

GLOBAL DESIGN STRATEGY FOR CANCER PATIENT EDUCATION MATERIALS: HAITI PILOT CASE STUDY

ABSTRACT

Cancer care providers at Queen Elizabeth Central Hospital (QECH) in Malawi identified a need for educational materials for their low-literacy patients. Global Oncology (GO), a non-profit focused on improving cancer care, research, and education in resource-limited settings, partnered with THE MEME Design to develop cancer patient educational materials (PEMs). The goal of the project was to create clinically relevant and culturally appropriate low literacy PEMs to improve clinical care, support services, and patient adherence in resource-limited settings. The team also aimed to develop a product / service strategy and business model for long-term sustainability.

The article will introduce the challenge from a global health perspective and the ways design can have significant impact. It will present the collaborative process of developing the “Cancer and You” booklet for multiple cultural contexts, and will focus on the results of a pilot study in Haiti evaluating the efficacy of the design in simplifying complex medical information, facilitating patient education and improving communication.

1. Introduction

Cancer is responsible for 1 in every 7 deaths around the globe – more than HIV/AIDS, tuberculosis, and malaria combined. (American Cancer Society, 2016) Seventy percent of these cancer deaths occur in low and middle-income countries (LMICs), where there it is difficult to diagnose and treat patients due to a staggering lack of resources (Stewart and Wild, 2014). This results in one of the biggest challenges in global health today – adoption of sustainable and scalable strategies, and the continual improvement of, cancer care delivery in low and middle-income countries (LMICs). The growing complexity and urgency of the challenges we face today as members of a global society demand an increasingly collaborative, strategic and multidisciplinary approach. This is particularly true in addressing complex issues that require attention to specific scientific domains, cultural contexts and socio-economic conditions.

Design for Social Impact is a growing field of design practice, with research and education focused on the application of design skills, tools, and methods to contribute to the solutions of the most pressing social issues of our time. Outcomes are not measured

in terms of commercial success and economic profit, but in how they affect attitudes, behavior patterns, and social dynamics in ways that are beneficial to both individuals and entire communities (Anderson, 2015). Low literacy and lack of education are a significant barrier to quality healthcare within LMICs, as it creates limitations on communication across the continuum of cancer care. Patients with little prior knowledge of cancer have limited access to information about the disease beyond their brief encounters with clinicians. Lack of knowledge about the disease undermines adherence to treatment, increasing the risk of poor health outcomes for already underserved patients. It also affects the psychosocial welfare of patients as it increases fear, confusion and stigma around cancer and its treatment.

In consultations in 2013 with Global Oncology, Inc. (GO), a non-profit focused on improving cancer care, research, and education in resource-limited settings, cancer care providers at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi identified a need for educational materials for their low-literate patient population. Many of their patients were experiencing the side-effects of treatment, such as nausea, weakness and hair loss, which made them feel worse, rather than better. Clinicians at QECH observed that patients were often stopping their treatment, and speculated this may have been due to patients' lack of understanding of the complexities of cancer treatment. Cancer patients in developed countries can access a wealth of information about their diagnosis and treatment; however, no educational materials existed appropriate for cancer patients in a low-resource, low-literacy setting like Blantyre, Malawi. Furthermore, clinicians did not have adequate time to spend with patients and families, which may have also contributed to miscommunication. As a result, GO partnered with THE MEME Design, a Cambridge-based strategic design consultancy, to initiate the development of cancer patient educational materials (PEMs) suitable for low-literacy populations worldwide.

This article will explore the role of design in addressing global health challenges in cancer care for low resource communities and multiple cultural contexts, within a collaborative design process. It will focus on the development of patient education materials on cancer care for low literacy populations to show design can significantly

improve cancer care for patients by simplifying complex medical information, facilitating patient education, and improving communication in the cancer care setting. The discussion will include design guidelines and protocols for adapting educational materials to diverse contexts, and on developing a strategy for long-term sustainability.

