

Pain Memories

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UKHCDO AGM Educational Day

What we will cover:

- ▶ Pain
- ▶ Trauma
- ▶ Pain Memories
- ▶ Current Research project
- ▶ Implications for Practice
- ▶ Future work



What is pain?

“An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage”

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Through their life experiences, individuals learn the concept of pain.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.

Pain in bleeding disorders

50% PWH report experiencing chronic musculoskeletal pain

(McLaughlin et al., 2020)

35–50% report current treatments for chronic pain are not effective

(McLaughlin et al., 2020)

Developing effective treatments for chronic pain clearly identified as a priority for research in bleeding disorders



**Physical
Health**

**Mental
Health**



Trauma

A potentially traumatic event is described as “being exposed to death, threatened death, or actual or threatened serious injury”

(American Psychiatric Association, 2013)

Multiple traumatic painful bleeding episodes

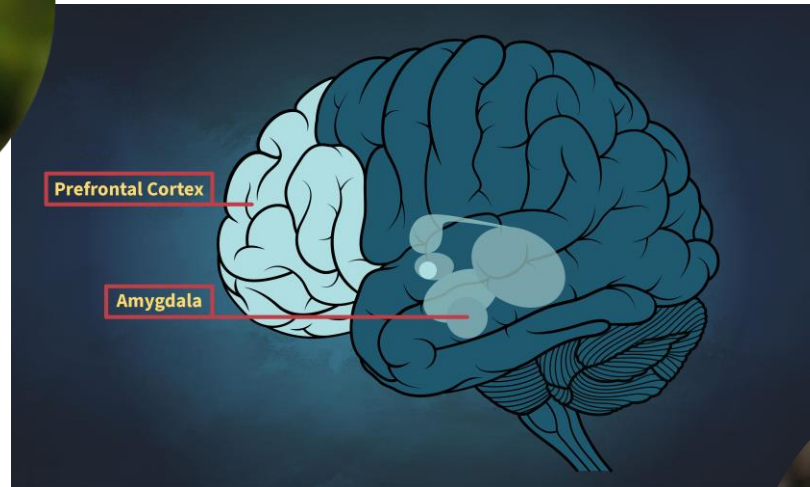
Frequency of contact with the medical system

Preliminary results demonstrate a high prevalence of PTSD and PTSS in PWH – prevalence increases with disease severity

Stahl et al. (2021)



Wise Owl & Barking Dog



What are Pain Memories?

Haemophilia

The Official Journal of the
World Federation of Hemophilia,
European Association for Haemophilia and
Allied Disorders and the Hemostasis &
Thrombosis Research Society



