



Accessing needed IBD (Inflammatory Bowel Disease) resources and information post diagnosis: A patient-led Alberta study.

Marcia Bruce¹, Doug McKay¹, Sherri MacLean¹, Lindsey Rizkalla¹, Kendra Vandenhoven¹, Jeanette Van Roosmalen¹, **Tatiana Kuzmyn¹**, Marlyn Gill², Esther Halton², Deirdre Walsh², Aida Fernandes³, Deborah Marshall^{3,4}, Nancy Marlett⁴

1: PaCER (Patient and Community Engagement Research) Intern; 2: Patient and Community Engagement Research Mentor; 3: The IMAGINE Chronic Disease Network; 4: University of Calgary

BACKGROUND

Inflammatory Bowel Disease(s) (IBD), are characterized by chronic, relapsing-remitting inflammation along the gastrointestinal tract. Patients navigate challenges affecting daily living and quality of life. Insufficient patient knowledge about IBD treatment negatively impacts medical adherence resulting in possible relapses. We, as PaCER interns, sought to understand the education, information and support IBD patients were supplied with following diagnosis versus what patients felt they needed.

RESEARCH QUESTION

Our guiding question was developed using input from our sponsor IMAGINE, initial patient interviews and confirmed by our literature review.

“Please describe what resources IBD patients need after diagnosis.”

METHODOLOGY

- Participants (n=13) were recruited primarily through word of mouth and personal contacts or at patient associations or support groups.
- Inclusion criteria: 1) Diagnosed with IBD 2) Over 18 years old 3) Fluent in English 4) Received IBD care in Alberta 5) Urban & rural settings.
- PaCER methodology was used to engage patients in peer-to-peer co-designed qualitative research.

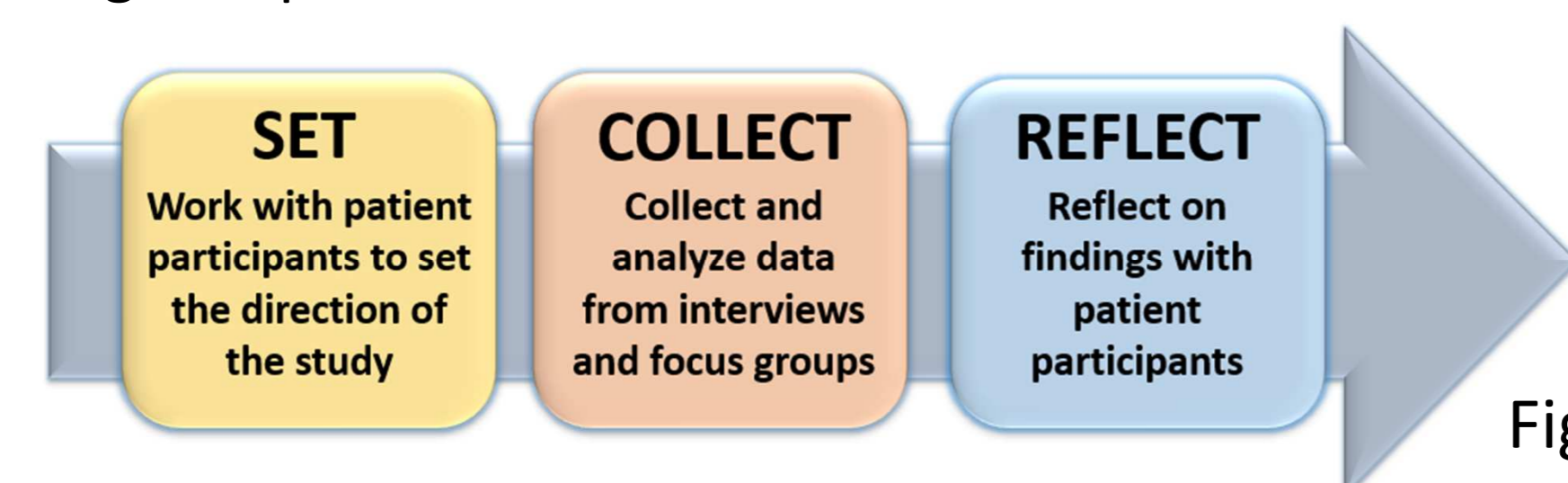


Figure 1

- Data analysis: Iterative questioning, thematic analysis and open coding elements from grounded theory.
- Narrative interviews and focus groups were held online via an encrypted videoconferencing platform.

FINDINGS

- During our Collect Phase patients stated that their experiences post diagnosis fell under four emerging categories: Timely Access, Peer Support, Education and Multidisciplinary Care.
- Timely Access was initially presented as its own category but eventually it became an overarching category that greatly influenced the effectiveness of the other categories.
- Participants ranked Education as the most important to them.