2. Framework

2.1 Low Literacy in Health Care

In their work for the Institute of Medicine, Nielsen-Bohlman, Panzer, & Kindig define health literacy as *“the degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate decisions regarding their health.”* (Nielsen-Bohlman L, et al., 2004)

Multiple studies in the U.S. have demonstrated the impact of low literacy in health care. It can undermine a patient’s ability to follow directions, to complete medical documentation effectively, (Baker D et al., 1996) and it creates negative emotions that keeps patients from asking questions and asking for help (Holt GA, 1992) (Schwartzberg et al., 2007). In many cases they feel that medical information was not explained in words they can understand, that treatment and medication instructions are hard to follow, and that procedures are unclear (Schwartzberg et al., 2007). Low literacy has been linked to deficient healthcare outcomes (Dewalt DA et al., 2004) (Berkman ND, et al., 2003) and to increased costs (Baker DW et al., 2002).

In LMICs, these impacts are many times amplified by the lack of medical resources within the healthcare system. Patient education materials are rarely available in written form in low-resource settings limitations, and provider time and energy needed to educate patients can be limited (Hubley J, 2006). Low health literacy also compounds other external barriers patients face in these settings, including lack of adequate infrastructure, transportation and long distances from patient’s place of residence (Zimmerman M et al., 1996). For those fortunate enough to receive medical care, adequate patient materials would make a big difference.

2.2 Design for Low Literacy in Healthcare

Design has an essential role to play in the battle towards better global cancer care, particularly when it comes to issues of low literacy. The National Institutes of Health (NIH) offers clear guidelines for developing print materials for low literacy (National Cancer Institute, 1994). Many of these recommendations share the same principles as

exposed in *Teaching Patients with Low Literacy Skills* by Doak, Doak and Root (1996), where they emphasize the qualities for effective materials for low-literacy in health, both in terms of content and visual representation.

Crafting language appropriately is essential in designing materials for low literacy audiences. Recommendations to improve readability include use of familiar words, replacing technical terms for simple language, avoiding long words and complex sentences, and using concrete examples instead of abstract ideas. Layout is also important as it organizes information and facilitates comprehension. Emphasis is placed on simple and clear headers, balance of white space and visual content, and the use of readable fonts.

Studies have demonstrated the effectiveness of well-crafted illustration in communicating complex medical information (Houts et al., 2006), especially in terms of changing behavior patterns for low literacy audiences (Delp C et al., 1996). In terms of visual representation, the main goal is to reduce the amount of text and keep the reader interested, motivated and provide clear instructions (Doak et al., 1996).

In order for the images to be effective they also need to be culturally appropriate. In a global health context language is not the only barrier. Many patients are used to forms of traditional medicine in their cultures that differ from what is being provided, and clear visual explanations can make a big difference (Ngoh LN, 1997). In that regards, offering images that are recognizable and where patients can identify elements of their own culture can be significantly more effective (Dowse R, Ehlers MS, 2001).

3. “Cancer and You” Booklet: A Collaborative Design Process

3.1 Needs Assessment - Target Audience

The QECH team of Blantyre, Malawi collaborated with volunteers from Global Oncology to evaluate the health care delivery system on-site. The following requirements and constraints for the use of patient education materials were identified:

- Understaffed team treating a large number of patients
- Lack of sufficient time to explain symptoms and side-effects
- Lack of culturally appropriate and legible tools to support every-day communication with their patients
- Lack of resources to easily reproduce and distribute education materials

In early stages of the project, similar requirements and constraints were also described at Partners In Health (PIH) collaborating sites in Rwanda and Haiti. In response to these challenges, GO and the QECH team worked together to outline the content of the materials. GO then formed a partnership with THE MEME to lead the design of the cancer patient educational materials (PEMs) and to adapt the materials for low-literacy populations worldwide. They needed to be a low-cost, easy to reproduce document that could be shared in local clinical settings, with or without provider involvement. A booklet that could be printed and copied on-site, or laminated and stored for patients to use on the wards, was agreed to be the best solution.

3.2 Content Development: Early pilots (Malawi and Rwanda)

The first “Cancer and You” booklet was created to describe lymphoma, a common type of cancer in Malawi, which illustrated the side effects of chemotherapy treatment. A patient log was also included for patients to document symptoms they experienced between chemotherapy cycles. This first draft was shared with oncologists in the U.S. to ensure the treatment and its side effects were accurately recorded, as well as low literacy experts from the Health Communication Core at the Dana Farber Cancer Institute to assess readability and ensure a clear and coherent structure. Medical staff from Malawi also reviewed the materials providing general commentary on the text for translation and guidelines for cultural appropriateness.

A second draft was developed based on this feedback. After a round of revisions, the focus on lymphoma was broadened to represent cancer more generally, chemotherapy treatment, common side-effects, and the identification of symptoms that may require urgent medical attention. Practical suggestions for self-care were added, in addition to information for family members about how to care for patients at home.

