (Focus Group)

Additionally, many service users described the environment in A&E as negative, dismissing or even hostile. Mental health professionals suggested that these experiences may have a reinforcing nature. Unfortunately, these negative experiences are common among individuals who display repeated DSH, which possibly makes re-experiencing them something familiar and predictable:

"They (service users) get a lot of 'you wasting my time' 'you did it to yourself' 'how can you spend resources like that'. The amount the hostility is so high, but they still show up. Maybe they are used to an invalidating environment. It is more of the same they get everywhere else. I know a patient who is regularly going to A&E. And they are treating her badly. She is scared as there is no alternative, but it does comfort her in a way." (P.1)

Theme 1.4. 'A quick fix' (SU.8)

Seven individual staff interviewees , five focus group participants and six service users raised the idea that attending A&E can be a convenient way to meet temporary needs without having to be involved in an effortful therapeutic process.

"When people (service users) in an emotional turmoil or emotional pain, people DSH for that immediate relief, and psychological therapies aren't giving that immediate relief. People are in pain now so they will go find relief in A&E" (P.1)

The 'quick fix' can also be a way to bypass the long process of referral to secondary care services. Participants mentioned that there are a limited number of psychological services that specialise in DSH, resulting in long waiting lists. This seems to create a gap between the time of the act of DSH and the time of starting therapy. Service users might not find therapy relevant at that time and would be less ready to engage with the provided treatment:

"The procedural aspect is not containing, and it increases disengagement. If someone been accepted a place, now we have the waiting time. Some services have a year response time; some are a bit quicker. I suppose if I get referred somewhere, and wait and wait, meanwhile self-harm again, and then eventually someone calls for something I did such a long time ago. It increases distrust. Why should I open up to you if you let me wait and harm myself more and more?" (P.4)

2. Expecting more of each other

The second superordinate theme concerns the gap between the views of service users and staff members about the treatment that is provided. Interviews suggested that these gaps are fertile soil for disappointment, suspicions and fears of the engagement process.

Theme 2.1 'They ask me to change, but how?' (SU.1)

Five individual staff interviewees, eight focus group participants and five service users strongly stated that services tend to promote treatments that prioritise the element of 'change' in patterns of behaviour, thinking or emotional state. However, it seems that service users tend to understand it as a change of their personality, and therefore respond with disbelief and suspicion. They often feel dismissed, unsatisfied and less motivated to enrol in this kind of treatment:

> *"They always say 'you need to change. There is nothing we can do for you'. And they signpost you to another service like the Samaritans… It feels that everyone tells you 'you need to change', but I don't know how I can do it. I'm coming back home mentally traumatised after trying everything. It just does not worth it. It feels like a complete waste of time."* (SU.3)

Staff members raised concerns over systems that prioritise 'change-based' attitudes and questioned whether repeated DSH is better seen as a chronic condition, which requires shifting from change-based to manage-based psychological treatments:

> *"A&E staff are saying 'you need to do something to manage your emotions. You need to change. This is the message they are getting. And this is part of the reason they back off service. As services offer them a solution that they need to change. But they say 'I have no clue how to do it' … 'I can't, I am overwhelmed, and need to get cared for'."* (P.6)

Theme 2.2. Mutual misconceptions

Another gap between service users and staff members concerns having limited knowledge and emotional capacity to adopt the perspective of the other. Six individual staff

interviewees, eight focus group participants and five service users expressed difficulty in understanding the needs and limitations of the other.

All service users shared that they expected more from health services concerning what the system should provide in relation to both practical and therapeutic aspects:

> *"Another thing is services tell me that my expectations are too high. I don't know if I supposed to tell you that, but I dealt with domestic violence in the past. And even then, when I was so vulnerable, services told me 'your expectations of mental health services in the NHS are far too high'. So as you can see, I've been let down a lot."* (SU.1)

Additionally, service users are attributing negative personality traits to staff members as a way to explain the reasons why services are operating in such a way:

> *"The doctor in A&E was there for a paycheck. She was there to get her pay and go home… That woman was like 'yeah I've got a lunch break to go to'. It was like I was invading her time... That woman is the example of why children kill themselves. They feel like they can't say anything without being judged or feeling like you're wasting their time."* (SU.4)

On the other hand, participants believed that there is a tendency among staff members that they have met in the past (unrelated to the interviewees of the current study) to react with disbelief about the reasons why they repeatedly self-harm, explanations such as 'wanting to manipulate the care system to receive financial benefits' or 'to seek attention' are common:

"You can pick up negative attitude in language. Names like "frequent flyers", or eye rolling. Negative body language. It creates suspicions towards them. There is a perception that they are doing something to themselves that they could stop doing. And maybe a misunderstanding about the extent which they have control over it." (P.3)

It seems that this friction accelerates a stance of mistrust, resulting in service users preferring not to dedicate efforts to participate in long-term psychological treatments. One service user described how this mistrust played out in the therapeutic relationship:

"You need to pretend to be happy so you can go. They just want you to play happily and not actually to get better. After that, I just gave up. I just gave up on everything on ever getting better or happy." (SU.3)

Theme 2.3. Fear of treatments

Five service users expressed great fear about how they might be treated by mental health services. They raised fears of being treated carelessly, which seems to promote a sense of hopelessness and having no control over treatment:

"I thought all services are doing is locking people up in cells or giving them drugs. And if you are not getting better, they will just hold you for some time until you play nice, and only then they let you go." (SU.2)

Five individual staff interviewees and ten focus group participants raised a common concern regarding the fear of confidentially and privacy:

"Service users might ask 'Does it mean I will be monitored?' Especially with the question of substance misuse. 'Do I have to disclose all this information?'. People don't really have the information about what it means to be treated by the system. 'Would it affect my kids? Will social services will be involved?'" (P.2)

3.Negative past experiences

The following two themes illustrate how past experiences with primary and secondary mental health services can be traumatic for service users and shape their unwillingness to re-engage in the future. These experiences were shared by all service users and backed up by the majority of staff members.

Theme 3.1. First encounter with emergency services

Seven service users mentioned negative encounters with emergency services as the main reason why they do not utilise secondary mental-health care. It seems that at the core of this experience is a perception of not being treated as a person but as an object, that is a burden on services. Two service users shared how insensitive their first encounters with services were, and what a great impact this had on their motivation to receive further help:

"Yes, I've been offered psychological therapy in the past. But I will not do it. Do you remember how I disclosed to you in A&E how I was treated? And if that's similar to what you call 'psychological treatment' then it is not good enough for me." (SU.1)

"A*fter that bad experience I really had bad episodes, and I refused to go back to the hospital, and I refused to have help from nobody. It was such a sensitive topic for me to come out and say I had a problem and the way that she (medical doctor) dealt with it was just awful."* (SU.4)

121

Five individual staff interviewees and nine focus group participants echoed the existence of this attitude towards service users. One staff member raised the possibility that it serves as a defence mechanism, protecting staff members from the emotional impact of treating individuals who repeatedly self-harm:

> *"There is a real need to distance yourself from the pain of the other person. And just think for a minute that if it is the reaction of the member of staff, just imagine how much frustration, anger, hate and sadness the service user feels. Maybe it is us who picked so much from them, and we can't tolerate it, so we push it back to them. And then, of course, a spiral."* (P.5)

Theme 3.2. Painful experiences with other healthcare services

Negative past encounters with services were mentioned by all service users who seemed to describe a picture where the treatment provided was neglectful and even hostile. Interestingly, the majority of the experiences took place in inpatient units:

> *"It depressed me. They didn't do anything. Absolutely nothing. They just locked you up and took everything off you. I ask if there is a therapist I can see? And then they say that I would see a doctor only when I will be considered to be discharged. They had very rubbish security. I drank, entered blades, just pointless… And then I understand that I'm not going to be saved and nothing is going to work out for me. Afterwards, I just got worse and worse overdosing again and again."* (SU.3)

4.What can be done differently?

All participants hypothesised what changes could be made in the relationship between service users and health systems that would increase participation in psychological therapies and reduce the use of emergency units. Service users and staff members identified the following elements that they believed to be the most necessary.

Theme 4.1. Being instead of changing

Seven service users and three individual staff interviewees identified a gap between health systems promoting change-based treatments and service users needing a more flexible framework:

> *"I want a therapy that would be with a therapist who adopts a more open way of thinking. Less rigid and with fewer rules. They will talk to you as a person — I think that there are different tools for different people."* (P.3)

Seven focus group participants were able to reflect on this subject and recognise these conflicting perspectives within their system:

> *"Therapies are about change. No one wants to keep something which is harmful. We used to be focused on processing and exploratory — acceptance models. Lying on the sofas 'Freud style'. But now, the emphasis is on change. We are where the evidence-base is. So most mental health practitioners are immediately all about 'what you are going to do to take control over your life' or 'how are you going to act differently'.And I think that for some of our clients, it is very overwhelming. And this is what is going on for the last 20 years. And we are part of it. We can't deny it."* (P.6)

Theme 4.2. Centralised services

Seven individual staff interviewees and seven focus group participants felt that primary and secondary services should operate within the same geographical facilities to improve A&E treatment by allowing non-mental health members of staff the opportunity to directly observe, learn from and consult with mental health professionals on the unique needs of individuals who display repeated DSH.

Staff members mentioned that being referred to a service in an unknown location with unknown staff members can be very anxiety provoking. Having psychological services within the same location as emergency services could decrease unpredictability and increase the level of trust. It can additionally improve communication between services, hopefully minimising the risk of service users 'falling between the chairs':

> *"The first thing that I would do is to make psychological services on site. I think that it is more familiar, and I don't understand why it needs to be outside. The referral will go to familiar people and not some unknown person in service so far away. Just going to the building next door. "*(P.2)

Theme 4.3. Chain of services

All individual staff interviewees, eight focus group participants and six service users described the need for additional therapeutic centres that will take the load off emergency units. They described a situation where many individuals who self-harm are in need of a place to calm down, talk to someone and be watched over while they are in crisis. In an absence of these services, emergency units will remain a place where non-emergency needs are met:

"I will also add more services in-between. Every Trust that I've been working in have only A&E as the first line of contact. Without the in-between services, the only solution is A&E, and I think that it only reinforces the problem." (P.4)

Theme 4.4. Being in touch

Six individual staff interviewees and eight focus group participants indicated that many individuals with less severe DSH would not be followed up in terms of making sure they received and were in touch with secondary mental health services. Six service users confirmed not being followed up after an act of DSH.

