Questionnaires used in complex trauma intervention evaluations and consideration of their utility for autistic adults with mild intellectual disability: a systematic review

Sarah Wigham[1], Iain McKinnon[2,3]

Keith Reid[2,4], Damian Milton[5], Ravi Lingam[2], Jacqui Rodgers[1]

Affiliations

[1]Population Health Science Institute, Faculty of Medical Sciences, Newcastle University, Baddiley-Clark Building, Richardson Road, Newcastle upon Tyne, NE2 4AX, United Kingdom

[2]Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust

[3]Population Health Science Institute, Faculty of Medical Sciences, Newcastle University, Wolfson Research Centre, Campus for Ageing and Vitality, Newcastle upon Tyne, NE4 5PL, United Kingdom

[4]Northumbria University Health & Life Sciences

[5]Tizard Centre, Department of Social Policy, Sociology and Social Research, University of Kent, Canterbury

Address for correspondence: Sarah Wigham

Abstract

Introduction: Research suggests some trauma symptoms e.g. avoidance are difficult to recognise in autistic people with intellectual disability while arousal/emotional and interpersonal difficulties may be useful signals. This review aims to (i) identify questionnaires used in general population complex trauma interventions to measure emotional and interpersonal difficulty and (ii) evaluate their psychometric properties to inform selection of a potential measure/s for use and/or adaptation for autistic people with mild intellectual disability and trauma related mental health conditions.

Methods: Stage 1: we searched Medline, Cinahl, Embase and PsycInfo for general population and clinical complex trauma intervention studies. Stage 2: we used a search filter in Embase to identify psychometric evaluations of relevant questionnaires used in Stage 1 studies and assessed these with the COnsensus based Standards for the selection of health based Measurement Instruments (COSMIN) checklist.

Results: five studies were identified in Stage 1 utilising three measures of emotion dysregulation and interpersonal difficulties. Thirty-three articles on their psychometric properties were identified in Stage 2. Strongest psychometric evidence was found for the Emotion Regulation Questionnaire (ERQ) and Difficulties in Emotion Regulation Scale.

Conclusions: Evaluating content validity/acceptability of the ERQ and DERS for autistic people with mild intellectual disability and trauma-related mental health conditions are useful next steps.

What this paper adds?

Questionnaires can facilitate information gathering, formulation and can be used to measure effectiveness of interventions for trauma-related mental health conditions. Questionnaires can also be used as outcome measures during clinical trials and so contribute to building an evidence base for clinical interventions for trauma-related mental health conditions. Current research and the evidence base on interventions for trauma-related mental health conditions in autistic people with intellectual disability is scant. In this review we identify and evaluate the psychometric properties of questionnaires used to measure emotional and interpersonal difficulties in general population and clinical complex trauma intervention evaluations. We focus on these questionnaires because research suggests that while some trauma symptoms e.g. avoidance may be difficult to identify in people on the autism spectrum with intellectual disability, emotional arousal and interpersonal difficulties may be useful signals. The review found strong psychometric evidence for the ERQ and the DERS. Useful next steps will be to evaluate acceptability and content validity e.g. during focus groups and/or cognitive interviewing to explore suitability of the ERQ and DERS for autistic people with mild intellectual disability and trauma-related mental health conditions. This paper contributes the preparatory work to inform selection of trans-diagnostic questionnaire/s with potential for future use and/or adaptation for autistic people with mild intellectual disability and trauma-related mental health conditions. These trans-diagnostic questionnaires could potentially have utility used in combination with the few trauma-specific measures currently available for people with intellectual disability e.g. the Lancaster and Northgate Trauma Scales.

1. Introduction

The purpose of this review is to address the limited availability of structured trauma assessments for autistic people with mild intellectual disability. We do this by reviewing self-report questionnaires used in general and clinical population complex trauma research in order to inform selection of one or more potential robust questionnaires for use and/or adaptation for autistic people with intellectual disability during research, screening or clinical formulation. This is important as trauma may be overlooked/missed in autistic people (Brewin, Rumball & Happé, 2019) and is a barrier to accessing appropriate support. Prevalence of autism is 1% of the population and is higher among people with intellectual disability (Brugha et al., 2016; MacKay et al., 2018). Research suggests autism spectrum conditions and intellectual disability may confer a susceptibility to experiencing adversities (Berg et al., 2019; Hoover, 2020). Most research to date on trauma and adverse life events considers autistic people and people with intellectual disability separately. For example, high levels of negative peer encounters relative to typically-developing peers was shown to be the experience of students and young people on the autism spectrum (Maiano, Normand, Salvas, Moullec, & Aimé, 2016; Sreckovic, Brunsting, & Able, 2014). Numbers of negative life events experienced by autistic adults (N=426) were elevated compared to those experienced by non-autistic adults (Griffiths et al., 2019). Similarly, a longitudinal cohort study indicated significantly higher exposure of adults with borderline intellectual functioning to childhood adversities and associated impact on mental health compared to peers (Hassiotis et al., 2019). Negative life events and adversities may result in trauma-related mental health conditions (American Psychiatric Association, 2013; WHO, 2018). Clinicians have reported difficulty identifying trauma in autistic adults with intellectual disability due to different expressions of trauma symptoms (Kildahl, Helverschou, Bakken, & Oddli, 2020b). Additionally, availability of trauma assessment methods and case recognition tools for autistic adults with intellectual disability is small, and

the further development of trauma resources for autistic adults with intellectual disability would be useful for using in combination with the few trauma-specific measures currently available e.g. the Lancaster and Northgate Trauma Scales (Wigham, Hatton and Taylor, 2011; 2021).

