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Research Article

The Distress Screening Tool: An Outcome Measure in the Work with Looked after Children and Unaccompanied Asylum Seeking Minors

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Abstract

In the UK a third of young people have experienced traumatic events (TE) and 7% of them develop PTSD. Early trauma experiences are also linked with changes in the brain structure and its pathways. Unaccompanied asylum seeker children (UASC), care leavers and looked after children (LAC) are among those who experienced a majority of ongoing traumatic events throughout their lives.

The Distress Thermometer (DT) was first introduced by NCCN as a screening for patients who were diagnosed with cancer. Recently, Draper and Marcellino [1] described the use of the Distress Screening Tool (DST) in their clinical work with unaccompanied asylum seekers children (UASC). In this work the tool helps to assess the emotional health of young people during times of potential distress in a non-pathologizing way. Our results clearly highlighted that, in a situation of ongoing trauma, the DST had the efficacy to decrease the level of distress and to capture any change.

Keywords: *Complex Trauma; Looked after Children; Unaccompanied Asylum Seeking Minors; Distress*

Introduction

According to the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-V, 2013) [2] traumatic events (TE's) are incidents of individual exposure to 'death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence'. Worldwide more than two-thirds of children reported at least one TE in their lifetime before they turned 16, with 13% of the population developing some Post Traumatic Stress Disorder (PTSD) related symptoms [3]. In comparison, a recent UK representative cohort study found one third of children reporting a TE, with 7% experiencing PTSD by age 18 years [4]. However, with the recent COVID-19 pandemic organizations have reported an increase of child abuse cases [5-7], with current data possibly being under representative due to cases being unreported and untreated due to school closures, hospital avoidance and disruption of child welfare services [8,9].

These sobering data predicts a possible crisis and need for trauma informed care in the coming future. Especially since research has repeatedly documented how experiencing trauma acutely or for long periods can impact the structure and wiring of the brain, forming new pathways of encoding [10]. Causing the brain to be highly sensitive to possible triggers due to exposure to this survival state, altering

the emotions and body [10,11]. Continuing a risk of a feedback loop reinforcing the neural pathway and maintaining further construction [12].

Common areas related to these commonly affected neural pathways are the amygdala, prefrontal cortex, and the anterior cingulate cortex. There is evidence that young people exposed to violence have a smaller hippocampal and amygdala volume and this increases vulnerability to depressive symptomatology [13] and is associated with behavioural problems [14].

Studies also demonstrate that childhood trauma is associated with inhibitory control and stress-related anterior cingulate cortex activation [15].

The distress screening tool

The Distress Thermometer (DT) was first introduced by National Comprehensive Cancer Network [16] as a screening for patients who were diagnosed with cancer. NCCN [16] described the DT as a single-item tool that goes from 0 (no distress) to 10 (extreme distress) point likert scale with a cutoff of 4 [17]. The DT has been validated using the Hospital Anxiety and Depression Scale (HADS) which is a reliable and valid tool for identifying and quantifying depression and anxiety [18].

Subsequently, Draper and Marcellino [1] described the use of the Distress Screening Tool (DST) in their clinical work with unaccompanied asylum seekers children (UASC). The Distress Screening Tool (DST) is described to be a tool used to assess the emotional health of young people during times of potential distress (e.g. before travelling). Draper and Marcellino [1] reinforced the idea that this is a non-pathologizing screening tool that detects the distress levels of a young person by using a thermometer. This tool was adapted in order to best fit the needs of UASC where contextual factors were considered. The DST aims to assess the emotional health and wellbeing of each young person during times of transitions e.g. moving to new placement, changing school, having contact with family.

There is often a theme of disempowerment when working with looked after children and unaccompanied asylum seeker children. Both cohorts of young people experience the institutions (e.g. host country or council/social services) as those who hold the power 'against' them. In this relationship of power imbalance, trust is difficult to be made. The DST aims to be a relational tool that professionals can use with young people rather than an assessment to perform on them. It is based on trust and relationship between two parties that are keen on working together. This tool, therefore, works on a variety of levels: one being relational and part of a shared decision making process; two being solution focused which enables the practice of mastery and control; three it can be used across the whole system, therefore it increases the communality of language as well as partnership working.

The distress screening tool and neuroplasticity

We know that children such as UASC and looked after (LAC) have experienced a significant number of adverse childhood experiences that may have impacted on their brain structure. It is therefore fundamental for clinicians who work with them to understand this impact and also support them to create new neural pathways from which the young people can thrive.