"Psych liaison used to allow outpatient follow-ups. Giving someone a call after a day or two. I think that it can make a real difference…It will feel different if people would get a call from the person that they saw in A&E that know the plan" (P.3)

Unfortunately, the majority mentioned that these changes are solely dependent on the allocation of further resources. One participant from the medical team emphasised this dependency, and illustrated it with great frustration and hopelessness:

"If you don't have the stake-holders' agreement, then nothing is not going to continue." (P.5)

4.Discussion

This study used framework analysis to explore what interpersonal factors between service users and health care providers influence the phenomenon of repeated DSH and not utilising psychological interventions.

Much of the research in the field on DSH explores the experiences of service users (Bergmans, Langley, Links & Lavery, 2009; McAllister, Creedy, Moyle & Farrugia, 2002) or staff members separately (Hadfield, Brown, Pembroke & Hayward, 2009; Lindgren, Wilstrand, Gilje & Olofsson, 2004). Moreover, these studies are description oriented, with limited attention given to the impact on the practical aspects of providing long-term psychological care (Holdsworth, Belshaw & Murray, 2001; Hume & Platt, 2007).

The present research, however, was underpinned by the assumption that the phenomenon of repeated DSH and the reluctance to be involved with services would benefit from a perspective that adopts a systemic point of view (Fortune, Cottrell & Fife, 2016) by focusing on the quality of the dynamics that exist between the two sides. Therefore, this research suggests a broader examination of repeated DSH and offers a shift from its view as a unipersonal conceptualisation (Brown, Linehan, Comtois, Murray & Chapman, 2009; Haines & Williams, 1997;) towards a more multi-personal view.

It is important to note that the analysis identified three additional themes, however, they were not included. The rationale behind this decision was that these extra themes were not supported by the majority of the participants. As this study utilised Framework analysis, which is more rigorous but less exploratory in relation to other qualitative methodologies

(e.g. thematic analysis), the validity of the findings was prioritised over additional less supported data.

4.1 S*ummary of main themes*

4.1.1 Mutual suspicions

The results suggest the presence of a vicious cycle between service users and health systems. This cycle seems to be fuelled by the limited knowledge both sides have about each other and consequently gives rise to negative assumptions and behaviours dictated by mistrust (Dickinson & Hurley, 2012; Patterson, Whittington & Bogg, 2007; Rees, Rapport, Thomas, John & Snooks, 2014).

All service users described dissatisfaction with the care provided, a great sense of contempt towards the health systems and disbelief in their will to help, change and improve, similar to findings by Owens, Hansford, Sharkey and Ford(2016). On the other hand, mental health professionals in both primary and secondary services identified a lack of understanding in relation to DSH and a need for a more flexible stance when attending to individuals who present with DSH (Rees, Rapport & Snooks, 2015; Wright & Wright, 2011).

It can be assumed that this vicious cycle is maintained by stressful work environments (Satija & Khan, 2013). Staff members do not have sufficient time to reflect and develop emotional capacity, that allows the empathy which is required for challenging negative assumptions (Rose, Horne, Rose & Hastings, 2004). A&E services are highly pressured environments that impact tremendously on the ability of staff members to attend to all service users compassionately and patiently. Unfortunately, the study results correspond to the

findings by Ross and Goldner (2009), which stress that due to a limited understanding of DSH, emergency staff members may adopt a defensive and sometimes even hostile stance.

Service users who display DSH, on the other hand, often meet the diagnostic criteria of Emotionally Unstable Personality Disorder (EUPD: Borschmann & Moran, 2015), which, according to Fonagy (2018), is characterised by low mentalisation skills: the ability to understand others and self by inferring the mental states that lie behind behaviours. It has been suggested that individuals with EUPD might have difficulties in thinking reflectively about the other and adopting different perspectives, especially in a time of crisis (Bateman, Fonagy & Allen, 2009). Poor mentalisation skills may contribute to mistrust and therefore the vicious cycle is maintained by inferring negative interpretations for the intentions and behaviours of staff members.

4.1.2 Maintaining factors in A&E

The results suggest that the experience of attending A&E for DSH can be negative and distressing and thus serves as one of the main reasons for turning down further psychological support. These findings have been well documented in the literature (Horrocks, Hughes, Martin, House & Owens, 2005; Hunter, Chantler, Kapur & Cooper, 2013; Owens, Hansford, Sharkey & Ford, 2016; Warm, Murray & Fox, 2002).

However, the results also suggest the possibility that A&E may be a place where needs are met, including being attended to (positively or negatively), a relief from loneliness and a distraction from emotional pain. Additionally, A&E may provide short and limited interpersonal support for those who find individual therapies anxiety provoking and

overwhelming. This means that experiences in A&E may potentially serve as a reinforcing factor in repeated and frequent attendance.

The results suggest that A&E can be a highly stressful environment for staff members, which can lead to a wide variety of negative responses towards individuals who repeatedly self-harm. High attendance rates for DSH can also be due to A&E becoming a place where all other services feel it is safe to send service users but without fully understanding the high pressure under which emergency staff members operate (Bindman et al., 1997; Drinkwater et al., 2013).

4.1.3 Practicalities do not meet the needs

All staff members and the majority of service users mentioned that the referral system to secondary mental health services operates according to practicalities that can potentially result in service users missing out on opportunities to engage with long-term psychological treatment.

Service users and staff members mentioned that due to the long waiting time in A&E some patients are leaving without being assessed by mental health professionals (Clarke, Dusome & Hughes, 2007). Additionally, a lack of resources prevents staff members from following up less severe cases of self-injury, thus increasing the risk for them repeating DSH in the future. The results also suggest that when secondary mental health services are located separately from emergency services this increases the sense of anxiety over a place that is unfamiliar and remote.

Another limitation at the service level is the long waiting time for psychological therapy in secondary services, where participants shared that it can take up to a year from referral to the beginning of an intervention. The need to provide faster support by services is acknowledged by NICE guidelines (2004), which clearly state that when individuals who have self-harmed are believed to be at risk for recurrence, an intensive treatment regime should be provided, including access to a therapist when needed, active outreach when an appointment has been missed and even the inclusion of a home-treatment team when necessary. Working according to these requirements may well address the challenge mentioned by participants, where delayed interventions make the therapy less relevant, and thus decrease significantly the motivation required for a long-term therapeutic process.

4.1.4 Changes required in the policy levels

A recurrent theme about what might improve the relationship between services and service users is the modification of policies. The majority of staff members mentioned the creation of new services that will take the load off emergency units, services that will answer emotional needs such as being cared for, distraction from distress and feeling less lonely.

According to Wood (2016), there are very limited physical places to find support for an emotional crisis, especially after working hours and over weekends, leading to multiple presentations at A&E in the search for emotional support or a place to feel safe. The benefits of providing community-based centres that serve as an alternative to A&E when medical intervention is not needed have been recognised by healthcare systems within and outside of the UK. These benefits mostly include fewer admissions to A&E (Wood, 2016) and similar clinical effects compared to traditional psychiatric wards, in addition to possibly lower costs

(Howard et al., 2010). However, the evidence for a significant impact is not robust due to the low number of randomised controlled trials carried out to date. This may be a helpful avenue for future research.

Another change at the policy level is locating psychological services together with primary healthcare services. Staff members identified great potential at both the organisational level (e.g. improving inter-services communication) and the clinical practice level (e.g. both services learning from the expertise of the other). Importantly, the participants were convinced that all changes require the provision of further resources. They perceived solutions to be feasible only by the active involvement of higher management and commissioners. This stance seems to limit any initiatives to come up with innovative solutions for current practices, that can be implemented promptly.

Nevertheless, some of the changes not only require changes of policies but also of service culture, especially in relation to how recovery is perceived. Service users strongly emphasised the difficulty in relating to interventions that rigidly, and sometimes exclusively, focus on the achievement of 'observable change'. With the presence of literature describing some emotional elements of EUPD as chronic (Ellison, Rosenstein, Chelminski, Dalrymple & Zimmerman, 2016; Lieb, Zanarini, Schmahl, Linehan & Bohus, 2004), the emphasis on change might clash with service users' experiences. Echoed by a mental health professional, the majority of service users find the strive for change as overly emphasised, counterproductive and intangible.

Consistent with NICE guidelines (2004), all interviewed staff members agreed on the underlying understanding that every treatment aims to achieve change, to facilitate a belief

that change is achievable and to promote a hopeful message when working with service users who display DSH. However, the results suggest the presence of diversity concerning what therapeutic modality would achieve this. Staff members raised questions on whether and how to shift to a different therapeutic stance or practice (e.g. harm-preventing vs. harm-minimising for DSH) when the focus on change seems too remote or anxiety provoking for service users.

4.2 Summary

The accounts provided by service users and staff members have allowed a deeper understanding regarding interpersonal factors between health systems and individuals who repeatedly self-harm that have a negative impact on engagement with secondary mental health services.

These findings offer system-level way to understand repeated DSH as a maladaptive behaviour with interpersonal contributing factors that prevent individuals from receiving timely and appropriate preventative psychological treatment. These interpersonal factors include a vicious cycle of mutual mistrust fuelled by limited knowledge and emotional capacity, treatment pathways that maintain the equilibrium of DSH as a maladapted coping mechanism and also negative past experiences with healthcare services. Additionally, all participants suggested practical changes that they believe are essential to increase engagement but they attributed the responsibility to higher management and policymakers.

4.3 Limitations

There are a number of limitations in this study. First, this study did not collect substantial demographic data from service users, as it was assumed that participants would be reluctant to engage if a lot of personal information is gathered. Insufficient data may have provided only a limited picture of the examined question. For example, regarding the role of factors such as socioeconomic groups or number of DSH episodes in how staff members and service users perceive disengagement, or whether differences in these factors should be considered in treatment plans. The answers to these questions might play a significant role when drawing conclusions or clinical recommendations.

Second, framework analysis is a qualitative technique that is sensitive to researcher bias (Lacey & Luff, 2001; Srivastava & Thomson, 2009). The literature suggests ways to minimise the risk of bias, including adopting a reflective stance and using an inter-rater reliability test between the primary and secondary data (Howell, 1992; Ritchie & Lewis, 2003). As the current study was part of a DClinPsy doctorate, there were insufficient resources to recruit a second-rater. To try and address this limitation, there was a use of supervision and joint discussions with another clinical psychologist.