Trauma questionnaires can be used during screening and clinical formulation and also as outcome measures in research and their limited availability for autistic adults with intellectual disability can be a challenge to building an evidence base. Effectiveness of CBT for an adult on the autism spectrum with intellectual disability and PTSD was successfully evaluated in a case study using the Revised Child Impact of Events Scale (Carrigan & Allez, 2017; Smith et al, 2003). However robustly designed clinical trials of interventions for PTSD in autistic people (with/without intellectual disability) are lacking (Rumball, 2018). The need for multi-dimensional trauma-focussed clinical assessments for autistic people with intellectual disability has been identified (Kildahl, Helverschou, Bakken & Oddli, 2020b). Research suggests adaptations may be needed to trauma assessments, informed by a conceptualisation of trauma relevant to autistic people e.g. it may be that hyper/hypo-sensitivities interact with expression of trauma symptoms (Kerns, Newschaffer, & Berkowitz, 2015). A previous systematic review suggested DSM-5 PTSD criteria have utility for autistic adults with intellectual disability though some symptoms may be missed (Kildahl, Bakken, Iversen & Helverschou, 2019). Clinicians views on the presentation of PTSD in autistic adults with intellectual disability (n=18) were that avoidance and re-experiencing may not be easy to identify, while emotion regulation difficulties (e.g. negative mood, anger) and interpersonal difficulties (e.g. difficulty trusting people and a negative interpretation of people's intentions) maybe important indicators and could be easier to identify (Kildahl, Helverschou, Bakken, & Oddli, 2020a).

General population research also suggests outcomes of trauma interventions may be improved for people by addressing interpersonal complex aspects and features and also that the development of complex PTSD assessment methods and measures is required (Clifford et al, 2018). Complex PTSD comprises PTSD (re-experiencing, avoidance and arousal) and disturbances in self-organisation (emotion regulation difficulties, negative self-concept and relationship difficulties) and may result from multiple and interpersonal traumas (Maercker, 2021).

The aims of the two stage systematic review are to (i) identify questionnaires used to measure emotional and interpersonal difficulties in general and clinical population complex trauma research and (ii) evaluate their psychometric properties. The purpose of this is to inform selection of robust questionnaire/s for use and/or adaptation for autistic adults with mild intellectual disability and trauma-related mental health conditions. Such measures could be used during research, screening, and clinical formulation for autistic people with intellectual disabilities and trauma related mental health conditions.

2. Stage 1: Method

The review protocol was published on PROSPERO (Registration number: XXXXXXXX). The aim of stage 1 was identification of questionnaires used in studies evaluating interventions for complex trauma in adults.

2.1 Search Strategy and Inclusion Criteria

Search terms combining free-text and MeSH subject headings were adapted for each database and conducted in June 2020 and updated June 2021. Given recent diagnostic conceptualisation of complex PTSD we searched for studies published in the past 15 years using the following terminology: complex PTSD or PTSD with a complex presentation. We consulted a librarian and the PsycInfo search strategy is shown in Figure 1.

Figure 1 around here

We searched four electronic databases (Medline, PsycInfo, Embase and Cinahl) and bibliographies of relevant reviews. Inclusion criteria according to PICOS components (participants, intervention, comparator, outcomes, study design) are shown in Table 1. Sifting titles/abstracts was carried out by XX with 20% screened by XX, XX and agreement was 95%. Full text screening was by XX with 20% screened by XX, XX and agreement was 77%. Ambiguous articles were included; stage 1 selection process is shown in Figure 2.

Figure 2 around here

3 Stage 1: Results

Five studies using three questionnaires measuring emotion dysregulation and interpersonal difficulty met inclusion criteria and were selected for Stage 2 (Table 2).

Table 2 around here

4. Stage 2: Method

In Stage 2 articles evaluating the psychometric properties of questionnaires identified in Stage 1 were located using a formal search filter adapted for Embase (Terwee, Jansma, Riphagen, & de Vet, 2009). Stage 2 selection process is shown in Figure 3. Methods of evaluating measurement properties in each study were appraised by XX using the COSMIN risk of bias checklist covering content validity, structural validity, internal consistency, reliability, measurement error, criterion validity, hypotheses testing, and responsiveness (Mokkink et al., 2018; Prinsen et al., 2018). 10% of articles were rated on internal consistency and structural validity by a second reviewer and agreement was 83%. The results of each study were rated against criteria for measurement properties: sufficient (+), insufficient (-), or indeterminate (?). Evidence from articles on psychometric evidence for each measure was summarized and synthesized narratively.

5. Stage 2: Results

532 articles were identified and 33 studies were selected for data extraction. A description of findings for each questionnaire is described below. Study characteristics are shown in Table 3 and COSMIN risk of bias assessments in Table 4.

5.1 Emotion Regulation Questionnaire (ERQ) (Gross & John, 2003)

The ERQ is a 10-item questionnaire assessing strategies used for regulating emotions including changing thoughts/interpretations of emotional stimuli and inhibiting and/or controlling behavioural expressions of emotion. There are two subscales (cognitive reappraisal and expressive suppression). Six studies exploring the psychometric properties of the ERQ were identified. In the first study a two-factor structure was confirmed in a general population (n=252) sample 60 years of age and over (Brady, Kneebone & Bailey, 2019). Gender differences were found in the relationship between ERQ scores and positive/negative affect including a positive correlation between suppression of emotionally expressive behaviour and negative affect in men but not in women.

In the second study a 2-factor structure was confirmed in Portuguese women with cancer recruited via an online survey (Brandao, Schulz, Gross, & Matos, 2017). In this study differential functioning of items across age and type of cancer was evaluated using item response theory. Items were found to be consistent across groups and moderately/highly discriminant for each subscale construct. A limitation was the small sample size (n=204) for this type of analysis. 6-week test-retest and internal reliability of the subscales was good and aspects of construct validity demonstrated including significant correlations with alexithymia (Brandao, Schulz, Gross, & Matos, 2017).