LETTER TO THE EDITOR

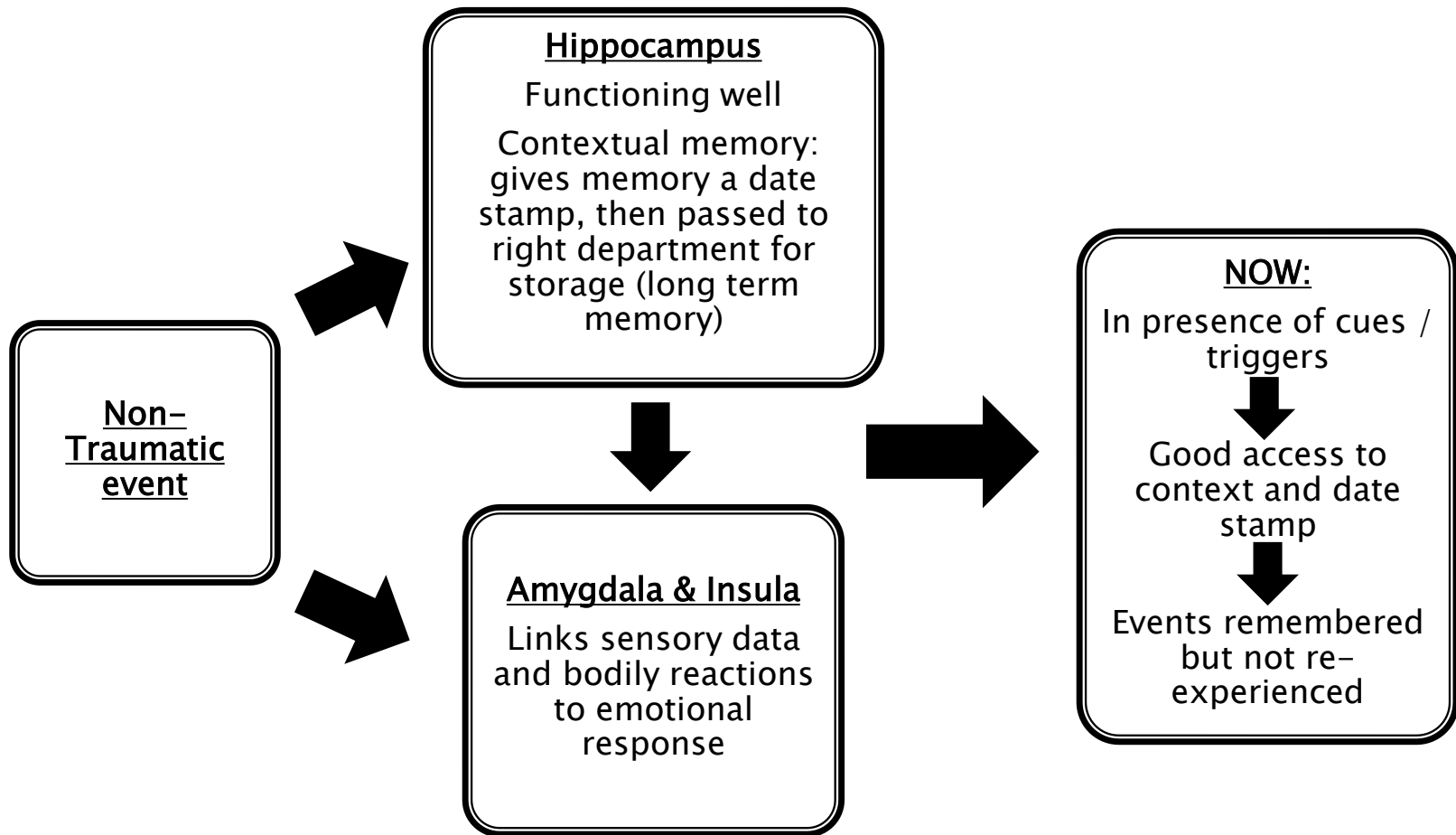
Pain memories: A new concept to consider in the management of chronic pain in people with haemophilia

Anna J. Wells ✉, Sarah Whitaker, Debra Gray, Sarah Mangles, Kelly Hislop-Lennie, David Stephensen

