“It’s time to listen closely, and be inspired to change.”

By Queen’s Psychology
Photo by Eric Brousseau

Queen’s Psychology PhD Candidate in Clinical Psychology Emma Dargie, has spent years researching a misunderstood pain condition that many dismiss or are unaware of: vulvodynia. “Because this pain condition involves the intersection of chronic pain and sexuality,” Emma says, “it may be seen as taboo to discuss.”

Emma has worked under the supervision of Dr. Caroline Pukall in the Sexual Health Research Laboratory since the second year of her undergraduate degree. “Caroline is a pioneer in field of vulvodynia research. Her extensive contributions have greatly improved how vulvodynia is conceptualized and understood. I am very fortunate to have the opportunity to conduct cutting-edge research in her lab,” Emma says. “I have learned a great deal about research from that experience, but the element that made the most profound impact was speaking with women who experience vulvodynia”. I quickly learned that this is a very common problem that nobody was talking about.

Vulvodynia, affecting an estimated 16% of women, is defined as “vulvar discomfort, most often described as burning pain, occurring in the absence of relevant visible findings or a specific, clinically identifiable, neurologic disorder.” There are two major types of vulvodynia based on pain location and quality. The first is localized vulvodynia, in which pain is restricted to a portion of the vulva, such as the vestibule, as in provoked vestibulodynia (PVD). The second is generalized vulvodynia (GVD), in which the pain is more diffuse, involving the whole vulva.

“I spoke to hundreds of potential participants on the phone, asking them a series of very personal questions to determine if they were eligible to participate in our studies,” Emma recalls. “For some of those women, I was the first person they could really talk to about such a personal topic. I am in a privileged position since I have the knowledge and sensitivity to ask questions women may not able to ask themselves, and empathize with their long struggle. These interactions have inspired me to take action and make significant improvements to the way vulvodynia is dealt with in clinical and research settings.”

Although there some are well-informed Health Care Professionals (HCPs) out there, many of these women are...
mistakenly told that the pain must be “all in their heads”, since there are no visible physical abnormalities. Some are even told that they should maybe just have a glass of wine and relax, or even have a baby to stretch the area out. Such assumptions can result in many years spent searching for pain relief, and/or avoidance of seeking further medical care. While this situation may seem extreme, Emma heard many variations of this story over the years, and these patterns are echoed in the literature.

Emma’s goal for her PhD research is to improve this process by developing a series of evidence-based, widely available vulvodynia resources for HCPs and patients. To accomplish that feat, Emma conducted a study confirming the validity of self-report information for forming diagnostic impressions. Now, she is developing a questionnaire (the Vulvar Pain Assessment Questionnaire; VPAQ) that will assist patients and HCPs to assess the pain quality of vulvodynia along with the impact it has on a woman’s life. She will then facilitate the creation of a website and accompanying application (“app”) that will display and score the VPAQ, as well as provide resources and further information (e.g., webinars, handouts, list of knowledgeable HCPs in various areas). Finally, with this easily accessible information, she will collaborate with HCPs across North America to test out the VPAQ in a clinical setting. “It is quite an ambitious project, but I feel a great responsibility to make substantial changes to a very flawed system.”

Emma hopes that this research will lead to improvements in the ability of health care professionals to diagnose women with vulvodynia, and also enhance the language they have to discuss issues related to sexual functioning with all women. She also hopes that it will also put such information in the hands of patients, so they may more effectively advocate for receiving treatment and support. “We already know that when we ask the right questions, the accuracy of diagnosis is quite high,” says Emma. “The results of this research will make that process much more accessible.”

Emma has received several scholarships throughout her graduate career, most notably a Vanier Canada Graduate Scholarship through CIHR (Canadian Institutes of Health Research). These awards are targeted at students who show academic and research promise, accompanied by a history of leadership and volunteering outside of academia. Emma’s leadership in many extra-curricular areas around Queen’s University, combined with her contributions to research at Queen’s Psychology resulted in a successful Vanier application. “I was thrilled to receive the award,” Emma says. “It has had a tremendous impact on my academic career, giving me the freedom and confidence to pursue a very well-rounded degree.”

Looking ahead long-term, Emma plans to follow a career path that allows her to pursue both her clinical and research interests, while also seeking the opportunity to teach. “Knowledge translation has become quite a passion of mine, along with quality assurance and program evaluation,” explains Emma. “I want to take all of the research skills that I have developed and apply them in real-world settings to promote education as well as improve diagnosis and treatment of clinical disorders”.

Emma is currently in need of participants for the online study that will result in the creation of the VPAQ. If you experience vulvar pain, please visit the following link and consider adding your voice to this research project. You can also contact Emma directly for more information at: sex.lab@queensu.ca

For more details, please visit the Vanier CGS website.