The 2-factor structure was replicated in the third study using confirmatory factor analysis (CFA) of a Croatian version of the ERQ (Gracanin, Kardum, & Gross, 2019). Internal consistency of subscales was good (reappraisal a = .80; suppression a = .75). Suppression was

shown to be significantly higher in men than women and reappraisal higher in women than men (both $p<.05$). There was no relationship to age (Gracanin, Kardum, & Gross, 2019).

The fourth study found significantly higher scores in men than women on the ERQ suppression subscale ($p<.001$) among university students (n= 1188) (Melka, Lancaster, Bryant, & Rodriguez, 2011). The two-factor structure was replicated, subscale internal reliability was good ($a \geq .73$) and invariance in measurement properties of the ERQ was demonstrated across gender and ethnic groups (African and European American) (Melka, Lancaster, Bryant, & Rodriguez, 2011).

The two-factor structure and good subscale internal consistency ($a \geq .76$) across 3 different general population groups in Australia was demonstrated as were aspects of construct validity e.g. cognitive reappraisal was found significantly negatively correlated with alexithymia (Preece, Becerra, Robinson, & Gross, 2020).

Finally, in a study recruiting participants from Australia and the UK the 2-factor structure was found a better fit on removal of 1 item ('*When I want to feel less negative emotion [such as sadness or anger], I change what I'm thinking about'*) (Spaapen, Waters, Brummer, Stopa, & Bucks, 2014). Measurement invariance analysis showed equivalence in ERQ properties across both countries. Gender differences in scores were found with higher suppression scores in men than women and higher cognitive reappraisal in women than men and gender norms were derived (Spaapen, Waters, Brummer, Stopa, & Bucks, 2014).

5.2 Summary: Gender differences in ERQ scoring profiles were demonstrated across studies (e.g. men scoring higher in suppression and women higher for cognitive reappraisal), aspects of construct validity were demonstrated and there was consistent support for a 2-factor structure across different language versions and mostly general population samples and one clinical sample (oncology) of 100% women.

Table 3 around here

5.3 Difficulties in Emotion Regulation Scale (DERS) (Gratz & Roemer, 2004)

Twenty-three studies were identified evaluating psychometric properties of various versions of the DERS.

5.4 Original Version (DERS-36)

In the developmental study 36-items (DERS-36) measuring aspects of emotion dysregulation (acceptance of emotional responses, difficulties engaging in goals when upset, impulsiveness, emotion regulation strategies, emotional awareness and clarity) were found significantly associated with self-harm (Gratz & Roemer, 2004). The DERS-36 was forward/back translated into Brazilian-Portuguese and CFA confirmed a 6-factor structure and overarching factor in the general population; limitations of the awareness subscale were identified (Cancian, Souza, Machado & Oliveira, 2019). Medium/large significant positive correlations with depression symptoms were shown and subscale internal reliability was good (a = 0.79 to 0.88) (Cancian, Souza, Machado & Oliveira, 2019).

Acceptable fit for six factors, internal reliability and measurement invariance across demographic groups (gender and ethnicity) and correlations with trauma and dissociation were demonstrated for the DERS-36; however also (unexpectedly) correlations with anxiety and depression, anticipated to be predictors of discriminant validity (Ritschel, Tone, Schoemann, & Lim, 2015).

A six-factor structure was replicated in an Italian translation of the DERS-36 completed by students and women with eating disorders; there were correlations with alexithymia and significantly higher scores for the clinical sample (Giromini, Velotti, De Campora, Bonalume, & Cesare Zavattini, 2012). The original 6-factor structure for the DERS-36 was not replicated in a Hungarian translation among adults living with chronic pain, though the sample size (n=207) was small for CFA (Kokonyei, Urban, Reinhardt, Jozan, & Demetrovics, 2014). A forward/back translated 36-item Chinese version had a similar factor structure and subscales

(all α >.68) after excluding 4-items (Li, Han, Gao, Sun, & Ahemaitijiang, 2018). A 6-factor structure was found for the DERS-36 in a Turkish sample (excluding 1-item) and limitations of the awareness subscale identified (Ruganci & Gencoz, 2010).

Similarly, 5 and 6-factors were acceptable fit (Tucker Lewis Index = .91) for the DERS-36 among consecutive mental health inpatient admissions (Fowler et al., 2014). 63% of participants had major depressive disorder and 32% personality disorder. The DERS-36 correlated with depression, anxiety and somatization symptoms (Fowler et al., 2014).

Good internal reliability was found for a community sample diagnosed with generalized anxiety disorder (GAD) (mean age 68 years). A cut-score of 62.5 demonstrated sensitivity (.76) and specificity (.86) for GAD (Staples & Mohlman, 2012).

5.5 Abbreviated versions: general population

Limited clarity of DERS-36 reverse-worded questions led to developing a modified version with a consistent question format (the M-DERS) (Bardeen, Fergus, Hannan, & Orcutt, 2016). Exploratory factor analysis (n = 743) supported 29-items across 5-factors, and was confirmed with CFA in another sample (n=738) (RMSEA = .053). An over-arching higher-order emotion regulation construct indicated validity of the total score (Bardeen, Fergus, Hannan, & Orcutt, 2016). In a third sample (n=918) the 5-factor structure was replicated, subscales showed good internal consistency (*a* = .88 to .95) and as hypothesized correlated with anxiety, depression and avoidance (Bardeen, Fergus, Hannan, & Orcutt, 2016).

A better model-fit was found for the M-DERS than the DERS-36 (Benfer, Bardeen, Fergus, & Rogers, 2019). While limitations in the strategies subscale were found overall multidimensionality supported appropriateness of subscales as did internal reliability (all *a* >.91).

The factor structure of a short form (DERS-SF) was confirmed in general population adults (n=797) (Kaufman et al., 2016); and a 6-factor structure identified using a Greek

translation excluding 6-items (Mitsopoulou, Kafetsios, Karademas, Papastefanakis, & Simos, 2013).

