HEALTHY MINDS WORK

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BEYOND BOUNDARIES THROUGH APPLIED QUALITATIVE RESEARCH

The Challenges and Resulting Impact of Crohn's Disease on the Patients' Family Members

Lorna Bonnici West

Introduction

- Chronic diseases have been defined as
  - *"conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both"* (Centers for Disease Control and Prevention, 2024).

- In its document on the state of health in the EU, the European Commission (EC) reported that 54% of individuals who are ≥ 65 years reported at least one chronic disease, with Malta also reporting similar figures (EC, 2019).
- The ever-increasing prevalence of chronic diseases elicited the need amongst Governments, including the Maltese one, to boost efficiency of care amongst patients with chronic diseases (EC, 2019).
- While certain chronic diseases are highly prevalent and possibly more researched, there are less mentioned ones, such as Crohn's disease, which may also have an impact on patients' and their relatives' lives.

Introduction

- Crohn's disease is an inflammatory condition affecting any part of the wall of the digestive system and its symptoms may interfere with patients’ daily routine and quality of life.
- It typically starts in the adolescent years, but the cause is still unidentified (Malta Association of Crohn’s and Colitis, 2020).
- Globally, in 2017, there were 6.8 million patients suffering from inflammatory bowel disease, which includes Crohn’s disease (GBD 2017 Inflammatory Bowel Disease Collaborators, 2020).
- In Malta, patients suffering from Crohn’s disease:
  - are entitled for medication under the Schedule V condition (Directorate for Pharmaceutical Affairs, 2024).
  - there is also a non-profit-making organisation, Malta Association of Crohn's and Colitis (MACC), which supports the needs of these patients (Malta Association of Crohn’s and Colitis, 2020).

Overall aim

- The overall aim of this inquiry was to contribute to knowledge in the field of Crohn’s disease
  - by examining the experiences of challenges faced by family members of individuals suffering from Crohn’s diseases, and
  - their experiences of encounters with healthcare professionals (HCPs) and support services for family members,

  in order to understand the impact of these experiences on these family members.

Research justifications

- A qualitative research methodology, using a mono method.
- Narrative inquiry, the methodology proposed for this research, justifies research from the (Clandinin, 2010):
  - *Personal perspective:* I am a relative of a patient suffering from Crohn’s disease and I am a HCP.
  - *Practical perspective:* There is a gap in the literature regarding the challenges faced by family members of patients suffering from Crohn’s disease.
  - *Social perspective:* A research gap was also identified in terms of the type of methodology used to understand the impact of Crohn’s disease on family members. Therefore, there is a “*theoretical justification*” (Clandinin, 2010) for the proposed research.

Research design

- Two interviews (semi-structured) with each participant over a one-month time-frame to enable the temporality.
- Two individuals participated who both have an immediate relative suffering from Crohn's disease.
- Participants were also asked to keep a journal in between the two interviews to record any experiences that they recall.

Approach

Three-dimensional aspects	**Approach**
Place	The family domain (their household) for relatives.
Temporality	Participants' experiences from disease diagnosis to the present date, as well as perceptions and impact of their experiences on the present and future were explored.
Sociality	Participants related their experiences while attention was given to relationships, including those between the participants and inquirer, experiences as lived over time and in distinctive places and multi-layered contexts (Clandinin and Caine, 2008). As the inquirer, I constantly reflected and inquired into my own experiences during the whole

Data analysis and interpretation

- Interviews were transcribed verbatim
  - including researcher notes and initial reactions on the transcripts.
- Analysis started from the narrative inquiry "*field*" and field texts were generated from the interviews, with constant consideration to the three-dimensional aspect and potential ethical issues (Clandinin, 2007).
- Interim research text (Clandinin, 2013) evolved from and concurrently with field text.
  - Transcript of the first interview was re-read a number of times to support reflexivity and possible questions for the second interview.
- Final transcripts were read several times, thematic narrative analysis was conducted, recording themes, similarities, and differences between participants' responses.
- The final research text (Clandinin, 2013) emerged from field texts and the interim texts.
  - These were conveyed to participants, as well as the final research text, to ensure that they agreed with the narratives and enhance credibility (Riessman, 2008).
- To facilitate the analysis, all transcripts were inputted in the MAXQDA software.

Results

- The narrative inquiry with:
  - Lucy (a pseudonym) – spouse of a patient with Crohn’s disease
  - Judy (a pseudonym) – daughter of a patient with Crohn’s disease