When a young person has experienced several distresses throughout their life, their brain is likely to trigger well-known pathways in order to 'survive' and sometimes the brain is stuck in this automatic response and struggles to switch it off. The main trauma responses are: freeze, fight, flight and fawn [19].

In 1890 James William [20] discovered that our brain has the capacity to make novel pathways and therefore changes due to its plasticity. Neuroplasticity means that the brain can make adaptive structural and functional changes [21]. An ability of our brain that appears to be present throughout the whole life stages [22] with a significant responsiveness and prominence in young brains [23].

It is therefore important as practitioners to preempt trauma responses which often occur during points of transition and punctuation in which we can support the brain to use the cognitive aspect of its ability rather than going into an automatic trauma response.

The institute of family therapy described transitions as points in individual families and systems from which change is occurring such as leaving, separation, divorce, and significant life events that form a state of uncertainty and raise anxiety [24].

Punctuations are understood as events that mutually influence one another, they are a complex way of interaction and support the examination of individual steps of the behaviour in response to a punctuating event [25].

The experience then becomes about the potential we have to make change happen and manage the distress we are experiencing. It also positions the child as an expert in their own life and knowing what works for them, what they can and are able to do. In being curious with lots of questions about the distress and what makes a difference that new realisations can take place and solutions found. In supporting the young person to develop their own distress management and solutions, they can start to embed this new pathway so that they can access solutions to problems or difficulties, which in turn reduces the distress they will experience.

This way of working is recursive at the point of transition and punctuation from which the brain pathways become established.

There is also an element of psychological construction approach in the DST as it supports young people to perceive events as constructed rather than fixed [26]. In this, a physiological arousal is interpreted as a sign that the person is ready to perform rather than indicating a threat to avoid [27]. The DST incorporates the research fundings about emotional granularity which is an aspect of emotional expertise and it refers to the ability to experience emotions in a precise and context-specific manner [28]. The DST helps young people to become granular individuals who make fine-grained differentiations in their emotions and categorise them. Without this ability, ineffective and indistinct responses may be performed across context with a negative impact. An extended emotional language refines the ability to categorise emotions (e.g. angry, happy, annoyed, furious) which then are associated and regulated in the context (e.g. letting go, going out).

It is only in the practice of constructed agency that a young person would be able to move from responding to imminent threat with all the behavioural difficulties that arise, therefore the use of the DST becomes part of constructing and managing the emergent meaning in the perceived event.

Context for present study

Within the UK mental health context there is a focus on personal recovery where individuals can live meaningful lives in the presence of ongoing distress [29]. Recovery is a unique and personal experience and yet studies have shown that recovery is more likely to occur when people experience relational connectedness, hope, renewed identity, meaning making and empowerment [30].

The present study reports clinical work with 18 young people (2 looked after children, 15 unaccompanied asylum seeker children and 1 care leaver) aged between 8 and 22.

This study explored the efficacy of using the Distress Screening Tool [1] in a group of young people who experience ongoing distress such as looked after children (LAC) and unaccompanied asylum seekers children (UASCs).

The young people were referred to the study by their social worker in Portsmouth. The clinical criteria for referral were the following:

- Difficulty in concentrating and learning,
- Easily distracted,

- Often does not seem to listen,
- Disorganised,
- Hyperactive,
- Restless,
- Difficulty in sleeping,
- Nightmares
- Antisocial behaviours.

Methods

The Distress Screening Tool was administered as part of the Trauma Informed Model of Care (TIMoC) which is based on the work described by Draper and Marcellino [1] in the chapter 'An early intervention framework for the emotional health and wellbeing of unaccompanied minors'. Draper and Marcellino have been consulting, supervising and supporting the development of this way of working across the system in Portsmouth. All staff, including social workers, foster carers, educators, housing staff etc. have been trained since 2019.

The data used in this research has been gathered as part of an audit process and its existing data within a social care setting, thus, none of the participants were recruited to a study but rather were receiving implemented trauma informed care which was established across the whole system. Therefore, ethics approval was not required for this paper. We utilised an online NHS decision tool to ascertain whether our study was classified as research. This tool indicated that our study was not considered research and did not require ethical approval within the trust (UK Medical Research Council Health Authority).