Psychometric strengths of the DERS-16 and DERS-36 Brazilian-Portuguese versions were demonstrated in the general population (82% women) though indicated limitations with the DERS-36 awareness subscale (Miguel, Giromini, Colombarolli, Zuanazzi, & Zennaro, 2017). DERS-16 subscales correlated with alexithymia.

5.6 Abbreviated versions: clinical populations

The DERS-16 was positively correlated with the DERS-36, anxiety and depression symptoms, and one-week test-retest reliability was demonstrated in a clinical sample (Bjureberg et al., 2016). A 30-item version was predictive of eating disorders in Australian women and 6 subscales confirmed using CFA (a >.81) (Cooper, O'Shea, Atkinson, & Wade, 2014). The DERS-SF, DERS-16 & DERS-18, were compared for factor structure and measurement invariance across adults (n=1807) and adolescents in inpatient mental health settings (Charak et al., 2019). While a 5 or 6-factor structure was a good fit across all abridged versions, only the DERS-SF had scalar invariance across age (Charak et al., 2019).

Five and six factor models had acceptable fit for the DERS-18 in a sample of refugees (57% from Iraq or Iran) experiencing multiple traumas (Doolan, Bryant, Liddell, & Nickerson, 2017). Post-traumatic stress symptom severity was significantly associated with DERS-18 subscales (including lack of access to emotion regulation strategies and emotional clarity) (Doolan, Bryant, Liddell, & Nickerson, 2017).

A bi-factor model and measurement invariance across anorexia and bulimia nervosa diagnoses (n=857) was shown for the DERS-16 and DERS-36; and criterion validity for eating disorders was suggested though there was no control group (Nordgren, Monell, Birgegard, Bjureberg, & Hesser, 2020). Finally, the DERS-SF, 16 and 18 total and subscales all had good

internal reliability, and significant associations with symptoms of personality disorder, depression and anxiety (Skutch, Wang, Buqo, Haynos, & Papa, 2019).

Table 4 around here

5.7 DERS-Positive (DERS-P) (Weiss et al, 2015)

The DERS-P derived from the DERS-36 has 15-items measuring difficulty regulating positive emotions in three areas (i) acceptance of them (ii) impulsivity and (iii) goal-directed behaviour. Exploratory factor analysis identified three factors and two-items were excluded; aspects of construct validity were supported for the 13-item version including correlations with dissociation (Weiss, Gratz, & Lavender, 2015).

A 3-factor structure was confirmed for the DERS-P in clinical (bipolar disorder) and forensic and non-clinical samples; scores were correlated with alexithymia and significantly higher in those with bipolar disorder compared to all groups, and higher in the forensic than community sample (Velotti et al., 2020). Three factors were also confirmed for the DERS-P in student and trauma-exposed community samples recruited via an online platform; total and subscale scores were associated with self-report PTSD symptoms ($p<.001$) (Weiss, Darosh, Contractor, Schick & Dixon-Gordon, 2019).

5.8 Summary

There were between-study differences in findings regarding the DERS, and limitations with the emotional awareness subscale and reverse-worded items may have influenced this. However overall, structural validity (5 or 6 factors) was quite consistent, across different abbreviated versions, languages, general and clinical populations. Aspects of construct validity were supported with correlations to alexithymia, dissociation and trauma. There were also correlations with anxiety and depression but different interpretations of whether this demonstrated convergent/discriminant validity.

5.9 Inventory of Interpersonal Problems (IIP-32) (Horowitz et al, 2000)

The IIP-32 is a widely used screening questionnaire on distress arising from interpersonal interactions. A number of versions (127, 64 and 32-items) are available and we evaluated the 32-item version which has eight subscales. Four studies evaluating psychometric properties of the IIP-32 were identified. Studies recruiting participants in Spain and the Netherlands found an 8-factor structure (Salazar, Marti, Soriano, Beltran, & Adam, 2010; Vanheule, Desmet, & Rosseel, 2006). In the USA 2-components (Bailey, Abate, Sharp, & Venta, 2018) and 5-factors were identified (Bush et al., 2012). Variations in structural validity may relate to different statistical analyses (only two studies used CFA: Vanheule, Desmet, & Rosseel, 2006; Bush et al., 2012), small sample size (e.g. n=100) (Bailey, Abate, Sharp & Venta, 2018) and different recruitment sources including university (Bailey, Abate, Sharp & Venta, 2018), mental health inpatient (Bush et al., 2012) and outpatient services (Salazar, Marti, Soriano, Beltran, & Adam, 2010; Vanheule, Desmet, & Rosseel, 2006). Variations in structural validity findings for the IIP-32 may also relate to cross-study heterogeneity in participant characteristics including 100% women (Bailey, Abate, Sharp & Venta, 2018), 47% personality disorder (Salazar, Marti, Soriano, Beltran, & Adam, 2010) and 87% substance use disorder (Bush et al., 2012).

Good sensitivity (82%) and specificity (75%) for personality disorder compared to general population participants was demonstrated and one-month test-retest reliability (Salazar, Marti, Soriano, Beltran, & Adam, 2010). Evidence for construct validity was limited but may relate to comparator measures e.g. a 3-item social support measure (Bush et al., 2012).

5.10 Summary: All IIP-32 studies apart from one recruited participants from mental health settings and one study demonstrated evidence of criterion validity for personality disorder (Vanheule, Desmet, & Rosseel, 2006). Findings from construct validity testing were inconsistent. All studies demonstrated good subscale internal reliability (mostly $\alpha > .70$)

however variations in factor structure of the IIP-32 were identified across studies. This possibly related to cross-study differences in design, theoretical perspective and scoring differences (whether raw or t-scores).