Third, readers should take into consideration that the account provided by service users might be limited due to participants' characteristics and research limitations. The former relates to the aim of the study to represent service users who do not engage with services. Such service user group may also be reluctant to cooperate with researchers representing the health systems in general (Shaghaghi, Bhopal & Sheikh, 2011). In order to

overcome it, the study included the accounts of frontline staff members who have unique and consistent access to service users considered "hard to reach".

As it was easier to arrange interviews with staff members, these were conducted prior to service users' interviews. The order of the interviews has a great significance in framework analysis, as the identification of themes can start before all the material is gathered. The possible risk is therefore to obtain an unbalanced representation of the accounts that were collected, underrepresenting the service users' narratives. This risk still exists even though preventative measures were taken as part of the analysis (e.g. reflective supervision, continuous referral to raw data, and use of coding matrix).

Fourth, several limitations should be acknowledged regarding the development and use of service users' interview schedule. Service users were interviewed using the same questions for two distinct studies. Additionally, the majority of service users were interviewed by another researcher with a distinctly different research question. As semi-structured interviews allow interviewers to gain further information by asking open-ended follow-up questions based on their research aims, data related to the aims of the current study might be only partially represented.

It is important to stress that in the development of the service users schedule there was no consultation with Expert by Experience (EbE). It is possible that relying solely on expert therapists is insufficient when conducting research with a population considered "hard to reach". A pre-consultation with EbE about the development and delivery of the schedule could have elicited further meaningful accounts from interviewees. It could have also enriched the understanding of how to approach such individuals and possibly increased sample size.

Finally, it is possible that due to the small number of participants, staff members were subject to social desirability (Crowne & Marlowe, 1964) and therefore were cautious about criticising current practices, possibly due to the fear of being identified by their direct managers. This may have reduced data validity, reliability and generalisability for the wider population of frontline care professionals. In order to overcome these potential risks, Participant Information Sheet (Appendix E), Consent Form (Appendix G) and emphasising their right to withdraw at any time were incorporated to increase levels of confidence and control. Additionally, the use of semi-structured interviews gave participants a high level of flexibility to elaborate on issues that they felt comfortable to discuss (Fylan, 2005).

Additional factors that risked reliability and validity were self-selection bias (e.g. volunteering participants only) and the fact that all service users were women. Although epidemiological studies suggest a significant gender differences in DSH (more women than men; Bergen, Hawton, Waters, Cooper & Kapur, 2010; Carr et al., 2016; Thomas et al., 2013), the disproportionate selection in the current study limits the ability to generalise the results to the wider mental health population. It is important to stress, however, that the consistent narratives provided by the participants suggest a level of homogeneity.

4.4 Clinical implications

This study provided useful information regarding both clinical and organisational factors that sustain, and might even intensify, barriers preventing participation. There is thus a need to intervene systemically along both direct and indirect pathways.

One indirect intervention that can address the long waiting lists, as well as the unfamiliarity with psychological services (which are usually located outside the hospital), is by implementing psychological services at the same site as the emergency unit. Service users

would benefit from immediate psychological support in a familiar location, thereby reducing the anxiety involved with the unpredictability of new services they have limited knowledge of.

Another indirect pathway is for policymakers to consider the possibility of initiating additional 'in-between' services, where emotional but not medical support is given to individuals in crisis; if this emotional support is not given, it can lead to DSH and further stress on emergency services. There is some empirical support for the effectiveness of 'crisis houses', measured by the decreased use of A&E (Wood, 2016) and the fact that these facilities are cost-effective (Byford et al., 2010; Howard et al., 2010).

Crisis houses are also an alternative to inpatient admissions for other comorbid mental health difficulties (Thomas & Rickwood, 2013) and have been found to be effective for improving the level of functioning (Adams & El-Mallakh, 2009; Ryan, Nambiar-Greenwood, Haigh & Mills, 2011). Crisis houses are perceived by participants as qualitatively different from other crisis services (e.g. the 'Samaritans') because they provide a physical facility where personal connections can be made. As shared by one service user:

"At that point (at a time of crisis) I would usually call Samaritans and they were a bit more helpful, but I think it's nice to kind of see someone in person and speak face to face. If you keep going to Samaritans it's someone different each time. They can't build a relationship with you. It's difficult." (p. 7)

Attention should be given not only to finding creative ways to increase the willingness to participate but also to the mechanisms that will allow service users to maintain a long-term therapeutic frame. At the direct clinical level, the desire of service users for a

more flexible therapeutic frame that prioritises the 'process' over 'striving for change' (e.g. 'they ask me to change but how') should be acknowledged when intervening with individuals who display repeated DSH.

Participants shared their desire for a more 'personal and acceptable' therapeutic relationship, as mentioned by one service user who agreed to engage with mental health services after many years of reluctance:

> *"The only good thing I had in psychological services is a guy name E. He is doing something that sounds like 'free psychotherapy' or something like that. Not a fixed thing like CBT. CBT does not see you as a person or as an individual. These sheets are just for everybody."* (SU3)

One possible option that could be explored cautiously due to limited available evidence is shifting the goals of therapies from abstinence to harm reduction of self-injury. In contrast to harm prevention, an approach that adopts zero tolerance to any act of self-injury, harm minimisation practices the belief that when a coping mechanism is being prevented this contributes to its exacerbation (Pengelly, Ford, Blenkiron & Reilly, 2008). Harm minimisation thus allows for a limited degree of self-harming behaviour to occur while offering psychoeducation and alternative ways of coping (Spandler & Warner, 2007). It can be argued that this approach can promote flexibility and a less dichotomous perspective by prioritising 'process' instead of 'striving for change'.

Several studies suggest that such a shift may increase effectiveness by minimising the dropout rate (Birch, Cole, Hunt, Edwards & Reaney, 2011; Mangnall & Yurkovich, 2008) and promoting good rapport (Pengelly, Ford, Blenkiron & Reilly, 2008; Shaw & Shaw,

2012). However, an ethical dilemma arises when allowing some degree of harm to occur in order to reduce a possible larger extent of harm in the future (Sullivan, 2017). The subject of harm minimisation is still debatable within the UK (Triggle, 2006) yet some elements are already appearing in NICE guidelines for the longer-term management of self-harm (2011), where discussion of less damaging or destructive methods of self-harm with the service user are considered.

4.5 Future research

The use of a qualitative method in this study has provided a unique opportunity to investigate closely why individuals who display repeated DSH do not utilise psychological therapies that might minimise or even prevent re-admissions to emergency units. The material provided by the interviews elicited the need to address heterogeneity, which was prevalent mostly among the service users with regard to reasons for disengagement. Taking into consideration that all the service users in this study were female, future qualitative studies would benefit from a more balanced representation of both genders.

Likewise, increasing heterogeneity is necessary from the perspective of services. Future studies would benefit from exploring the views of crisis resolutions and home-based treatment teams which in charge of providing treatments for individuals who are experiencing psychiatric crisis in the community (Jethwa, Galappathie, & Hewson, 2007). Exploration of their perspective was unfortunately above the scope of the current study.

Additionally, this study focused solely on interpersonal factors that might serve as barriers. However, it did not focus on intrapersonal factors, which also might have a unique impact on disengagement. Further understanding of the connections between interpersonal

and intrapersonal factors is needed to achieve a more holistic understanding of the investigated question.

Following a further and more extensive qualitative exploration, as mentioned above, feasibility studies regarding the potential acceptability of new interventions should be investigated. These interventions should provide treatment that will take place at the same site as emergency services, and therefore address the need for centralised services.

4.6 Conclusions

Service users and staff members provided new and valuable information about the dynamics between repeated DSH and mental health provision. This study proposes that these dynamics sometimes fail to meet the unique needs and characteristics of both service users and emergency departments, resulting in insufficient use of preventative psychological interventions in the community. The findings suggest that future research should investigate alternative clinical interventions and organisational modifications, which will bypass the barriers identified in this study.

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Part Three: Critical Appraisal

Introduction

This paper provides a number of critical considerations of the study, outlined in part 2 of the thesis, which examined what inter-personal factors might prevent service users who engage in repeated DSH from accessing secondary psychological care. The study was intended to enhance understanding of the dynamic relationship between service users and healthcare systems by giving a voice to both sides. By adopting a systemic approach, which locates the problem within the relationship and not within the individual, the study aimed to enhance the existing literature and promote an initial feasibility examination of new psychological interventions.

I will review first the challenges and barriers to engaging with individuals who do not engage with health services and who are therefore considered a population often labelled 'hard to reach'. Second, I will describe some personal challenges of the interviewing process and how I attempted to manage them through reflexivity. And finally, I will focus on my literature review, outlined in part 1, and discuss the potential benefits for clinical psychologists of having a basic understanding of health economics.

1. **Research with individuals who do not engage with health services**

1.1 Challenges and barriers

Failure to collect data from a specific population can have a number of negative consequences for both research and clinical practice. It can threaten the external validity and generalisation of findings (Johnson, 1990), resulting in the exclusion from new treatments of groups whose needs are unrepresented through a lack of knowledge (Rogers, 2004) and opportunities to effectively target high levels of illness burden to be missed (Singh, Azuine,

& Siahpush, 2012). These potential negative outcomes emphasise the need to critically outline one of the main difficulties of this research: collecting sufficient data from a population which, by definition, has limited contact with health services.

The current literature identifies several potential reasons for individuals not participating in health research. These include fear of authority (Furimsky, Cheung, Dewa, Zipursky, 2008), suspicions about the concept of research (Rugkasa & Canvin, 2011), a clash of cultural beliefs (McGraw et al., 1992) and concerns regarding confidentiality, privacy and exposure (Choudhury et al., 2012). Additionally, studies have identified organisational components that can contribute to recruitment difficulties, such as healthcare professionals failing to adequately represent the importance of the research, hesitating to approach disadvantaged populations or not being able to develop sufficient trust because of high rates of turnover (Bonevski et al., 2014).

During the recruitment process for this research, almost half of the potential participants decided not to participate. The majority of them did not explain their decision. However, several participants did share some concerns that corresponded to fear of exposure and suspicions about the concept of research, especially the necessity to record interviews.

Additionally, the hesitation of staff members to approach individuals meeting the inclusion criteria was particularly apparent. In accordance with the findings of Bonevski et al. (2014), some of the frontline healthcare professionals who were part of the recruiting team in this study appeared to believe that the individuals in question had neither the ability, the social skills nor the intellectual capacity to be considered good candidates for the research. As a result, they tended not to offer them the opportunity of being interviewed, thus limiting the potential sample significantly.