The following topics were included in the revised ‘Cancer and You’ booklet:

- General questions about cancer and chemotherapy
- Chemotherapy side effects
 - Hair Loss, Fatigue, Vomiting, Nausea, Constipation and Diarrhea
- When to go to the hospital
 - Chest Pain, Shortness of Breath, Fainting, and Fever
- Side effects recorder
 - Fatigue, Vomiting, Constipation, and Diarrhea
- Caring for people with cancer

- Resting, Eating Well, Drinking Water, Mouth Sores, Hand Hygiene and Hair loss
- Recommendations for care givers
- An optional patient registration form

The material was translated to Chichewa (Malawi) and Kinyarwanda (Rwanda) by professional translators from PIH. Student volunteers from GO traveled to QECH in Malawi and Butaro Hospital in Rwanda to work with local medical staff in the initial rollout and evaluation of the materials. Feedback was gathered via qualitative questions, informal interviews, and small focus groups with clinicians and patients, focused on quality improvement. In Rwanda, observational data was also collected regarding how clinicians, patients, and families were engaging with the materials on the wards. Implementation in Malawi and Rwanda yielded promising early results regarding the potential utility of the materials in low-resource settings, but clearly indicated more improvement and research was needed prior to scale up of the project.

3.3 Visual Design

The design process began with discussions about how to represent the specific medical terminology that described cancer, as well as the best way to illustrate the side effects of chemotherapy and the recommendations for patient care. In doing so, the team reviewed existing patient education materials targeted at low literacy populations in cancer care in the U.S., as well as global efforts for other medical conditions (e.g. diabetes, HIV). In particular, the balance between medical content and visual representation was discussed, regarding the clarity of language, illustration of complex information, and accuracy and readability for low literacy audiences.

After the initial review process, the design team centered on two different approaches to visual communication: abstract and representational.

The first approach (Figure 1), based on very simple drawings, was an attempt to focus on the medical symptoms and reduce any potential cultural biases to representation. By creating illustrations that were closer to abstractions of physical traits, the design team was aiming for a universal visual language by reduction and omission of nearly all details. The use of dark thick silhouettes with no facial expressions or clear gender rely purely on body language and gestures to illustrate the concepts.



FIGURE 1 - The top row of images represent an “abstract” style of illustration, focused on reducing detail. The bottom row of images portray the preferred “representational” style, providing more familiar details to users.

The second approach (Figure 1) based illustrations on line drawings that were closer depictions of physical conditions (symptoms and side effects). More detail was added to represent the emotional dimensions of the experience, to increase empathy, as well as to link to elements specific to local culture. This proved to be a more effective strategy and appealing visual style, and became the chosen approach for the booklet revisions.

In order to cater to resource constraints regarding booklet design and printing costs, illustrations would not use color, and would avoid references to specific locations or physical environments (ie. hospital, home, etc.) for more generalizability across countries and contexts.

3.4 Visual Design Refinement for Cultural Relevance

One of the most important criteria for the evolution of the booklet design focused on the need to communicate visually complex content in a diversity of cultural settings. Concerns regarding the representation of images that may have a negative impact or generate confusion for patients and providers in specific contexts were evaluated. It became clear that the materials would have better adoption rates if patients could associate themselves with the illustrations, and if the drawings considered particular local conditions.

This has become an important consideration since the materials are meant to be distributed globally across low resource settings and beyond language translation, it would be impractical to make completely different versions for each community or country. The challenge then becomes how to effectively assess the local needs and what should be the right amount of customization per specific location.

