

USING FREE ASSOCIATION METHODS TO ELICIT UNCONSTRAINED ACCOUNTS OF VISCERAL PAIN

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INTRODUCTION

Interviews or focus groups are typically guided by topics selected by the researcher, sometimes with expert by experience input. This risks content being overdetermined by researchers' biases, or missing key elements of participants' experience. Publishing interview protocols and positionality statements make it easier for readers to judge bias, but do not eliminate it.

AIM

We aimed to understand the pain experience in visceral diseases (namely endometriosis, inflammatory bowel disease (IBD), polycystic kidney disease (PKD) and bladder pain) using a novel free associations technique (Grid Elaboration Technique; GEM) that centralises the participants' experiences, and minimises researcher influences.

METHOD

The Grid Elaboration Method - GEM - asks the interviewee, in a 2 x 2 grid, to provide 4 drawings or words or phrases that represent the topic of interest. Then the interviewee is invited to talk further about each of these 4, until they have no more to add. The researcher can prompt for elaboration but asks no direct questions. This elicits the most salient concerns for the interviewee with minimal researcher bias, and allows contradictions and idiosyncrasies to emerge.

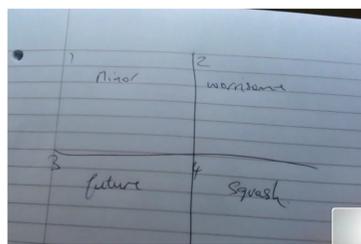
We have used GEM to interview participants with endometriosis and IBD, PKD interviews are currently ongoing and bladder pain will start soon. Adult participants were recruited through charities, had a diagnosis of the condition and chronic pain for at least six months. We aimed to recruit 15 of each gender where appropriate, to allow later analysis by gender, and interviews were conducted online.

"Please put down the first four things that come to mind when thinking about your [visceral disease] pain"

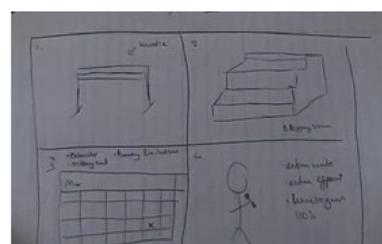
RESULTS

Most responses are words and phrases rather than drawings, but all provided rich elaborations concerning visceral pain in endometriosis, IBD and PKD. No participant had difficulty completing the grid or elaborating on it.

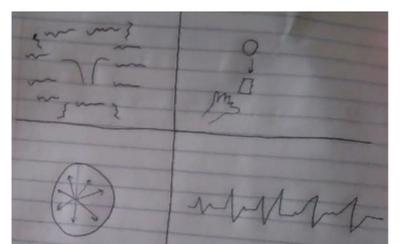
Responses from participants with IBD and endometriosis have been thematically analysed. Themes in both conditions considered the physical dimensions of pain and its effects, the emotional toll of chronic pain, the restrictions on daily life imposed by pain, the social impacts and the impacts on close relationships. Adverse experiences with healthcare were also important, and associated with worsening pain: participants from both conditions reporting misdiagnoses, a lack of care about pain, and inadequate treatment options. While participants in both conditions felt that their pain was misunderstood and stigmatised, this seemed especially prominent in IBD patients, often due to the bowel symptoms they experienced. Additionally, all women with endometriosis pain made direct links to female disadvantage, from the misogyny affecting their social and medical experiences to symptoms affecting their identity as women.



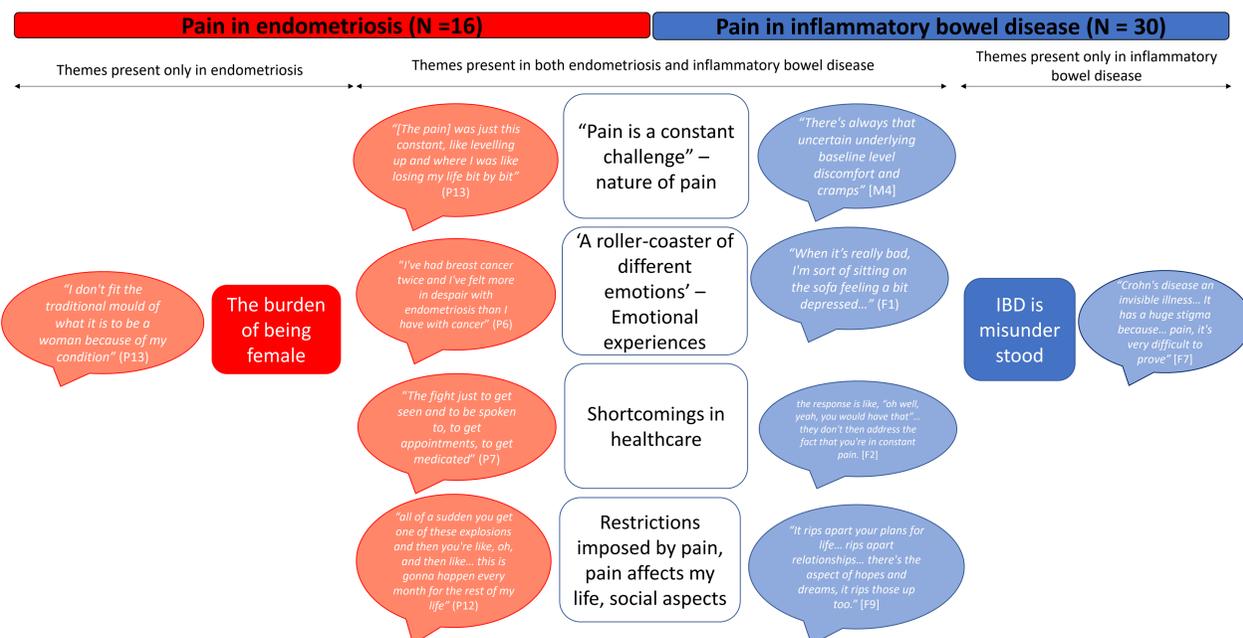
GEM response from participant with PKD



GEM response from participant with IBD



GEM response from participant with endometriosis



CONCLUSIONS

Current findings paint a rich tapestry of the pain experience in several visceral diseases. People with both conditions are affected by pain in many aspects of their lives, experiences that are often worsened by adverse experiences with healthcare, and frustrations at not feeling understood. Stigma surrounding these conditions also further complicates efforts to obtain support, both medically and socially. Our results suggest that the musculoskeletal model (fear and avoidance) may not adequately represent the challenges of pain in visceral diseases.

Through GEM, participants were able to authentically describe their pain experience. The GEM is a valuable tool for gathering qualitative data that minimises bias of the researchers, and is easy for participants to use online or in person.

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In affectionate memory of Tess Harris, 1968-2024, chair of our patient advisory group

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