1.2 Improving access

Fortunately, the available literature provides some action plans that can be implemented to increase rates of participation. Future research with individuals who repeatedly engage in DSH would benefit from integrating the following suggested recruitment plans.

First, Bonevski et al. (2014) recommend that researchers work with community organisations, which have unmediated access to under-represented populations, to create a form of 'Community-Research partnership'. Such a community-research partnership represents a shift in perceptions regarding engaging with a population that has limited contact with mental health facilities. This shift is best illustrated by the change in language both health and academic organisations use, preferring phrases such as 'populations that are difficult for researchers to access' or 'hidden populations' (Sydor, 2013). These changes are not only semantic, but emphasise the responsibility of organisations to obtain data that represent all clinical populations.

On a more practical level, this type of collaboration allows researchers as well as the organisations to benefit, in particular by learning from each other's expertise and increasing empirical knowledge about the target population (Benoit, Jansson, Millar, & Philips, 2005). It appears that even though this kind of convenience sampling might not represent the wider target group (i.e. people who tend not to engage with any form or support, whether governmental as secondary mental health services, or non-governmental as voluntary organisations), it could serve as a pragmatic solution to increasing sampling to some extent.

These changes go hand in hand with the clinical recommendations derived from part 2 of this thesis. For example, the empirical paper recommends that stakeholders consider

162

establishing 'crisis houses', safe facilities in the community for people experiencing emotional distress that could lead to self-harm. Such facilities already have empirical support (Howard et al., 2010) as an alternative to emergency services for emotional rather than physical interventions. Researchers and staff members working together in a non-medical facility have the potential to benefit from a fruitful partnership that can broaden access to these individuals by reducing the sense of threat of authority or suspicion about the concept of research.

2. Personal challenges of the interviewing process

The empirical paper was my first attempt at conducting qualitative interviews with those who engage in DSH. Unfortunately, it was a complex undertaking that gave rise to onerous emotional challenges that I did not expect to experience. I often felt distressed and hopeless after in-depth interviews with service users who presented with severe injuries, especially at a time of crisis, leading to an A&E admission. In this section, I explore the roots of those feelings, how they influenced the research process and my efforts to manage them through emotional processing and reflection.

2.1 Distress and anxiety during and after in-depth interviews

Conducting interviews in A&E proved to be an unexpected emotional challenge. I did not dedicate enough attention to preparing myself for work in such a high-tension environment, a place where I was exposed to the 'real world' sights and sounds of severe injuries and pain. Car accidents, cardiac emergencies and head injuries were only a few of the sights I encountered for the very first time.

Intense and unmediated physical encounters with life-threatening presentations were only part of the disturbing experience. Working long hours in A&E forces one to encounter

stories and narratives of hopelessness. Being around victims of violence, children in severe distress or the isolation and loneliness of the elderly became a weekly routine for me. The combination of physical exposure to injuries and the narratives of hopelessness stirred up complex personal memories in me about times when I myself had struggled with a life-threatening illness, almost 20 years ago.

Understandably, I found it almost impossible at times to maintain an attentive and reflective stance while interviewing service users in the middle of an emotional crisis. I felt overwhelmed and distracted from their narrative, and feared that it might sabotage the quality of my study. I became aware of that risk when I was interviewing one particular service user, whose description of hopelessness affected me greatly. Her words painfully described her, but also my, first awareness of hopelessness:

'And then I got really depressed, as I thought that they were going to save me but they just sent me home. Then obviously I got worse. I thought that they were going to save me. And then I understood that I wasn't going to be saved and that nothing was going to work out for me. I wouldn't be saved. Not even after admission. Afterwards, I just got worse and worse, overdosing again and again.'

The interviews were conducted at a very stressful time. Delays in data collection did not allow me to take a step back and process the fact that each interview was affecting me greatly. I tried to deal with this by being even more 'task-oriented', which unfortunately incurred further distress. I spoke with my friends and colleagues, and they helped me to understand that I needed to process things. I decided to bring my 'thesis life' into my private therapy—it was the only place where I could find a safe space to connect the past and the

present—and to take a pause from my other, non-work related, issues, the usual focus of my therapy. I believe that future researchers would benefit from coping in the same way.

2.2 Processing past traumatic experiences in order to deal with daily encounters with hopelessness

The impact of secondary exposure to distress was comprehensively covered as part of the clinical psychology doctorate course. We learned that the therapeutic process has a dual emotional effect, when the process of developing compassion requires therapists to identify with service users and with their emotional experience (Figley, 2002b). However, this process has a price, in that it consequently impacts upon therapists' own emotional experience at both a conscious and unconscious level (Newell & MacNeil, 2010).

The literature paints a comprehensive picture of the possible risks to the therapeutic process as well as to therapists' wellbeing (Hinderer et al., 2014). Among the various negative effects, I was especially concerned with 'compassion fatigue', a state of stress and preoccupation with the distress of service users through re-experiencing disturbing events and avoiding anxiety-provoking reminders associated with the service user (Figley, 2002). I had noticed how I needed to develop certain defences to keep myself distant and safe from the visions, sounds and stories that reminded me of my own painful experience of struggling with a life-threatening disease.

Fortunately, both the literature and the doctorate course emphasise the importance of noticing and dealing with the occurrence of compassion fatigue. Social and team support in the place where therapists encounter the distress (Munroe et al.,1995), enhanced supervision (Merriman, 2015) and other sources of self-care such as private therapy or social activities (Chaverri, Praetorius, & Ruiz, 2018) were mentioned as potential adaptive coping strategies.

Two kinds of support helped me throughout the emotional challenges of the interviewing process. First, I relied a lot on my partner in this research project. Having gone through it himself, I felt that he could understand the emotional burden, stress and pressure of working long hours in A&E. We set aside time for mutual processing, asked for practical help when the emotional stress was overwhelming, monitored each other's emotional state and used a lot of humour when necessary.

Secondly, I felt that even though we shared the same stressful working environment, our past experiences differed significantly. I felt the need to process my painful past and the sense of hopelessness that only individuals who have themselves encountered it can understand. There was no other place for me to process this heavy burden, and I did not want to risk distressing my research partner, and so I finally decided to introduce my private therapist to the experience that triggered my painful memories from the past. It felt secure and safe to allow the re-emergence of these feelings with a professional who was already familiar with a holistic picture of me as a child. It gave me a place to process my emotions, comforted by the notion that I would be contained, my therapist would be safe and that my distress would not affect those close to me.

Now that the research project is behind me, I am happy to admit that the support I received from both my research partner and my therapist was greatly needed. It allowed me to conduct high-quality interviews without being weighed down by concerns that my interviewees would be confronted by a detached and distant interviewer.

3. **Should clinical psychologists be familiar with the subject of health economics?**

In Part 1, I conducted a literature review on the cost-effectiveness of three leading treatments for EUPD. I was obliged to adopt a perspective that encompassed not only the

clinical effectiveness of treatments but also their economic aspects, a field about which most clinical psychologists have limited awareness. In other words, I was introduced, for the very first time, to the world of 'health economics' and to the striving of healthcare systems to gain optimal value for money by guaranteeing not solely the clinical effectiveness but also the low cost of healthcare delivery (Haycox & Noble, 2009).

At first, even though I was happy to rise to this unique challenge, I found it hard to understand what relevance economic knowledge had for a trainee clinical psychologist. I assumed that it might make sense in cases where the psychologist was also a member of higher management or an integral part of the process of decision-making. But as a third-year trainee with limited experience in clinical work, I often felt a bit lost and confused.

However, this attitude changed quite rapidly. I started to read up and educate myself on the crucial relevance of health economics to the daily practice of psychologists. For example, according to Baker, McFall, and Shoham (2008), in publicly funded healthcare systems the rising costs of treatments have great societal significance, with policymaking responsibility often being reassigned from clinical professionals to health economists or, in other countries, to insurers. The authors concluded that under these conditions, psychologists are losing their leadership role in public health decision-making processes (Baker, McFall, & Shoham, 2008).

The consequences of this trend can be seen in treatments that can be given without the need for psychologists. For example, there is a growing number of service users who receive treatment for mental health in the form of pharmacological interventions that can be administered by primary care medical practitioners (Mark, Levit, Buck, Coffey, & Vandivort-Warren, 2007; Zuvekas, 2005). At the same time, other professionals in secondary

care (the costs of employing whom compared with psychologists are significantly lower) can deliver psychological-informed treatments guided by treatment-manuals (Frank & Glied, 2006; Robiner, 2006; Tonga et al., 2016).

It became clear to me that efforts are being made to promote interventions that are considered cost-effective. Generally speaking, I learned that the cost-effectiveness of an intervention could be achieved in two ways: by increasing its clinical effectiveness, or by lowering its costs (see part 1 for cost-effectiveness calculations). I started to question where on that scale —which ranges from striving for lower costs on the one hand to striving for excellent clinical outcomes on the other—did the health systems of which I am a part of sit.

Unfortunately, because of my limited experience of working in the NHS I could only assume or hypothesise about what is prioritised by the services in which I have worked; as a trainee, one has limited access to information about decision-making processes and to asking questions about the cost-effectiveness priorities of stakeholders. I have therefore started to question what can be done to allow clinical psychologists access to the realm of the financially informed decision-making processes of health services. I believe that we can promote health economics education as part of the clinical psychology doctorate, thereby allowing clinical psychologists to have a crucial role in the decision-making process.

According to Browne (2017), due mainly to training focusing on work at the micro/meso level, clinical psychologists face several barriers that exclude them from contributing at the macro-level. Consequently, there is a growing risk of a 'policy-knowledge gap' among clinical psychologists (Hosticka, Hibbard, & Sundberg, 1983), especially in terms of the ways in which public health functions and the limitations within which it operates.

In her qualitative exploration of the influence of clinical psychologists at the macro-level, Browne (2017) suggested several fields that should be taught as part of the DClinPsy syllabus, including policies, applied psychology and a greater emphasis on leadership skills. However, the health economics aspect of future macro-level teaching appears to be missing.

I believe that the course should provide a broad introduction to the meaning and consequences of health systems working under the constraints of limited resources (Goodheart, 2010); and, to the logic behind the need for treatments to address both economic and clinical needs in order to allow all service users fair access to psychological interventions (Knapp, McDaid, & Mossialos, 2006).