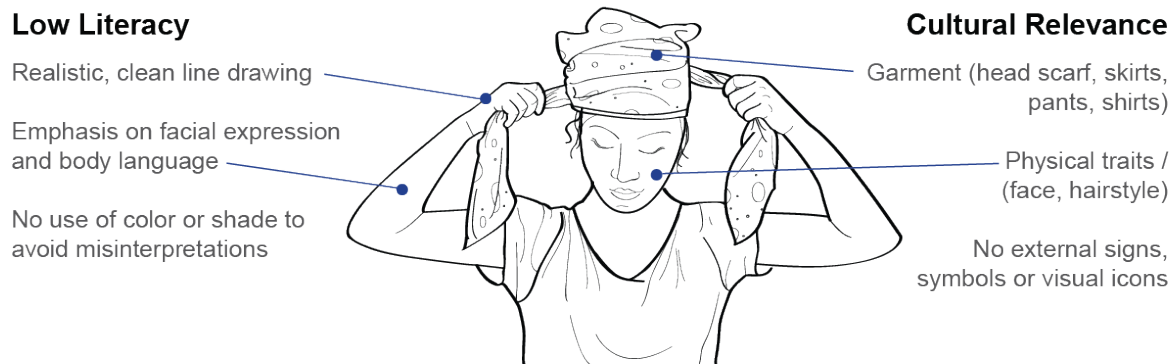


FIGURE 2 - Criteria for developing culturally relevant illustrations for low-literacy, and an example illustration from the materials.

Following feedback from Malawi and Rwanda, a first step in refinement was to include enough details in the illustrations to suggest specific physical traits, using hairstyle, physiognomy, and garment as a way to provide cultural references to specific contexts (Figure 2). The drawings were developed to represent both genders and multiple ethnic backgrounds. Clothing was kept primarily neutral, although there was a clear intention to reference warmer climates, modest skirt and sleeve-lengths, and specific styles of headgear (hair wraps) suggested for protection after hair loss, which were commonly used in the initial testing countries. The intention was to create appealing and culturally appropriate images that would facilitate dialogue and explanation of complex medical topics between medical staff and patients, and that would help patients visualize, comprehend, and reference diagnostic and treatment information on their own.

3.5 Cancer and You Booklet

The team took into consideration additional guidelines for design for low literacy in the organization of the information and general layout of the materials. Besides the use of simplified language and culturally relevant images, density of information was carefully planned to balance content, illustration, and white space for readability. The selection of simple large block fonts for titles are meant to facilitate readability in multiple languages.

All images are clearly labeled and are placed with simple explanatory text developed for low levels of literacy.

After translation and testing in Rwanda and Malawi, the booklet had been developed as a modular document where sections could be adjusted to meet different lengths in written content due to differences in grammatical structures across translations. It was also organized in sections that could be printed and used separately, making it easier to be customized for different countries. The symptom tracking form was streamlined by simplifying icons used to represent levels of intensity for each symptom, and to make this a more useful tool for patients at home. The patient registration page was also optional now, depending on the needs at each location.



FIGURE 3 - Visual design of the “Cancer and You” booklet, including cover, general questions, symptoms, side-effects recorder, tips for patient care, and patient registration form.

In its third iteration, the “Cancer and You” booklet was ready to be tested in a structured pilot study in order to assess if the design decisions and quality improvement efforts were successful in simplifying complex medical information, and were facilitating a better dialogue between patients and their caregivers. The team chose Haiti as the ideal pilot

site for formal evaluation, and to inform the development of a scalable process for implementation and continuous research in new settings worldwide.

4. Haiti Pilot Study

Partners In Health launched its first cancer program in Haiti in 2010 in collaboration with the Dana-Farber Cancer Institute and Brigham and Women's Hospital. The Oncology program is based at the tertiary Hôpital Universitaire de Mirebalais, which serves a catchment area of 4.5 million people. The team is composed of two physicians, a nursing team, and a mental health team with a psychologist and social worker. The small size of the team at HUM was ideal for piloting the materials, as we were able to enlist all members of the team and providers across multiple disciplines in the adaptation, implementation and evaluation process.

Due to the extreme lack of access to cancer care, low educational attainment and low literacy rate in Haiti, knowledge about cancer among patients is extremely limited. According to UNICEF (2015), Haiti's adult literacy rate is 48.7%. Approximately three quarters of the population attend primary school, but only one quarter attend secondary school. As of 2012, only 10% of the Haitian population uses the internet (World Bank, 2014). Despite caring for a patient population with little public health awareness of cancer or access to information, HUM did not have any cancer patient educational materials prior to this project.

4.1 Goals

The first goal of the Haiti pilot was to adapt the booklet for use in clinical care in Haiti. However, the Haiti pilot also provided an opportunity to research and formally evaluate the effectiveness of the materials in a low-resource, low-literacy setting. Through the pilot, the team aimed to establish a protocol for how to systematically adapt and implement the materials in new settings worldwide.