6. Discussion

6.1 Study Findings and implications

In stage 1 of the review we identified questionnaires used in general and clinical population complex trauma research to measure emotion dysregulation and interpersonal difficulties. The reason for this being that research suggests arousal levels (e.g. anger) and interpersonal difficulties (e.g. insecurity around and negative interpretations of others) may be useful indicators of trauma in autistic adults with intellectual disability (Kildahl, Helverschou, Bakken & Oddli, 2020a). In Stage 2 of the review, we evaluated the psychometric evidence of the measures of emotion dysregulation and interpersonal difficulties identified in Stage 1. We found the most consistent evidence was for the Emotion Regulation Questionnaire (ERQ) and the Difficulties in Emotion Regulation Scale (DERS). Both the ERQ and the DERS demonstrated structural validity across a range of different recruitment sources and various clinical settings, different population groups, and a range of international settings. Evidence for structural validity was demonstrated using the full and abbreviated versions of the measures and the total and subscale scores. There was less consistent psychometric evidence for the IIP-32 and this may relate to fewer studies on the psychometric properties of the IIP-32 being identified, and heterogeneity in study design, including whether the raw scores or t-scores were used in the analysis. The review findings suggest that the ERQ and the DERS have potential for further research and development regarding their utility for autistic people with mild intellectual disabilities and trauma-related mental health conditions.

Trauma related mental health condition intervention and provision available for autistic people with intellectual disabilities is limited and an area of clinical health and social care

important to develop. This review contributes to this gap by identifying potential trans-diagnostic questionnaires for further evaluation and/or adaptation for autistic people with intellectual disabilities and trauma-related mental health conditions; including their potential use as part of a toolkit of resources in combination with trauma-specific measures such as the Lancaster and Northgate Trauma Scales (Wigham et al, 2011; 2021).

6.2 Strengths and Limitations

A limitation of the review is that we did not assess cross-cultural validity. We searched one database (Embase) in Stage 2 so articles from other databases are not included in the review. We focussed on complex PTSD and excluded studies on PTSD alone. However complex PTSD was only recently defined (WHO, 2018) and so there is some overlap in conceptualisation between PTSD and complex PTSD in the research reviewed. A strength of the study is taking a translational perspective by considering application and transfer of trauma-related mental health research findings from general and clinical population groups to autistic people with intellectual disabilities. The aim of this is to facilitate selection of tools for further evaluation and potential development to improve mental health outcomes for autistic people with intellectual disabilities and trauma-related mental health conditions.

A strength of the review is evaluating questionnaires (the ERQ and DERS) measuring trans-diagnostic constructs (e.g. emotion regulation) used in complex trauma research/interventions. This can be important for exploring the diagnostic formulation. The construct of emotion regulation is also a relevant component in developing adapted interventions for autistic people with co-occurring mental health conditions (Cai, Richdale, Uljarević, Dissanayake, & Samson, 2018; Weiss, Thomson, & Chan, 2014). General population trauma questionnaires often require naming an index traumatic event – the ERQ and the DERS do not require naming specific events. This is important because while avoidance is a symptom of PTSD, it may be difficult to identify in autistic people with

intellectual disability (Kildahl, Helverschou, Bakken & Oddli, 2020a). Therefore, items in trauma questionnaires about avoidance in reference to a traumatic event, may work less well for autistic people with intellectual disabilities. Additionally, the traumatic events experienced by autistic people with intellectual disabilities may be different to those experienced by the neuro-typical population (Botha & Frost, 2020; Milton & Sims 2013; Milton, 2016).

6.3 Future Research

Future research could explore whether the ERQ and DERS questions have sufficient content validity and/or whether/how wording requires adapting to increase relevance and accessibility to autistic people with intellectual disabilities. Further exploration of the ERQ and DERS with respect to any gender, age and scoring differences for autistic people with intellectual disabilities will be important. As will evaluation of comprehensibility of wording and response options and whether changes to wording and visual prompts would be useful to improve accessibility. We focussed on autistic people with mild intellectual disability and the findings will have less relevance for autistic people with moderate/severe intellectual disabilities though adaptation of the ERQ and DERS into observer report format could be a potential avenue to explore in future research.

6.4 Conclusions

The review findings suggest the potential of exploring utility of the ERQ and the DERS as trans-diagnostic measures for autistic people with mild intellectual disabilities and trauma-related mental health conditions. They could potentially be used in combination with trauma-specific measures (Wigham, Hatton and Taylor 2011; 2021). Important next steps are consultation and evaluation of acceptability, accessibility, comprehensibility and content validity of the ERQ and the DERS for autistic adults with intellectual disability and trauma-related mental health conditions.

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Table 1 Stage 1 Inclusion criteria

Inclusion criteria
Participants: adults (≥19 years of age) with life-course trauma/ life-course perspective
Intervention: interventions for complex trauma
Comparator: any
Outcomes: complex trauma symptoms; measure of emotion dysregulation and/or interpersonal difficulty
Study Design: cohort, before-after, controlled trials, prevalence studies
Peer-reviewed articles published in English after 2005
Exclusion criteria
Evaluations of PTSD interventions
Children; interventions for families/couples
Case studies, qualitative studies

Table 2 Stage 1 studies

Study	*Sample description and recruitment source*
Classen, Muller, Field, Clark, & Stern (2017)	Complex trauma: attendees of a mental health outpatient clinic program (n=54)
Clifford, Meiser-Stedman, Johnson, Hitchcock, & Dalgleish (2018)	Complex PTSD: sexual assault survivor clinical referrals (n=15)
Schlumpf, Nijenhuis, Klein, Jancke, & Bachmann (2019)	Complex PTSD: inpatient mental health service (n=28)
Mahoney, Karatzias, Halliday, & Dougal (2020)	Complex trauma (n=44) custodial setting
Classen et al., (2021)	Complex trauma (n=32) trauma therapy programme
Questionnaires	*Study*
Inventory of Interpersonal Problems (IIP-32)	Classen et al., (2017)
Horowitz, Alden, Wiggins, & Pincus (2000)	Classen et al., (2021)
Emotion Regulation Questionnaire (Gross & John, 2003)	Schlumpf et al., (2019)
Difficulties in Emotion Regulation Scale (Gratz & Roemer, 2004)	Mahoney et al., (2019)
	Schlumpf et al., (2019)
	Clifford et al., (2018)
	Classen et al., (2017)