Future clinical psychologists would also benefit from being introduced to the subject of health economics, and how it shapes the treatments provided by mental health services. I believe that the main methods of health economics, including cost-effectiveness, cost-utility and cost-benefit analyses (as presented comprehensively in part 1 of this thesis) should also be taught as part of research methods and statistics. Additionally, I believe that the course should teach about the different roles and unique contribution of all professions, including health economists, that take part in decision-making processes. Familiarisation and better understanding of other professions would hopefully help to promote healthier collaborations, as required in publicly funded healthcare organisations.

4. Conclusions

This thesis explored several dimensions relating to the phenomenon of repeated DSH, allowing a better understanding of the interpersonal barriers that service users face when engaging with psychological services in secondary care. In this critical appraisal, I reviewed the complexities involved in conducting a qualitative study on populations that

are hard for researchers to reach, and the negative ethical and clinical consequences that can occur when such complexities are not adequately addressed. New and more creative ways of engaging with hard-to-reach population have been suggested, such as creating new collaborations with services in the community that are less intimidating and hierarchical than are medical institutions.

I referred as well to the need to address the wellbeing of the individual researcher. By sharing my personal experiences, I gave an overview of the potential emotional difficulties that can accompany in-depth familiarisation with individuals who repeatedly DSH. I then went on to describe methods that future researchers can adopt in order to overcome them, including emotional processing with colleagues as well as more professional support in cases of secondary trauma.

The final reflection dealt with the question of whether health economics should be taught as part of clinical psychology training. By reflecting on my literature review, I made suggestions about what elements of health economics might broaden the perspective of future DClinPsy trainees, and how this might open up new paths to quality leadership and more significant contributions.

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Appendix A

Details concerning each individual's contribution to the joint research project

Part two of this thesis is a research study which was part of a joint project with fellow DClinPsy student Daniel Harris (Harris, 2019). Both Daniel and myself were involved with developing the study protocol and interview guides, recruitment, interviewing service users and interview transcription. Daniel interviewed approximately 70% of the service users, while I interviewed the remaining 30%, this in addition to all staff members (seven individual interviews and one focus group).

Daniel's project focused on intra-personal factors affecting individuals who repeatedly self-harm and the utilisation of psychological therapies in the community. His paper used thematic analysis, which is expropriative in nature. It allowed the investigation of new ways to understand the internal world of these service users, and in what ways do they shape help-seeking behaviours. In my study, I utilised Framework Analysis to understand interpersonal relationships between service users and mental health staff members, to investigate current policies and clinical practise, how they are being experienced by both sides, and the effects that they have on not being involved with psychological therapies.

Together, our independent studies compose one major project, examining what roles interpersonal and intra-personal factors play in the decisions of some service users who repeatedly self-harm to turn down psychological treatments.

Appendix B

Data Extraction Form

Authors:

Date:

Title:

Journal:

Part 1: Eligibility

Type of study

Quantitative: YES / NO

What design? Full/Partial economic evaluation

Type: Cost-effective / Cost- utility / Cost-benefit

Participants

Are the participants used have a diagnosis of EUPD/BPD?

YES UNCLEAR NO

Are all participants over the age of 10?

YES UNCLEAR NO

If you have answered NO to any of the questions please STOP HERE. If you have answered YES for all questions, please proceed to Part 2.

Part 2: Information About the Study

Characteristics of the study

Country?

Was the study funded and if so how?

Currency?

Price year?

Characteristics of the participants

Inclusion criteria (please describe)

Exclusion criteria (please describe)

Number of potential participants (i.e. those approached for inclusion)

Number who did participate, including reasons for exclusion

Demographic characteristics

Age range (mean, S.D.) of participants

Gender – number/% of males and females

Ethnicity of participants

Therapy type

DBT: YES / NO

Group included: YES / NO

MBT: YES / NO

Group included: YES / NO

SFT: YES / NO

Comparator: CBT/Psychodynamic/Systemic/Other

Outcome measures

What outcome measures were used?

Were these measures standardised?

Results of outcome data

Are significant differences reported?

Appendix C

The Consensus Health Economic Criteria list (Evers et al., 2005) and the Cochrane

Collaboration's tool for assessing the risk of bias (Higgins et al., 2011)

Appendix D

Participant Invitation Letter for Staff Members

Why do some people who repeatedly present to A&E with deliberate self harm not accept offered mental health support?

<u>Who are we?</u>

Our names are Daniel Harris (daniel.harris.16@ucl.ac.uk) and Itamar Cohen (Itamar.cohen.16@ucl.ac.uk). We are supervised by Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk). We are trainee clinical psychologists conducting research towards a doctorate in clinical psychology at UCL.

<u>Purpose of the Study</u>

Many people struggle with experiences of self-harm, for which they seek treatment and support from accident and emergency services. People who present to A&E for this reason are often offered support from a referral to mental health services. We know that for some people these services are not something that they decide to use. The aim of our study is to gain an understanding of people's reasons for choosing not to use mental health services, and how services could adapt in the future to help more people.

We plan to do this by speaking and listening to the people who are affected by this problem.

<u>Why you?</u>

We are looking to speak with staff from A&E and Psychiatric Liaison, as you will be likely to have had contact with the group we are interested in. We will be running a number of focus groups to hear about your experiences.

For any other information or if you would be interested in sharing your experiences and knowledge please contact Itamar Cohen (Itamar.cohen.16@ucl.ac.uk) or Daniel Harris (Daniel.harris.16@ucl.ac.uk).

Appendix E

Information sheets- Staff and service users

A. Information sheet for staff members

Why do some people who repeatedly present to A&E with deliberate self harm not accept offered mental health support?

Who are we?

Our names are Daniel Harris (daniel.harris.16@ucl.ac.uk) and Itamar Cohen (Itamar.cohen.16@ucl.ac.uk). We are supervised by Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk) We are trainee clinical psychologists conducting research towards a doctorate in clinical psychology at UCL.

Purpose of the Study

Many people struggle with experiences of self-harm, for which they seek treatment and support from accident and emergency services. People who present to A&E for this reason are often offered support from a referral to mental health services. We know that for some people these services are not something that they want. The aim of our study is to gain an understanding of people's reasons for choosing not to use mental health services, and how services could adapt in the future to help more people.

You have been invited to participate as you have been identified as someone who works closely with people affected by the issues we are investigating.

Do I have to take part?

No, participating in the study is entirely up to you and any decision you make will have no impact on any other aspect of your job role or career. Before you decide we would like you to read this sheet to understand why the research is being done and what it would involve for you. One of our team will be happy to answer any questions that you may have. You are welcome to take as much time as you need to read this sheet and consider whether you would like to participate in this research. Please feel free to talk to others about the study if you wish.

What would taking part involve?

The study will consist of several focus groups (guided discussions of the questions and issues) which will take up to 60 minutes. The focus groups will take place at IMPART, and we will attempt to run them during team meetings. If attendance is not possible, we will attempt to facilitate individual interviews at either your workplace or at UCL.

The interview will be recorded and transcribed for analysis. We are aware that some participants may prefer not to be recorded, therefore in one to one interviews there will be the option for only written notes to be taken.

Any information you have provided that may make you identifiable (locations, names, ages etc.) will be removed from transcriptions. It is possible that quotes will be included in a publication, however these will be completely anonymous.

After we have conducted all the interviews, the notes and transcripts will be analysed by the researchers, using a technique called framework analysis, to identify themes present across the interviews. This process will help us to understand the experiences of the participants in the research. Part of this process involves getting further feedback from you about the themes we have found. You will be given the option to be sent the themes that we have found and be asked for feedback. We will ask you at the end of the interview if you prefer the themes be sent by email, post, or not at all.

The results of the study may be published in peer reviewed scientific journals, internal reports, and conference presentations. These may form multiple publications. Any publications related to this research may contain fully anonymised quotations from the interviews.

Possible Risks

Due to the subject of the research, during the interview some questions may ask about subjects which are difficult to talk about. If you do not wish to answer a question, if you wish to take a break, or if you wish to end the interview at any point then you are free to do so and do not have to give a reason.

It is possible that some of the questions might elicit topics that involve criticism about the way the department functions, or disagreement regarding practices and management issues. It will be at your discretion to decide what you do and do not wish to share.

What if something goes wrong?

If anything goes wrong or you have any concerns related to your involvement in this study, then you can contact the principal investigator, Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk). Alternatively you can contact your most convenient Patient Advice and Liaison Service (PALS). The closest office is at Whipps Cross Hospital (0208 535 6438, WXpals@bartshealth.nhs.uk). Other PALS departments maybe be more convenient for you and their contact details can be found be going to www.nhs.uk, searching 'PALS' and selecting the top result.

Confidentiality and Rights

If you agree to take part in the study you will need to sign and date the 'Informed Consent' form attached. Your unique registration number will be used in any study documentation make sure you cannot be identified outside the trial. All information, which is collected, about you during the course of the research will be treated as strictly confidential.

Your legal rights will not be affected by agreeing to take part in or withdrawing from the study. You are free to withdraw from the study at any time without giving a reason. If you decide to withdraw from the study this will not affect the standard of your routine care in anyway.

You will be informed of any significant new findings that occur during the study as this may change your decision to continue.

Data Management Information

UCL is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The researchers will keep your name, and contact details confidential and will not pass this information to UCL. The researchers will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from UCL and regulatory organisations may look at your anonymised research records to check the accuracy of the research study. UCL will only receive information without any identifying information.

The researchers will securely store the anonymised data from this study for 20 years after the study ends, in order to ensure regulatory compliance. Any identifiable information (for example contact details and consent forms) will be destroyed at the end of the study.

The data protection officer is Lee Shailer (data-protection@ucl.ac.uk).

Further Information

If you decide want support with any of the issues raised in this topic then a directory of psychological therapy services can be found at https://www.nhs.uk/Service-Search/Psychological%20therapies%20(IAPT)/LocationSearch/10008 or you can speak to your GP. If you need access to emergency services then you can call 999 or go directly to your local A&E. To speak anonymously Samaritans can be contacted at any time on 116123. A variety of other helplines can be found at https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/.

All data will be collected and stored in accordance with the General Data Protection Regulation (GDPR).

This study has been reviewed and approved by West of Scotland Research Ethics Committee 3. [Project ID No]: **242128**

Why do some people who repeatedly present to A&E with deliberate self harm not accept offered mental health support?

Who are we?