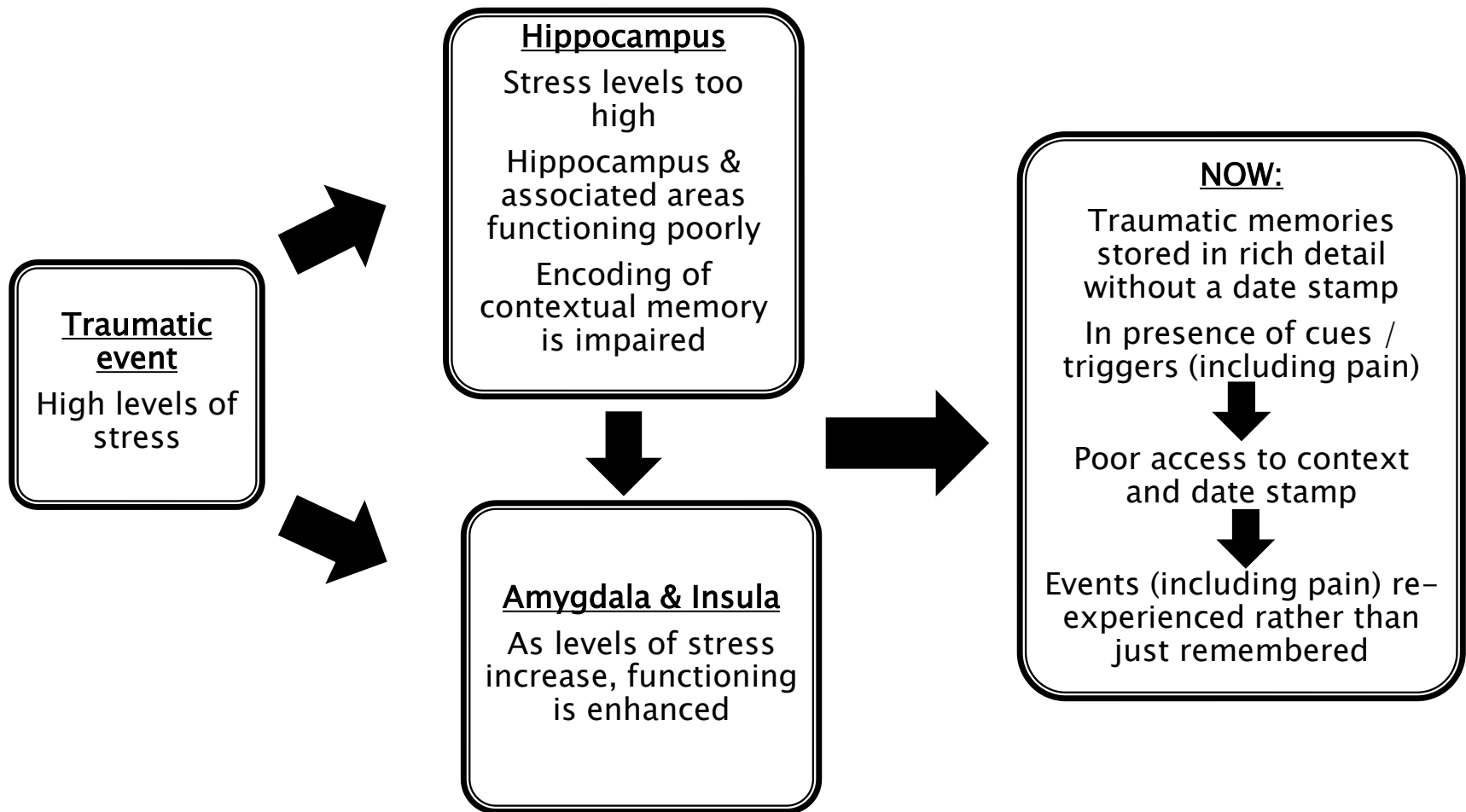
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Processing of non-traumatic memories



Processing of traumatic memories: the experience of pain memories / flashbacks



Pain memories

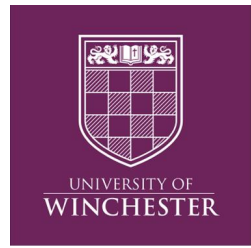
Pain memories can elicit somatic pain in the here and now

Pain memories are experienced by almost half of people with PTSD

Memories encoded under conditions of extreme stress

Pharmacological & physical pain management techniques may prove ineffective

Research



Aims

- To explore the prevalence of pain memories and PTSD symptoms in PWH and how this affects the current pain experience

Participants

- Men who have experienced a physically painful event associated with their haemophilia and who continue to experience current pain from their haemophilia were recruited through the UK Haemophilia Society

Recruitment

- Fourteen semi-structured interviews were completed between November 2022 and January 2023
- Participants were aged between 21 and 71 (mean 41.5)

Analysis

- Data was analysed using multi-perspective thematic analysis

Research: results



“And what that pain memory brings is flashbacks, weirdly ... I can remember exactly where I was and it’s a weird thing that your brain does but I can see and feel the pain. I can feel it.”

“Pain is just one part of that spectrum of trauma, and is no different, in the sense that the memories are retrievable so immediately that, it's as if it was yesterday.”