Table 3 Characteristics of Stage 2 studies

Study	*Country*	*Sample (N)*	*Mean age years (SD)*	*N (% female)*
Emotion Regulation Questionnaire (ERQ) (Gross and John, 2003)				
Brady et al., (2019)	Australia & New Zealand	GEP	66 (NR)	252 (48%)
Brandão et al., (2017)	Portugal	Oncology	49 (7)	204 (100%)
Graˇcanin, Kardum & Gross (2019)	Croatia	Students/GEP	25 (10)	347 (72%)
Melka et al., (2011)	USA	Students	19 (3)	1188 (55%)
Preece et al., (2019)	Australia	GEP	49 (16)	1048 (60%)
Spaapen et al., (2013)	Australia & UK	GEP	39 (20)	1033 (72%)
Difficulties in Emotion Regulation Scale (DERS) (Gratz & Roemer, 2004)				
Bardeen et al., (2016)	USA	GEP	35 (12)	743 (54%)
			34 (11)	738 (49%)
			36 (11)	918 (68%)
Benfer et al., (2019)	USA	GEP	36 (11)	564 (59%)
			34 (12)	825 (61%)
Bjureberg et al., (2016)	Sweden	Personality disorder	25 (6)	96 (100%)
		GEP (trauma)	22 (2)	482 (100%)
		GEP (mood dysregulation)	24 (10)	102 (64%)
Cancian et al., (2019)	Brazil	GEP	34 (10)	377 (70%)
Charak et al., (2019)	USA	Inpatient mental health	35 (14)	1807 (48%)

Cooper et al., (2014)	Australia	GEP	19 (NR)	486 (100%)
Doolan et al., (2017)	Australia	Refugees/asylum seekers	36 (11)	147 (33%)
Fowler et al., (2014)	USA	Inpatient mental health	36 (15)	592 (51%)
Giromini et al., (2012)	Italy	Students	25 (7)	384 (78%)
		Eating disorders	24 (8)	76 (100%)
Gratz & Roemer (2004)	USA	Students	23 (5)	357 (73%)
Kaufman et al., (2016)	USA	Students	24 (6)	797 (60%)
Kőkőnyei et al., (2013)	Hungary	Chronic pain	52 (13)	207 (83%)
Li et al., (2018)	China	GEP	26 (5)	862 (59%)
Miguel et al., (2016)	Brazil	GEP	30 (10)	725 (82%)
Mitsopoulou et al., (2013)	Greece	GEP	37(14)	708 (57%)
Nordgren et al., (2020)	Sweden	Eating Disorders	26 (8)	857 (96%)
Ritschel et al., (2015)	USA	Students	21 (4)	1050 (75%)
Rugancı & Gençöz (2010)	Turkey	Students	22 (2)	338 (61%)
Skutch et al., (2019)	USA	Students	20 (5)	1181 (71%)
Staples & Mohlman (2012)	USA	GEP & GAD	68 (6)	74 (66%)
Velotti et al., (2020)	Italy	GEP (n=497);	39 (14)	1044 (12%)
		Bipolar Disorder (n=83)	47 (14)	
		Forensic (n=464)	39 (12)	
Weiss et al., (2015)	USA	Students	23 (5)	360 (73%)
Weiss et al., (2019)	USA	Students	19 (4)	229 (67%)

		GEP (trauma-exposed)	36 (11)	353 (58%)
Inventory of Interpersonal Problems (IIP-32) (Horowitz et al, 2000)				
Bailey et al (2018)	USA	Students	21 (2)	100 (100%)
Bush et al (2012)	USA	Inpatient mental health	35 (14)	1368 (49%)
Salazar et al (2010)	Spain	Mental health outpatient (190); GEP (66)	36 (NR)	256 (70%)
Vanheule et al (2006)	Netherlands	Outpatient mental health (382); students (287)	38 (17) 20 (2.4)	669 (76%)

NR: not reported; GEP: general population; GAD: generalised anxiety disorder

Table 4. COSMIN risk of bias assessments ~~Methodological quality~~ of articles in Stage 2

Article	*Internal consistency*	*Reliability***	*Content validity*	*Hypothesis testing*[A]	*Structural validity*	*Criterion validity*	*Responsiveness*
Emotion Regulation Questionnaire (ERQ) (Gross and John, 2003)							
Brady et al., (2019)	V (+)	--	--	V (+)	V (+)	--	--
Brandão et al., (2017)	V (+)	V (+)	--	V (+)	A (+)	--	--
Graˇcanin, Kardum & Gross (2019)	V (+)	--	--	V (+)	V (+)	--	--
Melka et al., (2011)	V (+)	--	--	--	V (+)	--	--
Preece et al., (2019)	V (+)	--	--	V (+)	V (+)	--	--
Spaapen et al., (2013)	V (+)	--	--	V (+)	V (+)	--	--
Difficulties in Emotion Regulation Scale (DERS) (Gratz & Roemer, 2004)							
	Version						
Bardeen et al., (2016)	M-DERS	V (+)	--	--	V (+)	V (+)	--	--
Benfer et al., (2019)	M-DERS	V (+)	--	--	V (+)	V (+)	--	--
Bjureberg et al., (2016)	DERS-16	A (+)	V (+)	--	V (+)	--	--	--
Cancian et al., (2019)	DERS-36	V (+)	--	--	V (+)	V (+)	--	--
Charak et al., (2019)	DERS-SF/16/18	--	--	--	--	V (+)	--	--
Cooper et al., (2014)	30-items	V (+)	--	--	V (+)	V (+)	--	--
Doolan et al., (2017)	DERS-18	V (+)	--	--	V (+)	V (+)	--	--