Our names are Daniel Harris (daniel.harris.16@ucl.ac.uk) and Itamar Cohen (Itamar.cohen.16@ucl.ac.uk). We are supervised by Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk) We are trainee clinical psychologists conducting some research that we think you might be able to help us out with. We are running this study as part of training towards a doctorate in clinical psychology at UCL.

Purpose of the Study

Many people struggle with experiences of self-harm, for which they seek treatment and support from accident and emergency services. People who present to A&E for this reason are often offered support from a referral to mental health services. We know that for some people these services are not something that they want. The aim of our study is to gain an understanding of what factors make mental health services difficult or unappealing for some people, and how services could adapt in the future to be more accessible.

You have been invited to participate as you have been identified as someone who may have experience of the issues we are investigating.

Taking Part in The Study

We'd like to invite you to take part in our research study. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. We'd suggest this should take about 15 minutes. Please feel free to talk to others about the study if you wish. Your decision of whether to take part in the study will have no impact on any care or support to which you may be entitled.

What would taking part involve?

The study will consist of an interview by telephone asking about your experiences and views. This will last about 30 minutes. Initial questions will ask about your experience of being offered mental health services and psychological treatments, and factors affecting your decisions about those offers. Later questions will ask about what services could do to be more appealing to you. In compensation for your time you will receive a £5 voucher.

The interview will be recorded and transcribed for analysis. Any information you have provided that may make you identifiable (locations, names, ages etc.) will be removed from transcriptions. It is possible that quotes will be included in a publication, however these will be completely anonymous. Yet, we are aware that some participants can still feel uncomfortable with audio recordings. Therefore, a non-electronically recorded interviews will be offered to participants who would prefer not to be recorded electronically.

After we have conducted all the interviews, we will take an in-depth look at what people have said. Part of the process of doing this involves identifying common themes that have come up when talking to people. It can be helpful to get further feedback from you about the themes we have found. After the interview you will be asked if you wish to be involved in reading the themes we create and giving us any further thoughts you have. We will send everyone the themes, unless you ask us not to, but you do not have to provide feedback unless you wish to. We will ask you at the end of the interview if you prefer the themes be sent by email or post, or not at all.

Possible Risks
Due to the subject of the research, during the interview some questions may ask about subjects which are difficult to talk about. If you do not wish to answer a question, if you wish to take a break, or if you wish to end the interview at any point then you are free to do so and do not have to give a reason. Upon completion of the interview, whether you have ended it early or not, you will receive a the voucher as compensation for the time you have given us.

If during the telephone interview you wish to stop the interview we will ask you if you are ok, and if you are upset we will provide you with some ideas of how to manage using the distress sheet. We will then ask if you wish for us to ring you back at another time or if you do not want to have any further contact with us.

If during the course of the telephone interview you disclose anything indicating serious risk to yourself or another person then the interviewer may be obligated to contact emergency services on your behalf.

Confidentiality and Rights

If you agree to take part in the study you will need to sign and date the Informed Consent Form attached. Your unique registration number will be used in any study documentation make sure you cannot be identified outside the trial. All information, which is collected, about you during the course of the research will be treated as strictly confidential.

Your legal rights will not be affected by agreeing to take part in or withdrawing from the study. You are free to withdraw from the study at any time without giving a reason. If you decide to withdraw from the study this will not affect the standard of your routine care in anyway.

The Study has been reviewed and approved by (ETHICS COMMITTEE).

You will be informed of any significant new findings that occur during the study as this may change your decision to continue.

What if something goes wrong?

If anything goes wrong or you have any concerns related to your involvement in this study, then you can contact the principal investigator, Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk). Alternatively you can contact your most convenient Patient Advice and Liaison Service (PALS). The closest office is at Whipps Cross Hospital (0208 535 6438, WXpals@bartshealth.nhs.uk). Other PALS departments maybe be more convenient for you and their contact details can be found be going to www.nhs.uk, searching 'PALS' and selecting the top result.

Data Management Information

UCL is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep identifiable information about you for 3 months after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Dr Janet Feigenbaum.

The researchers from UCL will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. NELFT will pass these details to UCL along with the information collected from you. The only people in UCL who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

NEFLT will keep identifiable information about you from this study for 3 months after the study ends.

The data protection officer is Lee Shailer (data-protection@ucl.ac.uk),

Further Information

If you decide want support with any of the issues raised in this topic then a directory of psychological therapy services can be found at https://www.nhs.uk/Service-Search/Psychological%20therapies%20(IAPT)/LocationSearch/10008 or you can speak to your GP. If you need access to emergency services then you can call 999 or go directly to your local A&E. To speak anonymously Samaritans can be contacted at any time on 116123. A variety of other helplines can be found at https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/.

All data will be collected and stored in accordance with the General Data Protection Regulation (GDPR).

This study has been approved by X

[Project ID No]: **242128**

Appendix F

Contact details collection form

<p style="text-align: center;"><u>**Contact details collection form**</u></p>

<p style="text-align: center;"><u>**Project Title - Why do some people who repeatedly present to A&E with deliberate self-harm not accept offered mental health support?**</u></p>

This study has been approved by the West of Scotland Research Ethics Committee 3.

<u>Who are we?</u>

Our names are Daniel Harris (daniel.harris.16@ucl.ac.uk) and Itamar Cohen (<u>Itamar.cohen.16@ucl.ac.uk</u>). We are supervised by Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk) We are trainee clinical psychologists conducting research towards a doctorate in clinical psychology at UCL.

<u>Purpose of the Study</u>

Many people struggle with experiences of self-harm, for which they seek treatment and support from accident and emergency services. People who present to A&E for this reason are often offered support from a referral to mental health services. We know that for some people these services are not something that they decide to use. The aim of our study is to gain an understanding of people's reasons for choosing not to use mental health services, and how services could adapt in the future to help more people. For this research we are seeking to do one off interviews with people who may have experiences that enable us to better understand what reasons people may have for choosing not to use mental health services. The interviews may last for up to an hour.

<u>Why have I been offered this sheet?</u>

You have been offered this sheet as it is possible that your experiences and knowledge are relevant to questions that we are researching. If you provide your contact details then we will contact you in approximately one week to provide full information about the study. If we are unable to contact you or you choose not to participate in the study, your contact details will be destroyed.

<u>Confidentiality Information</u>

UCL is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already

obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The data protection officer for the study is Lee Shailer (data-protection@ucl.ac.uk).

Participants Statement

I have expressed interest in the study titled above and have consented to provide my contact details to the researchers so that they may contact me at a later date with further information about the study.

Name –

Phone number –

Email address –

Address –

Times and days that would be good to contact me –

Signature –

Date -

Appendix G

Consent forms

NELFT *NHS*
NHS Foundation Trust

Project Title - Why do some people who repeatedly present to A&E with deliberate self-harm not accept offered mental health support?

This study has been approved by the West of Scotland Research Ethics Committee 3.

Participants Statement

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Name of Researcher:

		Initial Here
1	I confirm that I have read the information sheet dated10/12/18 (version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3	I understand that interviews may be recorded (electronically or in written format) and stored.	
4	I understand that data related to my participation in the study will be stored for up to 3 months past the conclusion of the study.	
5	I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	
6	I understand that the results of the study may be published in peer reviewed scientific journals, internal reports, and conference presentations. These may form multiple publications.	

7	I understand that any publications related to this research may contain direct fully anonymised quotations from the interviews.	
8	I would like to be contacted to be provided with the themes from the study.	
9	I would like to be contacted to provide feedback on the themes from the study.	
10	I understand that if I withdraw from the study, the researchers will retain any information which they have already collected from me for inclusion in their data analysis.	
11	I agree to take part in this study.	

Name of Participant	Date	Signature

Name of Person taking consent	Date	Signature

<u>Researcher's Statement</u>

I ……………………………………………………………………..

confirm that I have explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits.

Signature -

Date –

Project Title - Why do some people who repeatedly present to A&E with deliberate self-harm not accept offered mental health support?

This study has been approved by the West of Scotland Research Ethics Committee 3.

Participants Statement

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

Name of Researcher:

		Initial Here
1	I confirm that I have read the information sheet dated 10/12/18 (version 1.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3	I understand that interviews may be recorded (electronically or in written format) and stored.	
4	I understand that data related to my participation in the study will be stored for up to 3 months past the conclusion of the study.	
5	I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.	

6	I understand that the results of the study may be published in peer reviewed scientific journals, internal reports, and conference presentations. These may form multiple publications.	
7	I understand that any publications related to this research may contain direct fully anonymised quotations from the interviews.	
8	I would like to be contacted to be provided with the themes from the study.	
9	I would like to be contacted to provide feedback on the themes from the study.	
10	I understand that if during the course of the interview I disclose anything indicating serious imminent risk to myself or another person then the interviewer has a duty of care to contact emergency services on my behalf.	
11	I understand that if I withdraw from the study, the researchers will retain any information which they have already collected from me for inclusion in their data analysis.	
12	I agree to take part in this study.	

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Person   Date   Signature
taking consent

Researcher's Statement

I …………………………………………………………………..

confirm that I have explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits.

Signature -

Date-

Appendix H

Interview Schedules

Interview Schedule – Service users

Hello, thank you for agreeing to speak with me today.

Researcher introduces themselves.

Before we begin can I please confirm that you have read the information sheet and consent form that you have been sent?

- Yes – continue
- No – offer to read the PIS and consent form out loud to the participant, ensure that the participant has access to the PIS and consent form and rearrange the interview for at least 24 hours later, with the explanation of giving them time to consider the content of the PIS. If participant requests to not reschedule the interview, continue as long as they have read or heard the full PIS.

Do you have any questions about any of the information you have been given, or about anything else related to the research?

- Yes – answer questions
- No - continue

Having read the information sheet and consent form are you happy to continue with the interview?

- Yes – Proceed to consent form
- No – End the conversation

If the interview is taking place over the phone

Thank you, before we begin I will read the consent form, which is the same as the one you were previously sent (adjust if the consent form was read to them on a previous phone call). After each item of the consent form I will ask if you do or do not consent to it. If you have any questions regarding the contents of the form I will be happy to answer them. If you would like any additional time to consider any of the contents, then I will be happy to reschedule the interview.

- If the participant consents to all items (excluding 7 and 8, which are not crucial to this stage of the study) proceed with the interview. If they do not, end the interview.