Within this study the DST was administered and as per individualised needs was re-administered within a period of 1 and 19 months from which the solution focused plan was actioned. The distress screening tool was then repeated to see if there was any change in the level of distress.

First phase: The distress screening tool Draper and Marcellino [1] helps us to rate the level of distress from 0 to 10 experienced in the past week as well as the ability to break down the distress through the problems list. As part of the process it is important to consider future distress free possibilities. In doing this the young person can start to think about the plans they can make, the people they can recruit to support them and the things that are needed to enable them to manage the punctuation and transition that is taking place.

In this phase, the young person is supported to name their emotions and differentiate them. This process will support them to experience emotions in a precise and context specific manner, through the emotional granularity [28,31]. This will benefit the young person in understanding and engaging in specific actions that are beneficial in particular circumstances, including actions aimed to regulate their own emotion [32,33].

Second phase: It proceeds with the ability to break down the distress through the problems list. It therefore incorporates potential stressors such as spirituality (loss of pace, loss of hope, loss of spiritual practice and/or community, unhappy with how living life), family (e.g. bereavement, loss of contact with family, concern about family safety), emotional (e.g. fear, anxiety, nightmare, hypervigilance) and

physical (fatigue, sleep, indigestion and constipation). Young people are encouraged to think about any other potential stressor they may have experienced in the past week.

Third phase: The DST also incorporates a solution focused process which supports the young person to gain a sense of control and agency over their emotions and actions. It promotes their capacity to learn how to recognise, name and manage their distress and how to identify what support they would need to reduce their distress.

There are 3 key principles [34] when working in a solution focused way which are: if it isn't broken, don't start fixing it; once you know what works, do more of it; if it's not working, do something different.

Results

The 18 young people who participated in this study are constantly triggered by multiple stressors including going through the asylum claim, change placement, being removed from their families, learning a new language.

A t test was carried out in order to understand whether there was a decrease of their level of Distress in the learning they were doing from constructing their own responses rather than being fixed into a trauma response. The aim was to see whether the DST captured this change in experience through a distress narrative.

The main transitions and punctuations pre-DST were: loss and grief; bereavement; family safety; sleep; loss of family; moving to London; getting angry; nothing to do; unhappy with the placement; anxiety; missing family.

N	DST pre-intervention M(SD)	DST post-intervention M(SD)
18	5.00 (2.28)	3.44 (2.28)

Table 1: *Pre and post intervention DST scores.*

The results showed that the difference between the pre-treatment and the post-treatment was significant at a level of $p < .0479$ ($t = 2.0526$ $DF = 34$) with distress levels decreasing.

Descriptions given by the young people post-DST intervention work were: doing well; happy to be talking to their mum; more happy and waiting for his interview; everything is going well; the young person likes his bedroom and house.

Despite the statistical change, young people were still able to describe their distress level as part of the ongoing process from which the DST is used.

Discussion and Conclusion

In this study, 18 young people with trauma-related presentations completed the Distress Screening Tool (DST) over a period of 19 months. The sample included unaccompanied asylum seeker children, care leavers and looked after children. The aim was to investigate the effectiveness of using the DST as an outcome measure when working in a trauma-informed way.

Results clearly highlighted that, in a situation of ongoing trauma, the DST had the efficacy to decrease the level of distress and to capture any change. Although the relocation of young people made it difficult to gather further data, this data is still significant in showing changes over time.

However, given that the length of time occurring between the first and second completion of the DST is highly varied among participants, further research would need to be conducted to address which elements of the DST are attributing to the change observed. This said we would contend that the clinical use of the tool is relational, solution focused and shared decision making as an ongoing process of habit formation from which change occurs. Therefore, there is the need for longitudinal study from which the complexity of this way of working can be fully captured and described.

Limitations of the Study

A limitation of this study is that the data were gathered from a small group of male between the age of 8 and 22.

There were only two looked after children, one care leaver and 15 unaccompanied asylum seeker children whose clinical notes have been used to create the analysis of this study. Therefore, the results cannot be generalised to these cohorts.

In order to assess gender and age differences in DST outcomes, further studies should include female participants and a wider age range of young people.

Within this study, another limitation was inconsistent administration of the DST over a defined period of time (e.g. every three months).

Despite the limitations, this study has shown remarkable shifts within this cohort and highlights how naming each stressor and working with a solution focused approach helps to reduce feelings of distress.

Future studies should aim to assess the efficacy of these promising results, by replicating this study using standardised measures and a larger sample size.

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