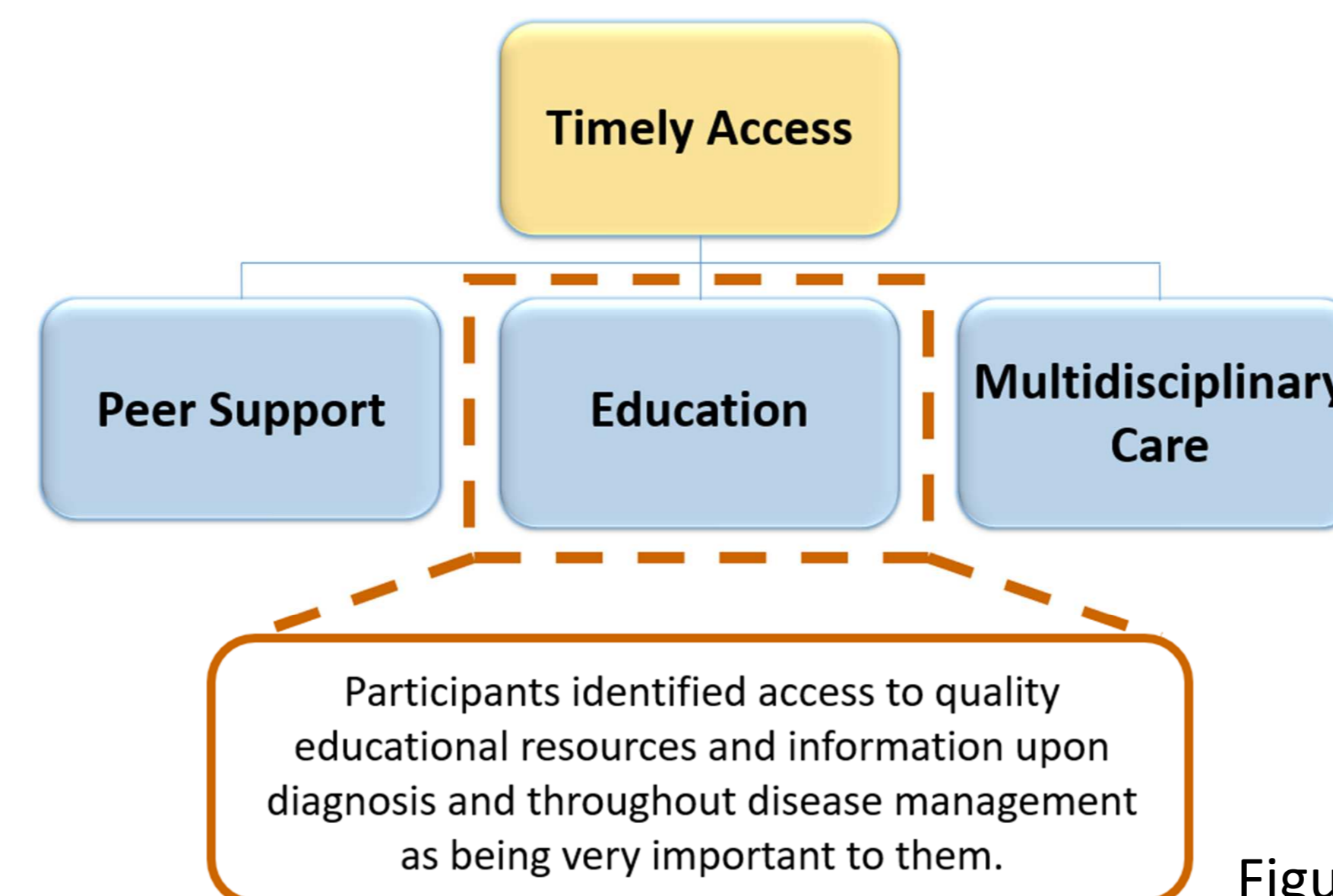


Figure 2

- Several quality online resources exist for patients in Alberta; however, our research concluded that online education (done in isolation) can lead to poorer adherence and lower certainty.
- Benefits of increasing in person patient educational opportunities delivered by IBD physicians and/or IBD nurses leads to empowerment, lower anxiety and lower isolation.