If the interview is in person

Thank you, before we begin the interview we will go through the consent form, which is the same as the one you were previously sent (adjust if the consent form was read to them on a previous phone call). Please take as much time as you need to read this consent form, signing all items that you consent to. If you have any questions regarding the contents of the form I will be happy to answer them. If you would like any additional time to consider any of the contents, then I will be happy to reschedule the interview.

- If the participant consents to all items (excluding 7 and 8, which are not crucial to this stage of the study) proceed with the interview. If they do not, end the interview.

All participants

Thank you. I'll just remind you that if at any time you wish to stop the interview, take a break or ask a question to please just let me know.

As you will have seen/heard from the information sheet, we are conducting the study to further our understanding of factors that prevent people from using current mental health services and also factors that might make them more appealing to someone like yourself.

Before we begin, I would like to remind you that if you want to take a break or stop the interview at any time, just let me know.

PART A

Please could you tell me about your experience of being offered support from mental health services during or following a visit to A&E.

> Possible Prompts and follow up questions – What were you offered? Who offered it to you? How was it offered? What was your initial reaction to being offered X? Did you google, ask anyone or read about the service?

When you were offered this support, what was your experience of the staff members involved?

> Prompts – Did you have ideas about what they were thinking? Did you find their attitude helpful or unhelpful? Was there anything they could have done differently that you would have preferred?

When you were offered the support, what did you imagine using it would be like?

> Possible prompts – What made you think that?

What, if anything, about the offer that was appealing to you?

Tell me about your what affected your decision of whether to take up the offer of support from mental health services.

> Possible prompts – Pros? cons? was it a difficult decision? Did you discuss it with anybody else? How confident were you in your decision? Did you know anything about the service that was offered to you? If so, what? Do you know anyone else who has used that service or anything similar to it?

What factors ultimately led to you choosing not to take up the offer of support from mental health services?

> Possible prompts – Did you have any thoughts about what other people would think if they knew about you using mental health services? What beliefs do you have about people who use mental health services? Is there anything about mental health services that worries you? Did you think that anything bad would happen to you if you used mental health services?

PART B

Part of why we are doing this research is to help us make services more appealing to people. What could have been done differently when you were offered support from mental health services to make you more likely to use them?

If there were a therapy group or mental health service that you might be willing to use, what features would that group have?

Prompts: Go through main points of concern mentioned previously, asking if they have any ideas about what, if anything, services could do to address that issue.

Are there any issues that you have mentioned that you don't think could be addressed by mental health services?

We also wanted to ask your opinion on some more specific aspects that we were thinking about.

Do you have a preference for, and by who, you were offered support?

What locations for a group would suit you?

-   Public? NHS location? Libraries? Health Centres? Community Centres?
-   What about X location makes it more appealing to you?

What times of day would suit you best?

-   What about those times works best for you?

If other formats of support (rather than face to face) were available such as email, telephone or online, would these be more or less appealing to you?

-   What about X makes it more or less appealing?

If you were offered self-help reading resources would these be appealing to you?

-   What about these makes them appealing/unappealing to you?

Interview Schedule – Staff Members and focus group

Questions and follow up prompts – to be used for focus groups or one to one interviews with staff.

Many people struggle with experiences of self-harm, for which they seek treatment and support from accident and emergency services. People who present to A&E for this reason are often offered support from a referral to mental health services. We know that for some people these services are not something that they decide to use. The aim of our study is to gain an understanding of people's reasons for choosing not to use mental health services, and how services could adapt in the future to help more people.

We would like to invite you to help us to understand the issues you encounter when you work with these people and what you think of how best to help these individuals. We will be interested to hear your perspective regarding the following subjects:

1.What are your views regarding repeated use of emergency facilities after an act of DSH? We will be interested to hear what do staff think about the reasons for repeated self harm? what are these individuals who self harm seeking by coming to A&E departments? How these are different for different types or severity of the injury?

2. What are your views regarding the reason why these individuals do not take up the help offered by mental health services? What are the barriers that might prevent their engagement? In what why are the characteristics/demographics of these individuals influence their refusal to engage with mental health services? are there administrative shortfalls that might affect it?

3. What are the cultural factors that might contribute to the refusal to take up the help offered by mental health services? what are the effects of a possible stigma, fear or shame?   How do you think might be best to overcome these?

4. How best to motivate people to take up an offer of help from a mental health service?

5. Can you think about practical useful information regarding facilitation of a useful future intervention that would target this population needs?

we are interested to hear your views about the nature of the facilities (NHS vs Community), characteristics of the facilitators, the level of the Intensity of prompts, suggestions for delivery (time of day, day of the week, weekend) and how to ensure confidentiality.

Appendix I

Letter of Ethical Approval

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow
and Clyde

Dr Janet Feigenbaum
Senior Lecturer in Clinical Psychology
UCL
Goodmayes Hospital, Barley Lane, Ilford
London
IG3 8XJ

West of Scotland REC 3
Research Ethics
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ
(Formerly Yorkhill Childrens Hospital)

Date	18 December 2018
Direct line	0141 232 1805
E-mail	WoSREC3@ggc.scot.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

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Dear Dr Feigenbaum

Study title:	**A qualitative investigation of factors affecting non-engagement with mental health services following repeated use of A&E for Deliberate Self Harm – from service user and staff perspectives**
REC reference:	**18/WS/0198**
Protocol number:	**18/0235**
IRAS project ID:	**242128**

Thank you for your letter of 11 December 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/WS/0198	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

███████████
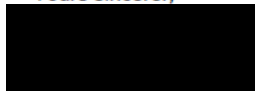
On behalf of
Mrs Rosie Rutherford
Chair

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments*
	"After ethical review – guidance for researchers"

Copy to:	Mrs Jessica Broni-Tabi
	Ms Fiona Horton, North East London Foundation Trust (NELFT)
	HRA.Approval@nhs.net

Appendix J

Initial index and coding

I: So is everything clear before we start?

C: Yes

I: Good

I: Let's see let's see. So first of all C I want to understand. Please could you tell me about your experience of being offered support from mental health services during or following a visit to A&E.

C: I had nothing offered from mental health services at all. I was offered nothing

Itamar	anger	
Itamar	not always being offer	

I: OK. And they didn't offer you any mental health support for the self-harm or for the personality disorder in the past.

C: In the past yes. I'm talking about months from now. But I will not do it again. You remember how I disclosed to you in AE how I was treated. And if that's similar to what you call psychological treatment then it was no good for me.

Itamar	feeling disrespected	
Itamar	I expect more	

I: So tell me exactly what you had been offered. How was it for you?

C: Not positive. Quite the opposite. My last treatment was absolutely devastating. I was interrupted by the manager of the mental health services. I didn't like this manager at all. There were a lot of incidents that I felt not listen to. We didn't understand each other. For example, I was asking him to leave the room when I was upset and he refused. And I know I can be sarcastic sometimes with the things I say. But he related to that as if I am making fun of him. He told me things like 'Listen C, don't go to AE so many times ,You need to think of other ways of dealing with how you feel'. It was hard to hear. So what I have done was to get myself safe in different ways. I had a problem with housing back then, so I moved to another location to be less stressed. I booked a room in an hotel, and told him 'look, I am following your guidelines

Itamar	Bad past exp	
Itamar	Not being listen to	
Itamar	Miscommunication	▼
Itamar	friction	
Itamar	I need to use defences to	▼
Itamar	Falling with translation	
Itamar	Your ways of dealing with things	
Itamar	Asking to change	
Itamar	Acting out the need to show it	

212

Appendix K

Initial charting of themes

		1	**2**	**10**
Why A&E?	"Hot potatoes"	Lines 59-61	Lines 4-11, 20, 37	Lines 90-96
-	Is it physical ? Is it MH?	Lines 54, 80	Lines 23	Lines 45-49, 50 - 53
-	exhausting services	Lines 70-73	Lines 24, 40	Lines 54-58
-	Familiar/validating environment	x	x	Lines 10-13, 17-30
	secondary gain	x	x	Lines 7-9
	Services fault	Lines 7	Lines 4	Lines 34-37, 40, 50-53, 70, 83-85, 96-100
Clashing forces	forced motivation	Lines 21, 53, 74-80	Lines 15	Lines 60-63, 80-83
-	"Your ways are wrong"	Lines 19-20	Lines 14	x
	"I don't trust you"	x	Lines 30, 70	x
-	SU asks too much of services	Lines 85, 105-110	Lines 6, 20	x
Services stigma	transparent people	Lines 18, 23, 114	Lines 22, 35, 40-50, 56	x
-	past pain	Lines 33, 52-55	x	x
What need to be change	Being, not changing	Lines 89-92	Lines 55, 80	x
-	everyone in one place	x	x	Lines 41-45, 85-90
-	reaching out	Lines 125, 130-140	x	x
-	Knowing the person	x	Lines 60, 85	Lines 90-95
	close, face to face, and convenient	x	Lines 60, 85	x
	chain of services	x	x	x

214

Appendix L

Final charting of themes

Superordinate themes	Subordinate themes		Participants	
		SU 1	**SU 2**	**SU 3**
All rivers run to A&E	"Hot potatoes"	Lines 59-61	Lines 4-11, 20-21, 37-38	Lines 14, 48
-	Practically falling between the chairs	Lines 7-12	Lines 4-5,	Lines 14, 22, 32-34
-	Reinforcing environment	x	x	Lines 10
-	"A quick fix"	x	Lines 23-24	Lines 22, 46
Expecting more of each other	"They ask me to change, but how?"	Lines 21, 53, 74-80	Lines 15-16	Lines 18, 32, 34
-	Mutual misunderstanding	Lines 85, 105-110	Lines 24-25, 40-41	Lines 14, 18
-	Fear of treatments	x	Lines 50, 56	x
Services hurt me	First encounter with emergency services	Lines 9-10	Lines 22, 35, 40	Lines 18
-	Painful experiences with other health services	Lines 33, 52-55	Lines 30, 70	Lines 38, 56, 64
What would I do differently?	Being instead of changing	Lines 89-92	Lines 55, 80	Lines 53
-	Centralised services	x	Lines 86-87	Lines 32
-	Chain of services	x	x	Lines 38
-	Being in touch	Lines 125, 130-140	Lines 60, 85	Lines 82 76 84