Fowler et al., (2014)	DERS-36	V (+)	--	--	V (+)	V (+)	--	--
Giromini et al., (2012)	DERS-36	V (+)	V (+)	--	V (+)	V (+)	--	--
Gratz & Roemer (2004)	DERS-36	V (+)	V (+)	--	V (+)	A (+) (EF)	--	--
Kaufman et al., (2016)	DERS-SF	V (+)	--	--	V (+)	V (+)	--	--
Kőkőnyei et al., (2013)	DERS-36*	A (+)	--	--	V (+)	A (+)	--	--
Li et al., (2018)	DERS-36*	V (+)	A (+)	--	V (+)	V (+)	--	--
Miguel et al., (2016)	DERS 16/36	V (+)	--	--	V (+)	V (+)	--	--
Mitsopoulou et al., (2013)	30-items	V (+)	A (+)	--	V (+)	V (+)	--	--
Nordgren et al., (2020)	DERS-16/36	--	--	--	--	V (+)	A (+) ED	--
Ritschel et al., (2015)	DERS-36	V (+)	--	--	V (+/-)	V (+)		
Rugancı & Gençöz (2010)	DERS-36*	V (+)	V (+)	--	V (+)	A (+)	--	--
Skutch et al., (2019)	DERS-SF/16/18	V (+)	--	--	V (+)	--	--	--
Staples & Mohlman (2012)	DERS-36	V (+/-)	A (+)	--	V (+)	--	V (+) GAD	--
Velotti et al., (2020)	DERS-P	--	--	--	V (+)	V (+)	--	--
Weiss et al., (2015)	DERS-P	V (+)	--	--	V (+)	A (+) (EF)	--	--
Weiss et al., (2019)	DERS-P	V (+)	--	--	V (+)	V (+)	--	--

Inventory of Interpersonal Problems (IIP-32) (Horowitz et al, 2000)

Bailey et al., (2018)	A (+)	--	--	A (+/-)	A *(n=100)* (+)	--	--
Bush et al., (2012)	V (+)	--	--	A (+/-)	V (+/-)	--	--
Salazar et al., (2010)	V (+)	A (+)	--	--	V (+)	V (+) PD	--
Vanheule et al., (2006)	V (+)	--	--	--	V (+)	--	--

Key: rating against criteria for good measurement properties (sufficient (+) / insufficient (-) / indeterminate (?); quality rating: V: very good, A: adequate; I: indeterminate; COSMIN rating not evaluated: --; *modified version; **test-retest; PD: personality disorder; GAD: generalised anxiety disorder; ED: eating disorder; [A]: clear description of comparator measure; statistical method appropriate; ≥50% of hypotheses confirmed; EF: exploratory factor analysis; M-DERS: modified DERS; DERS-SF: DERS-short form.; DERS-P: DERS positive

1	exp posttraumatic stress disorder/	56487
2	complex.mp.	1428589
3	1 and 2	2858
4	exp therapy/	6731361
5	treatment.mp.	5853390
6	intervention.mp.	897978
7	4 or 5 or 6	9742127
8	3 and 7	1661
9	exp prevalence/	718947
10	rate.mp.	2743523
11	9 or 10	3345253
12	5 or 6 or 11	8562927
13	7 or 11	11369818
14	3 and 13	1818