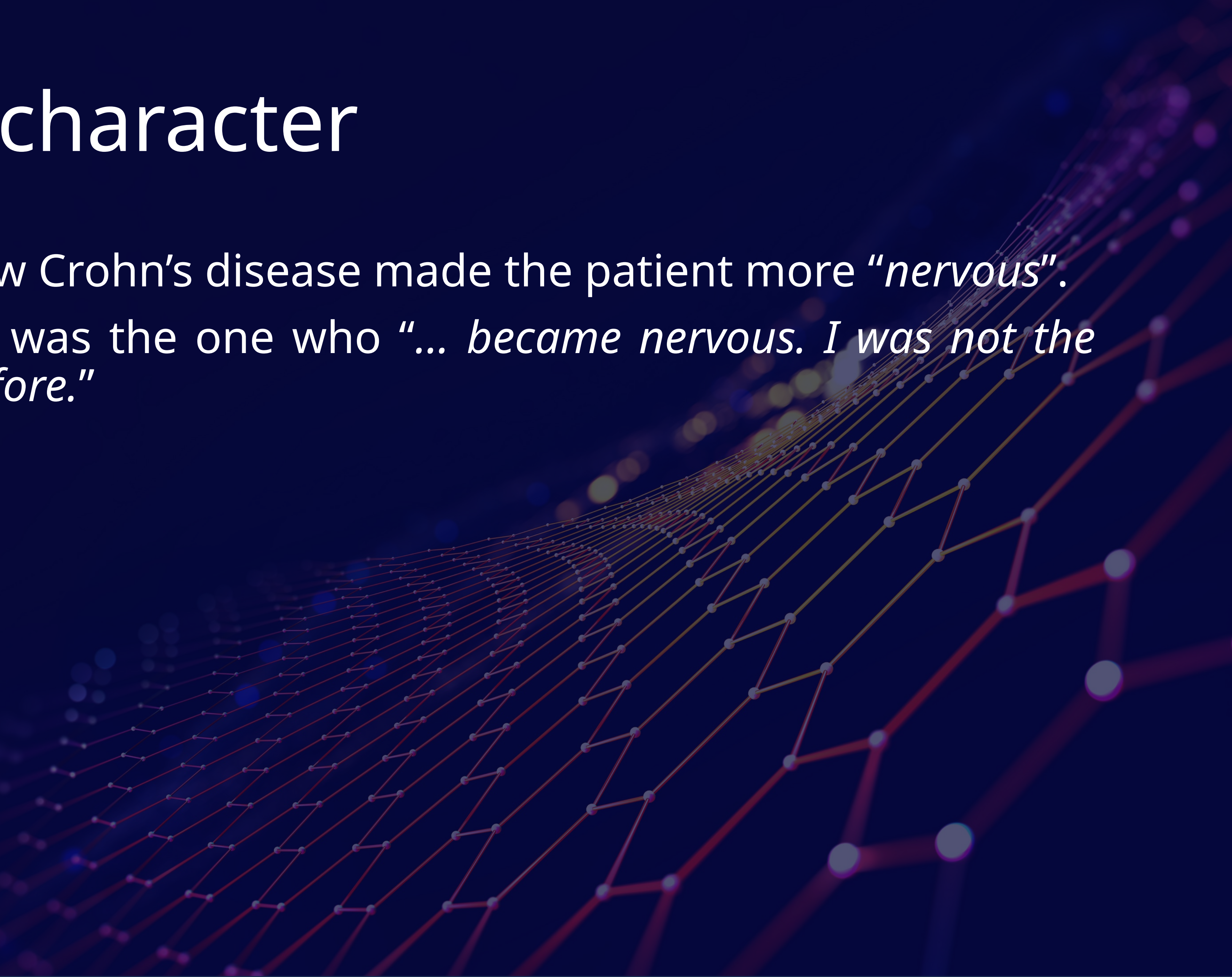
Impacts of the challenges faced by family members of individuals suffering from Crohn’s diseases
Financial impact
Impact on character
Family impact
Social impact
Emotional impact
Religious impact

Financial impact

- The most strongly discussed impact by participants.
- Despite the financial difficulties, Lucy highlighted that she could not work overtime “*not even on weekends so that I can go back home early, because I had to look after the family and after him.*”

Impact on character

- Judy described how Crohn’s disease made the patient more “*nervous*”.
- Lucy felt that she was the one who “*… became nervous. I was not the same person as before.*”



Family impact

- *“So, our life, when we were young until we grew and had our lives, since we were young and dependent on them, our lives became inexistent, and we were only coping with his new reality. Our life became his illness.”*

[Judy]

Social impact

- Lucy narrated how her husband refused to even hold events at home, *“as outsiders, he did not want anyone at home, neither family nor friends. We became isolated alone.”*

Emotional impact

- Fear that her father would die was one of the emotions that Judy felt during her journey.
- To this day, she requests a number of medical check-ups, both on her and others, without need, as she is afraid that she or her relatives will get sick. This, however, also meant that she is not afraid of hospitals.
- Looking back on her experiences, Judy feels self-pity, *"I still pity the little girl I was, and I feel I still need to protect that little girl. No one gave us emotional support."*

Religious impact

- Judy narrated how living with a family member suffering from a chronic illness shaped her religious beliefs,

  "He used to be very sick, then we used to pray, and he used to get better. So, this helped me believe religiously."

Support provided to family members

- Through the participants' experiences in relation to any support and support services provided to family members of individuals suffering from this condition, two themes emerged:
  - 1) social support
  - 2) professional support

Impact of findings on practice

- Educational curricula for HCP students should address the impacts of chronic diseases not only on the patient but also on the immediate family members.
- When establishing support services, the needs of both the patient and the immediate family members must be considered, understood, and met.
- Upon diagnosis, it would be beneficial if an automatic referral is generated to a multidisciplinary team of professionals to support the patient and immediate family members.

Limitations

- Small sample size, findings cannot be generalised.

Potential future research

- An extension of the current research on a larger sample.
- Exploration of compassion fatigue amongst family members.
- Overall impact on quality of life of the new support services.

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