Superordinate themes	Subordinate themes	Participants		
		SU 4	SU 5	SU 6
All rivers run to A&E	"Hot potatoes"	Lines 14, 20, 28-2, 40-42	Lines 21-24	x
-	Practically falling between the chairs	Lines 40-42, 52)	Lines 45-47, 74, 96	Lines 24-28, 49
-	Reinforcing environment	x	Lines 87-90	x
-	"A quick fix"	x	Lines 73-75, 98	Lines 22-23
Expecting more of each other	"They ask me to change, but how?"	Lines 52 60 82-84	Lines 95-97	x
-	Mutual misunderstanding	Lines 20-24 ,50, 68	x	x
-	Fear of treatments	x	Lines 1-5, 5-6, 54-57	Lines 9-12, 53
Services hurt me	First encounter with emergency services	Lines 20 44 80	Lines 1-5, 6-7, 62	x
-	Painful experiences with other health services	Lines 20 44, 50-56, 62-66, 68	Lines 15-17	Lines 69-70
What would I do differently?	Being instead of changing	x	Lines 103-104	Lines 65-67
-	Centralised services	Lines 58-60, 94	x	Lines 87-88, 91-92
-	Chain of services	Lines 94-98	Lines 65-66, 121	Lines 85-87
-	Being in touch	Lines 106, 116	Lines 37-40, 110-112	x

Superordinate themes	Subordinate themes		Participants	
		SU 7	**SU 8**	**P1**
All rivers run to A&E	"Hot potatoes"	Lines 41-42, 48-52, 79	Lines 6-9, 20-21, 45	Lines 14
-	Practically falling between the chairs	Lines 2,3, 60, 83	Lines 25-28, 31, 36-37, 40-42	Lines 31-32
-	Reinforcing environment	Lines 53-54	Lines 50-54, 69-70	Lines 8-13
-	"A quick fix"	Lines 43-44, 55-56	Lines 12-15, 18-19	Lines 3-5
Expecting more of each other	"They ask me to change, but how?"	x	x	x
-	Mutual misunderstanding	Lines 2-3. 11-13, 52-56	Lines 10, 15-18, 31, 42-43	Lines 21-24
-	Fear of treatments	Lines 72-73	Lines 17-19	Lines 41-43
Services hurt me	First encounter with emergency services	Lines 2-3, 15-16, 51-52	Lines 2-3, 16-17, 64-66	x
-	Painful experiences with other health services	Lines 10, 21-22, 73-76	Lines 39-43	Lines 52-56
What would I do differently?	Being instead of changing	Lines 77, 88-89	Lines 71-75,	x
-	Centralised services	Lines 106-107	Lines 58-61, 63-64, 71-73	Lines 48-51
-	Chain of services	Lines 80-81, 102-103	Lines 81-84	Lines 57-63
-	Being in touch	x	Lines 77-78	Lines 38-39

Superordinate themes	Subordinate themes		Participants	
		P 2	**P 3**	**P 4**
All rivers run to A&E	"Hot potatoes"	Lines 90-96	x	Lines 98-101, 106-111
-	Practically falling between the chairs	Lines 34-37, 40, 50-53, 70, 83-85, 96-100	Lines 16-23, 35-40	Lines 49-52, 100-102
-	Reinforcing environment	Lines 17-30	Lines 83-86	Lines 2-4, 11-12, 16-21, 69-71
-	"A quick fix"	Lines 7-9)	Lines 76-80	Lines 12-15, 22-24
Expecting more of each other	"They ask me to change, but how?"	Lines 60-63, 80-83	x	x
-	Mutual misunderstanding	Lines 54-58, 90-95	Lines 92-97	Lines 25-27, 110-117
-	Fear of treatments	x	x	Lines 37-39, 55-56,
Services hurt me	First encounter with emergency services	Lines 61-62	Lines 1-3	x
-	Painful experiences with other health services	Lines 11-12	x	Lines 53-55
What would I do differently?	Being instead of changing	x	x	x
-	Centralised services	Lines 41-45, 85-90	Lines 4-5, 11-15	Lines 36-37, 91-95
-	Chain of services	Lines 47-51	Lines 49-51, 54-62	Lines 104-109
-	Being in touch	Lines 42-44, 98-100	Lines 33-35, 46-48	Lines 99-102

Superordinate themes	Subordinate themes		Participants	
		P 5	**P 6**	**P 7**
All rivers run to A&E	"Hot potatoes"	Lines 12-13. 120-126, 144-149	Lines 1-2, 4-7, 11	x
-	Practically falling between the chairs	x	Lines 9-12, 23-24	Lines 3-5, 10-11, 23-27
-	Reinforcing environment	Lines 4-5, 68-71, 79-83	Lines 34-35, 37, 41	x
-	"A quick fix"	Lines 1-3, 62-64,	x	Lines 32-35, 41-45
Expecting more of each other	"They ask me to change, but how?"	Lines 56-60, 140-144	Lines 50-53, 61, 71	Lines 54, 57-59, 90-93
-	Mutual misunderstanding	Lines 27-30, 33-40, 89-94, 105-109,	x	x
-	Fear of treatments	Lines 87-89, 116-120	x	Lines 66-69, 71-73, 75-79
Services hurt me	First encounter with emergency services	Lines 4-8, 93-98	Lines 42-48	Lines 1-4, 13-14, 19
-	Painful experiences with other health services	Lines 25-27, 134-137	x	x
What would I do differently?	Being instead of changing	x	Lines 63-66, 71	Lines 90-93
-	Centralised services	Lines 70-73, 100-103	x	Lines 82-85, 87
-	Chain of services	Lines 8-11, 15-24, 149-152	Lines 12-16, 80-81, 84, 87	Lines 82-84
-	Being in touch	Lines 83-87, 156-157	x	x

Superordinate themes	Subordinate themes		Participants	
			Focus group	
All rivers run to A&E	**"Hot potatoes"**		5-7, 50-53, 55-58, 60-62, 108-115, 205-213	
-	**Practically falling between the chairs**		17-22, 62-65, 77-80, 81-84, 106-108	
-	**Reinforcing environment**		1-4, 5-6, 7-8, 23-27, 70-76, 97-104, 108-112, 157-161	
-	**"A quick fix"**		11-13, 15-18, 65-69, 86-90, 151-152	
Expecting more of each other	**"They ask me to change, but how?"**		118-122, 124-128, 180-183, 191-193, 196-201	
-	**Mutual misunderstanding**		65-69, 91-96, 184-189	
-	**Fear of treatments**		30-33, 39-43, 48-50, 94-102, 132-136, 138-143, 145-149, 167-169, 174-180	
negative past experiences	**First encounter with emergency services**		18-21, 63-64, 181-186	
-	**Painful experiences with other health services**		161-164, 166-170	
What would I do differently?	**Being instead of changing**		65-70, 118-122, 123-128, 190-194	
-	**Centralised services**		247-249, 251-252, 266	
-	**Chain of services**		82-85, 247-249, 251-252	
-	**Being in touch**		207-213, 245-246, 254	

Appendix M

**Pie Graph and tables representing number of participants endorsing themes –
staff members**

Number of staff members mentioning each theme
N=7

- "Hot potatoes"
- Practically falling between the chairs
- Reinforcing environment
- "A quick fix"
- "They ask me to change, but how?"
- Mutual misunderstanding
- Fear of treatments
- First encounter with emergency services
- Painful experiences with other health services
- Being instead of changing
- Centralised services
- Chain of services
- Being in touch

	"All rivers run to A&E" (SU. 4)				Expecting more of each other			Negative past experiences		What can be done differently?			
	"Hot potatoes" (SU. 3)	Practically falling between the chairs	Reinforcing environment	"A quick fix" (SU. 8)	"They ask me to change, but how?" (SU. 1)	Mutual misconceptions	Fear of treatments	First encounter with emergency services	Painful experiences with other healthcare services	Being instead of changing	Centralised services	Chain of services	Being in touch
TRP 1	X		X	X	X		X	X			X	X	
TRP 2					X						X	X	
TRP 3	X	X	X	X		X	X	X	X	X		X	
TRP 4	X	X				X				X	X		
DC1				X								X	X
DC2	X	X	X			X	X	X					
DC3							X	X			X		X
CP1			X	X	X	X							
CP2	X		X	X			X	X	X	X		X	X
CP3	X	X	X				X	X					X

Table C. (continued)

CP4					X		X	X	X		X	X	X
CP5		X	X		X	X	X						
CP6										X	X	X	X
OP1			X	X	X			X	X	X			
OP2		X	X		X	X	X		X		X	X	X
OP3						X	X	X	X	X			X
OP4	X	X	X		X	X			X	X			

TCP= Trainee Clinical Psychologist; DC= DBT or CBT therapist; CP = Clinical Psychologist; OP = Other Professional

Appendix N

Pie Graph representing number of participants endorsing themes – service users

Number of service users mention each theme
N=8

Legend:
- "Hot potatoes"
- Practically falling between the chairs
- Reinforcing environment
- "A quick fix"
- "They ask me to change, but how?"
- Mutual misunderstanding
- Fear of treatments
- First encounter with emergency services
- Painful experiences with other health services
- Being instead of changing
- Centralised services
- Chain of services
- Being in touch

Appendix O

Letter to Participants to Disseminate Theme

Email to service users about themes

Dear X

I am emailing as you gave permission for me to contact you again following your interview with us about your experiences of being offered psychological support that you did with us on (DATE). You also told us that you may be interested in giving us some feedback on our findings. I have attached to this email a copy of the transcript from your interview and also a summary of the themes that we have extracted from the collation of all interviews conducted.

We would be grateful if you could read these and provide us with your thoughts on them. This can be done either via phone or email, whichever is more convenient for you.

If you are still interested in this, then please let us know and we can arrange a time to get feedback. If not, then you are under no obligation to complete this task.

If you have any questions please do not hesitate to contact us.

Best wishes, Daniel Harris and Itamar Cohen (Under the supervision of Dr Janet Feigenbaum)

Email to staff about themes

Dear X

I am emailing as you gave permission for me to contact you again following the interview/focus group that you attended on (DATE). You also told us that you may be interested in giving us some feedback on our findings. I have attached to this email a copy of the transcript from your interview and also a summary of the themes that we have extracted from the collation of all interviews conducted.

We would be grateful if you could read these and provide us with your thoughts on them. This can be done either via phone or email, whichever is more convenient for you.

If you are still interested in this, then please let us know and we can arrange a time to get feedback. If not, then you are under no obligation to complete this task.

If you have any questions please do not hesitate to contact us.

Best wishes, Daniel Harris and Itamar Cohen (Under the supervision of Dr Janet Feigenbaum)