



support for women and girls
resources and training for all

Hidden Pain?

People with learning disabilities who self-injure

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What do we already know?

- **People without learning disabilities**
 - Research considering their views exists
 - Self-injury has a clear function
 - It is largely used as a coping strategy for dealing with intense emotional distress
 - Interventions: usually counselling or therapies, to enhance self-esteem / develop a repertoire of coping skills
- **People with learning disabilities**
 - Little or no research considering their views
 - Self-injury generally understood within a biological framework
 - Regarded as ‘challenging behaviour’
 - Interventions: often behavioural responses and sometimes medication

Aims of the research

- To find out more about the experiences of people with learning disabilities who self-injure and their carers/supporters
- To explore in what ways they have been supported by the services and professionals with whom they are involved
- To identify ideas and then produce resources for training and policy development.

Recruitment of research participants

- Advertised through self-injury, mental health and learning disability networks
- Used, had used or were eligible to use learning disability services
- 14 years+
- Self-injured (a clear definition given)
- That the person was able to relate their experiences using their usual means of communication. Minimum requirement was that the person was able to indicate yes or no and to be able to show the researcher if they wanted to stop the interview.
- Excluded if they were unable to understand the purpose of the research.

Preliminary Visits

- To explain in full about the research project, including a summary of the interview questions.
- To ensure their understanding
- To get to know the person
- Find out their preferences about the interview
- Check permissions for that area
- Obtain written consent and whether we had permission to contact their family/carers/professionals (confidentiality between any linked interviews was assured)
- Let them know about post interview support

Our definition of self-injury

The Hidden Pain? project defined self-injury:

“a wide range of things that people do themselves in a deliberate and usually hidden way which are damaging” *

Within this the project recognised the specific typographies of self-injury more commonly presenting in people with learning disabilities, such as hitting one’s body with or against an object, biting, self scratching, self pinching, ingesting/inserting objects and eye poking (Emerson et al 1997)

* Camelot/Mental Health Foundation 2006

Research participants

25 people with learning disabilities (104 visits)

- 19 women and 6 men
- Ages 14 – 65 (mean age = 34 years old)
- England, Scotland, Wales and N. Ireland
- Range of types of self-injury
- Range of circumstances (own home – secure unit)

Family members

7 linked to participants, 5 non-linked

Professionals

21 linked to participants, 9 non-linked

Type of injury carried out by people in the study

Scratching	52%
Cutting	52%
Hitting self	48%
Biting self	24%
Taking an overdose	24%
Hitting out at something else	20%
Head banging	16%
Burning self –scalds/chemical burns	16%
Self-strangulation	12%
Gouging/picking skin/ pinching self	12%
Swallowing objects	12%
Dangerous activities	8%
Inserting objects into body/eye poking	8%
Eye poking	8%

Approximate age when self-injury started

Young childhood (before 6 yrs)	4%
Childhood (6-12)	28%
Teenage (13-19)	32%
Young adulthood (20-25)	20%
Adulthood (26+)	8%
Not known	8%

The frequency of self-injury at the time of the study

Daily	24%
Weekly	16%
Fortnightly	4%
One to two monthly	16%
More than two months but less than a year	12%
More than a year ago	8%
Occasional/ sometimes	20%

What people say about why they self-injure

1. The circumstances leading up to self-injury
2. The feelings a person has before they self-injure
3. The particular functions that self-injury serves



The circumstances leading up to self-injury: External factors

Being in disempowering circumstances

- Not feeling listened to
- Being told off
- Being told what to do
- Too many demands and not enough support
- Being treated like a child
- People talking about you

The circumstances leading up to self-injury: External factors

Lack of control within living environment

- Other residents
- Noise/too much going on
- Lack of autonomy
- Not much to do
 - “I used to do that (self-injure) when I couldn’t get out”

The circumstances leading up to self-injury: Interpersonal factors

Being bullied

- Physically
- Picked on
- Name calling
- Making fun of person
- Being laughed at