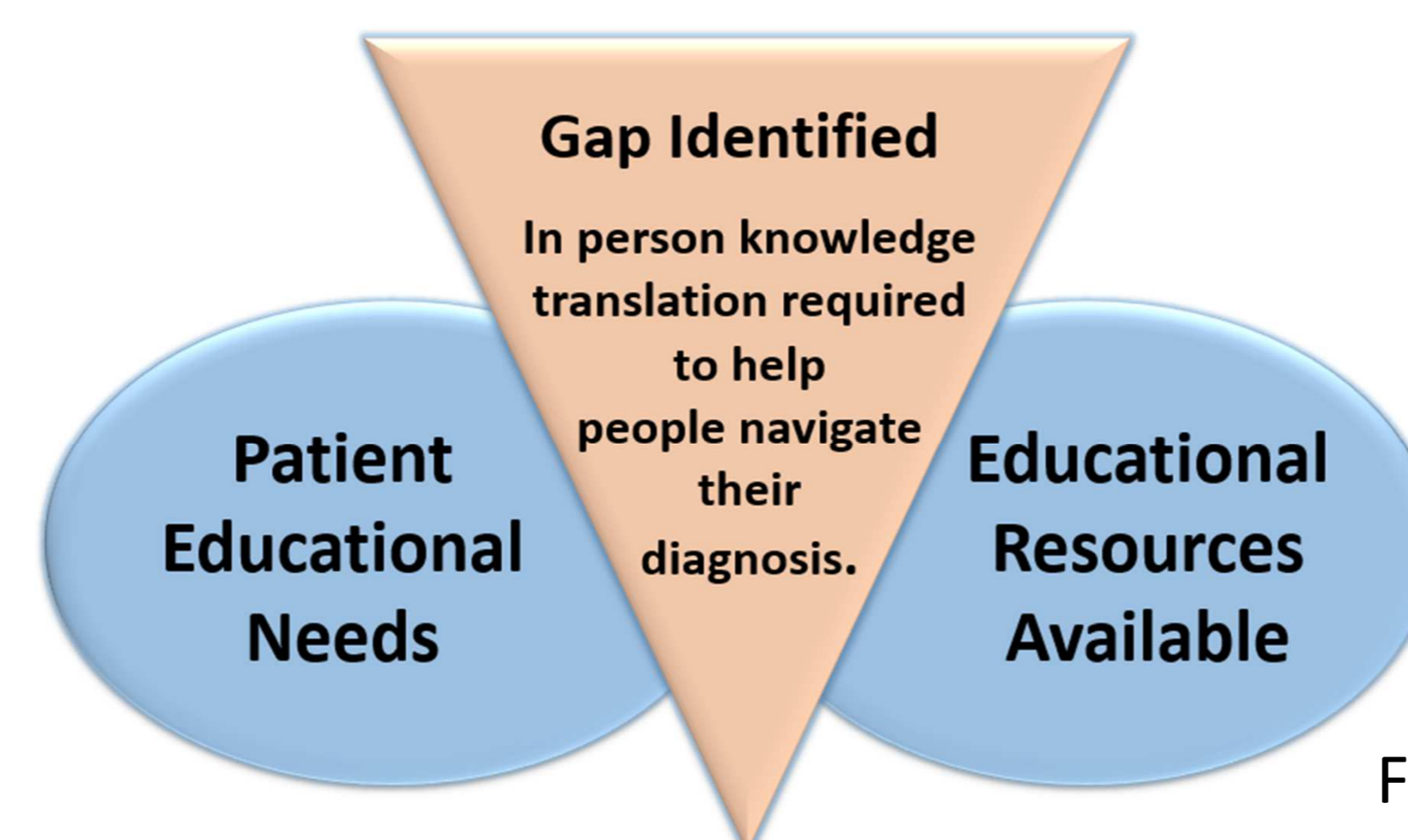


Figure 3

RECOMMENDATIONS

1. Determine responsible entity within Alberta Health Services for delivery of IBD patient education (e.g. Primary Care Networks, Alberta Healthy Living, IBD clinics).
2. Develop education pathways for IBD that include in person sessions and scheduled follow-ups for newly diagnosed patients to ensure they receive resources and standardized education (e.g. post-natal care model).
3. Promote and encourage the delivery of education by IBD professionals (e.g. physicians, nurses, nurse practitioners).
4. Provide newly diagnosed patients with the following resources:
 - A contact, go-to individual, in charge of fielding questions and concerns (e.g. IBD Nurse).
 - A list of trusted IBD websites, incl. GI apps for managing disease.
 - Information on peer support options (e.g. Crohn's and Colitis Canada).
 - Tips and tricks (e.g. diet, lifestyle factors, bathroom finder app).
 - Decision tree schematic (e.g. for worsening symptoms, medication options).
 - Mental health support for patients and their families.
5. Ensure that educational materials are appropriate and inclusive:
 - Age appropriate, readability level, accessibility.
 - Delivered in a variety of ways (e.g. in person, online, printed, webinars).

CONCLUSIONS

- IBD patients prioritize education as being very important to them. IBD patients value **in person** interventions particularly upon diagnosis and during key disease transition periods.
- Highly educated patients, who are actively engaged in their healthcare, are more likely to be empowered, thereby increasing their medical adherence and improving their quality of life.

ACKNOWLEDGEMENTS

We would like to acknowledge and thank the IMAGINE Chronic Disease Network, the PaCER teaching team, Dr. Maria Santana and our patient participants. IMAGINE Network is one of five chronic disease networks in the SPOR (Strategy for Patient Oriented Research) initiative of CIHR (Canadian Institutes of Health Research) with funding from several partners.