“If I think about the bleed, there's no physical pain, but I can sense the mental pain and that the memory comes back of that pain”

Research: results

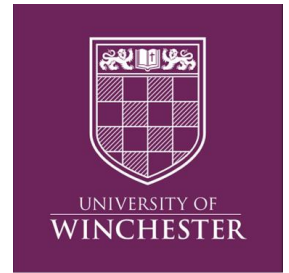
PWH experience many pain memories which are clear and vivid.

These can include visual, somatic and emotional elements in finite detail.

Pain can be experienced in the present when experiencing a pain flashback.

Pain from arthropathy in the present can be a trigger to recalling and re-experiencing memories of pain in the past.

Research: results



“we kind of build this little, put 4 walls around us, and no one comes in. And this was like, up until a few years ago, (how) I dealt with pain.”

“This is the first time I’ve spoken about this.”

“you talk about stuff that happened with other people who have been through it and decompression is the best way of solving that future PTSD”

Implications for Practice

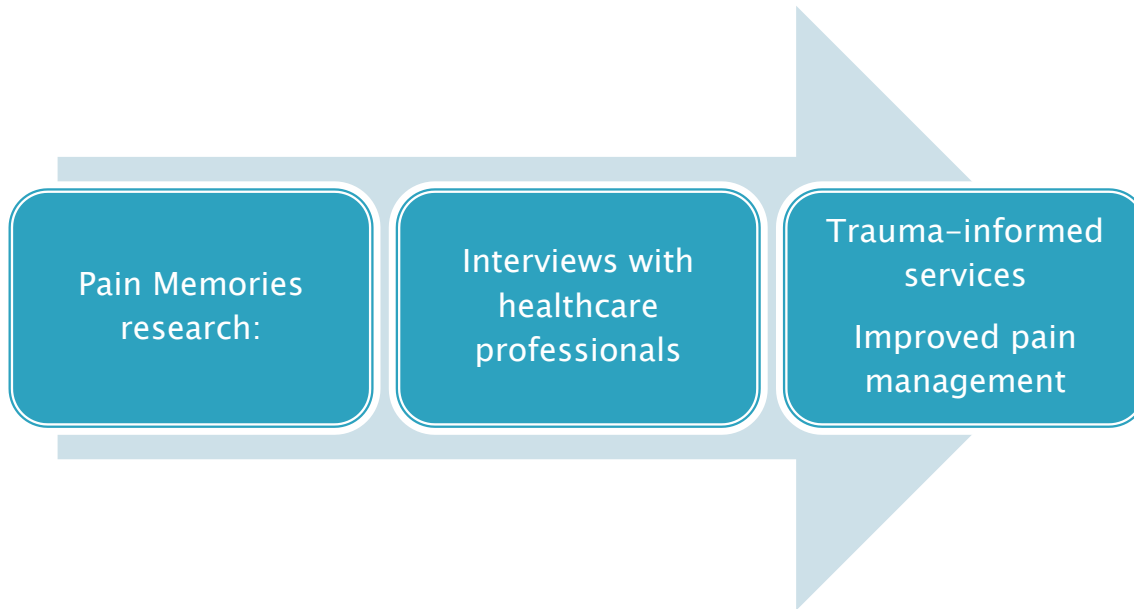
Consider physical &
non-physical
drivers of pain

Trauma may affect
a number of our
patients

Trauma rarely
discussed with
healthcare
professionals

Consider wise owl &
barking dog

Future Research



Psychologist research into proactively reducing traumatic response for children having venepuncture

Conclusion

Chronic pain is complex and is often now the most prevalent and challenging co-morbidity of haemophilia

Pain is not just a 0–10 physical sensation; it includes emotional and perceptual aspects which can be difficult to articulate or explain

Pain memories are experienced by PWH and need to be explored further, both with research and in the clinical setting

Haemophilia services need to become trauma-informed to enable better outcomes for those people impacted by trauma



Thank you

Dr Debra Gray

Dr Margaret Husted

Dr David Stephensen

Dr William McKeown

Dr Rich Gorman

Roger Newman

Dr Sarah Mangles

Dr Sarah Whitaker



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