4.2 Methods

The Haiti pilot was carried out by a Harvard Medical School student in collaboration with Haitian staff at the Hospital Universitaire de Mirebalais (HUM) between March - July 2015. The research project was approved by both the Harvard Medical School Institutional Review Board and the Zanmi Lasante Research Committee, PIH's sister organization in Haiti.

There were four phases of the study:

- **Phase 1: Initial Provider Feedback** -- Providers at HUM were shown the translated Creole materials and informally interviewed for feedback on content and design, similar to the design process carried out in Rwanda and Malawi. Limited changes were made to the materials on the basis of this feedback to create the final pilot version, including modifications to the text in Creole and the addition of content on palliative care.
- **Phase 2: Implementation Pilot and Patient Feedback** -- The pilot version was implemented in clinical care and formally assessed via patient interviews (n=20) and focus groups (n=13) with patients presenting to HUM for chemotherapy. Interviews were conducted in Creole by the medical student and Oncology team psychologist over a five week period. Patients were counseled by the psychologist using the booklet, and prompted with open questions immediately afterwards about their impressions of the booklet, the material being learned, and what could be added to the booklet. Patients were encouraged to ask questions during the presentation of the materials and questioned as to whether they had any unanswered questions at the end of the presentation. During focus groups, patients were asked similar questions and presented with line drawings without captions to assess visual comprehension. Observational data also provided insight into how the booklet was distributed and how patients, providers, and others interacted with the materials in clinical care.
- **Phase 3: End of Pilot Provider Feedback** -- Preliminary analysis of patient data informed the development of a provider questionnaire administered towards the end of the 5 week implementation period. The questionnaire was geared towards eliciting general feedback on booklet content and design, including the layout of the booklet and illustrations, proposing revisions to inadequate or ineffective sections of the booklet, and assessing the implementation of the booklet in clinical care.
- **Phase 4: Collaborative Re-Design** -- Provider and patient data was synthesized into preliminary recommendations for modifying the booklet, which were then presented to the entire Oncology team during a focus group discussion. This enabled the staff who were involved in the implementation of the booklet to contribute final input on potential modifications and to brainstorm ways to better communicate information to patients, both visually and textually. A summary of these recommendations was presented to the design team from GO and THE MEME and categorized as Haiti-specific or globally applicable recommendations, based on whether the proposal aimed to make the materials more suitable to the

local context in Haiti (e.g. modifying illustrations, adding population-specific content) or would be broadly applicable to all contexts.

4.3 Results

The patient education materials served as a conversation starter, facilitating a dialogue between patients and providers and prompting patients to ask questions they might have otherwise left unanswered. All participants in the study—and many patients not part of the study—requested a paper copy of the booklet to take home in order to teach their families and friends about cancer, and to encourage others they suspected have cancer to seek treatment for the disease.

Content

Patients felt that the most valuable information in the booklet was about side effects and ways to take care of themselves while receiving chemotherapy. Patients were comforted by this knowledge and felt reassured by the booklet. They felt it prepared them for what to expect while receiving chemotherapy and how to manage the side effects. Topics most often cited as new or important during patient interviews included (n=20):

- Side effects of chemotherapy (70%; n=14)
- Caring for yourself/precautions to take while receiving chemotherapy (65%; n=13)
- What is cancer? (40%; n=8)
- Importance of seeking care when sick (35%; n=7)
- Palliative versus curative treatment (30%; n=6)

Both patients and providers identified several topics that were missing and could be added to the booklet. These topics were listed by providers as important questions or topics discussed with patients, and were brought up by at least 2 separate patients during interviews or focus groups:

- What causes cancer? (e.g. hereditary risk, smoking, environmental exposure)

- Whether cure is/is not possible
- Progression of disease and importance of early detection
- Importance of receiving chemotherapy on schedule
- Importance of avoiding pregnancy during chemotherapy

Including this additional content will better address patients' most common questions and misconceptions about cancer in Haiti, and enhance the effectiveness of the materials as a tool for improving adherence to treatment and quality of care. Providing more scientific information about the causes and risks for cancer can help reduce fear and stigma towards cancer among patients' family, friends and the community at large, and encourages early detection. Explaining how cancer can progress will help patients understand why cure is or is not possible, and justify why adherence to treatment is so vital.