The circumstances leading up to self-injury: **Interpersonal factors**

Arguments

- Arguing with someone else
- Overhearing other arguments

The circumstances leading up to self-injury: Internal factors

Physical health issues

- Physical illness
 - “I just saw myself as a person covered in sores and I just hated myself’.
- Mobility impairment
- Tiredness, exhaustion

The circumstances leading up to self-injury: **Internal factors**

Memories of difficult experiences in the past

- Abuse – 10 reported serious abuse, 7 of these sexual.
- Bereavement – 9 people.
- Professionals/carers not always aware

The feelings a person has before they self-injure

- Circumstances that were difficult to deal with led onto the development of quite intense feelings
- All of the people in the study were able to identify feelings they experienced before self-injuring
- Most commonly reported feelings leading directly to self-injury:
 - Feeling angry
 - Feeling frustrated, wound up
 - Feeling sad, depressed, low
 - Feeling upset
- Some bottled up emotions/others crossed personal threshold.

The feelings a person has after they self-injure

- People often had a mixture of emotions after they had hurt themselves
- Most commonly reported feelings after self-injury were:
 - Feeling mixed, better and worse
 - Feeling bad or worse
 - Feeling better in some way
 - Feeling upset, sad
 - Feeling calmer
 - Feeling annoyed or ashamed

The function or meaning of self-injury

- An expression of emotional pain
 - Communication, feeling unheard, talking about feelings is difficult, verbal communication difficult
- A legacy of difficult experiences in the past
- Control - Wanting control or more control of something
- A release
- Coping mechanism
- Habit/addiction
- Suicidal actions or thoughts
 - Half had thought about suicide
 - Some people had inconsistent/active suicidal thoughts
 - Several had actually attempted to kill themselves, 3 so seriously that they had required resuscitation

Quotes

- *“I feel good and bad, it depends what I did, but it made me feel better, it made me feel more alive...it made me feel better basically’.*

I: ‘So that’s the good bit, it makes you feel more alive, it makes you feel better; what’s the bad bit?’

‘In some ways I wish I didn’t do it’.

Quotes

- P: *All I can remember is the relief of the pain inside, so again, that's all I can say.*

I: *So the pain that you were feeling inside...*

P: *Yeah*

I: *It made it go away?*

P: *Better, yeah.*

I: *It made it better?*

P: *For a while*

The importance of communication

- The Hidden Pain? research found that three quarters of the people with learning disabilities who self-injured wanted someone to talk with and someone to listen to them
- This included people with limited speech
- Some wanted to talk before they self-injured
- Some wanted to talk afterwards
- Some wanted to be prompted
 - Permission, encouragement

Messages from people with learning disabilities for support workers

- Learning new strategies for distraction
- Think about communication
- Help to understand emotions
- Access to support when needed
- Recognising the importance of peer support.

Conclusions

- Self-injury is a very individual affair
- Self-injury is largely used in response to difficult circumstances and emotions
- Hidden distress
- Understanding and dealing with difficult feelings seemed to be problematic
- Self-injury is of least frequency or intensity when people are contented
- Self-injury can make people feel better and worse

Conclusions

- People may already be taking action to limit or stop their own self-injury
- There was often a difference between what people with learning disabilities thought was helpful support in relation to stopping their self-injury and what others provided them with
- Understanding what people find most helpful is important
- Helping a person change their ways of thinking can be as effective as helping someone change their ways of behaving.



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Personal story - Sarah



Recommendations

- Acknowledge self-injury as an issue in its own right and take it seriously
- Address self-injury in people with learning disabilities as it is addressed in anyone else
- Strive to create conditions in which people can be in control as much as possible
- Work with people to help them understand, clarify and manage their emotions
- Start with strategies that people are already using to manage their self-injury and build on these

Recommendations

- Work individually and creatively with individuals in a person-centred way
- Consistency is key
- Put systems in place to help people with learning disabilities explore past experiences
- Consider peer support for people with learning disabilities who self-injure
- Practice listening skills, and be mindful of always being non-judgemental, accepting and respectful.



Any questions?

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