Figure 1. Stage 1 Search Strategy in PsycInfo

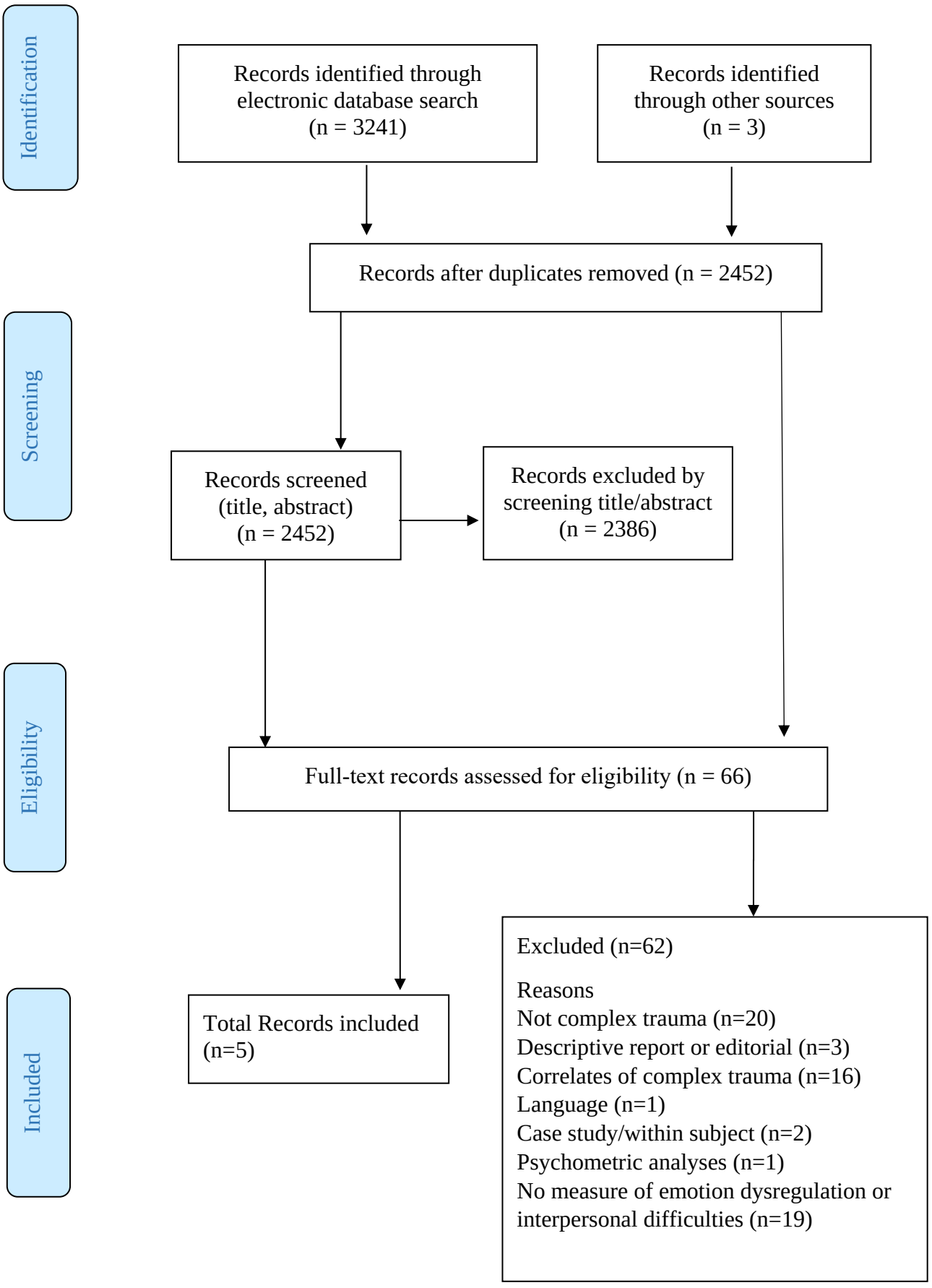

Figure 2. Stage 1 PRISMA Flowchart summary of selection process

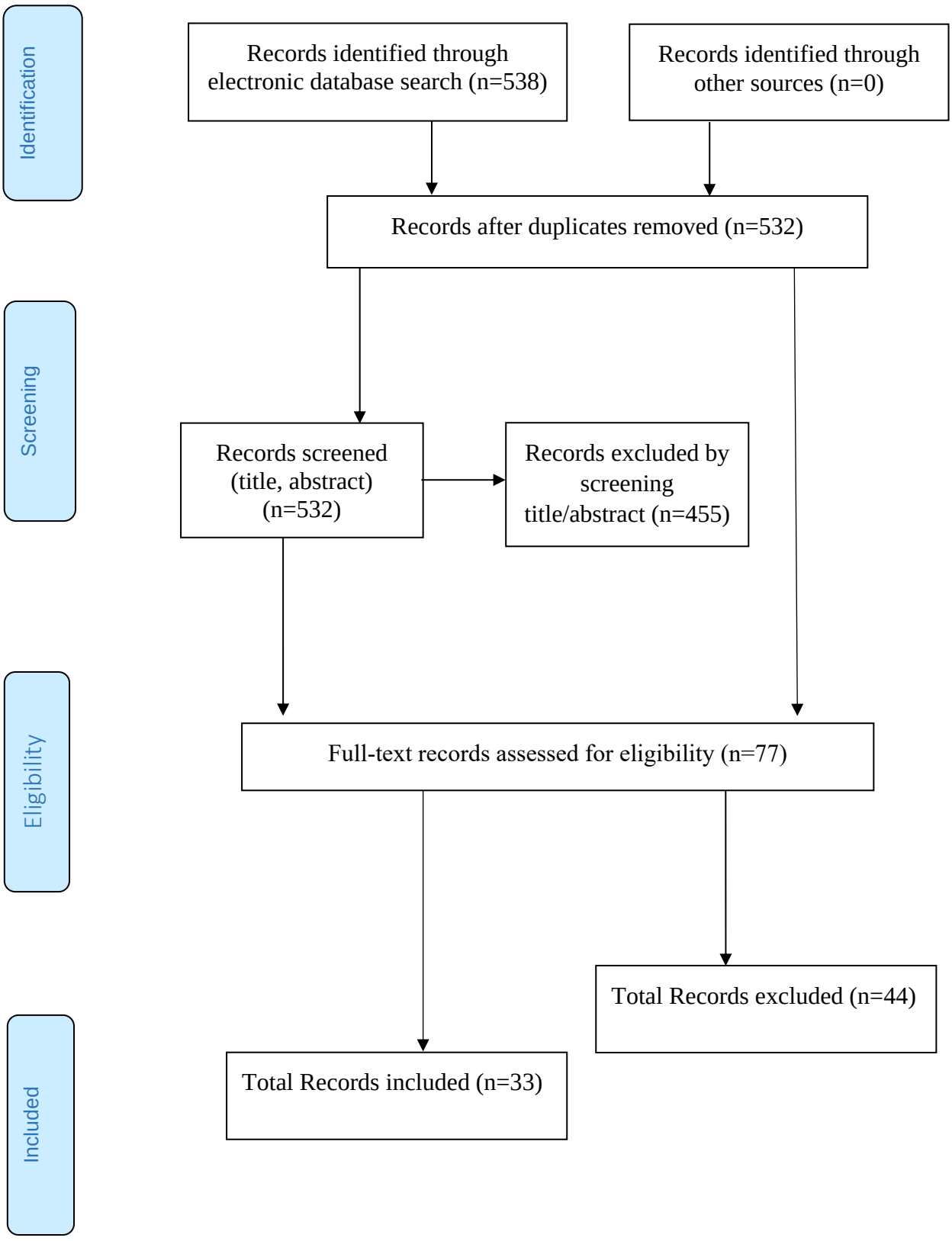

Figure 3. Stage 2 PRISMA Flowchart summary of selection process