A major theme from the patient focus group was how important it is to encourage patients to keep taking chemotherapy even if they feel sick. Delays in care and loss to follow-up is a major challenge in Haiti, and patients need to understand that delaying or stopping treatment for any reason can result in the progression of their disease. The pilot version of the booklet did state that patients should continue with chemotherapy even if they have side effects. However, the pilot results demonstrated that an essential message of the materials for patients is the importance of receiving chemotherapy on schedule and as such, should be reinforced explicitly and repeatedly.

Many patients at Mirebalais are breast cancer patients of childbearing age who are at risk for pregnancy, which would require them to stop chemotherapy and risk progression of the disease. Negotiating contraception in Haiti is challenging. The staff felt that including a section counseling patients to avoid pregnancy would help those patients, who could show the materials to their partners to explain why they should not become pregnant over the course of treatment.

Literacy level and comprehension

The booklet serves as a resource not just for patients, but also for their families and members of the community at large in central Haiti. While the HUM patient population does include people with no education at all, many patients have attained primary or secondary school education or have family members who did. Information in the booklet must be presented in a way that not only targets low literacy audiences but is conveyed effectively to an audience with varied levels of education.

Choosing the right words for a diverse audience can be a difficult balance to strike. One approach is to say the same thing two different ways, for example: “Is cancer contagious? Can people who have cancer give it to other people?” Patients with no education did not know the word “contagious,” however, patients with higher levels of education found the question “can people who have cancer give it to other people?” confusing.

When it comes to anticipating comprehension of specific wording, an effective strategy for future translations of the materials is to defer to the judgment of the providers who know their patients best. The materials should be adapted to reflect providers’ priorities for content and also for the style in which they communicate information, which has been honed by years of practicing with their particular patient population. In this way, the process of translating the materials becomes a process of cultural adaptation. This process must be carried out collaboratively with the US-based design team and medical professionals, so that local preferences for communication are reconciled with the state of knowledge in the field to ensure the terminology used is both understandable and accurate.

Illustration: Line drawings

During Phase 1: Initial Provider Feedback, the staff at HUM raised concerns about the effectiveness of the line drawings representing “Fatigue” and “Hair Loss.” Of the 16 interview participants unable to read the booklet on their own, less than half were able to identify Fatigue (40%; n=6) or Hair Loss (44%; n=7) accurately. Patients in both focus groups were also not able to identify either of these drawings. Most participants thought

“Fatigue” represented headache or a person who is thinking very hard. Participants thought “Hair Loss” represented head cancer, headache, or some other problem with the person’s head.



FIGURE 4 - Drawings for “Fatigue” and “Hair-loss”.

In order to revise these drawings, participants in both the patient and provider focus groups were asked how best to represent these concepts. They suggested depicting fatigue as a patient sitting or standing with shoulders slouched, head tilted sideways and eyes half closed. Hair Loss could be depicted as a patient brushing their hair with hair falling out on the brush. New versions of the illustrations reflecting variations of these recommendations are currently being tested with patients to assess comprehension.

Side Effect Recorder

Not a single participant in the interviews or focus groups understood the directions for how to use the Side Effect Recorder as written, and many were unfamiliar with the provided scale. The staff also expressed confusion regarding how the page was intended to be used and who should fill it out. After the psychologist explained the chart to patients and described what each smiley face represented, most patients were able to answer questions about what to mark and when.

DIRECTIONS

Circle which emotion you feel for each symptom you experienced. Circle how you feel after each cycle of treatment.

Date	Fatigue	Vomiting	Constipation	Diarrhea
CYCLE 1	  	  	  	  
CYCLE 2	  	  	  	  
CYCLE 3	  	  	  	  

FIGURE 5 - Fragment of the Side-Effects recorder page.

More important than documenting side effects alone, the team found that the recorder encourages patients to report their symptoms and discuss the side effects they experience with their doctor. New instructions were written collaboratively with the providers to emphasize this point: *“You should help your doctors by telling them how you feel after chemotherapy. Use this page to record the problems you have after each chemotherapy visit. For each problem, mark the face that represents how you feel.”* Patients were instructed to fill out the recorder at home between visits and return with the booklet to every chemotherapy appointment.

Layout - Separating Cancer and Chemotherapy

Provider feedback also addressed the layout of the booklet sections. Modularity of topics and the question and answer format was effective as it focused conversations around specific topics with patients. Providers felt the first page “Questions About Cancer” should be expanded to include additional content, and reorganized into two pages: “Questions about Cancer,” and “Questions About Chemotherapy.” This change would decrease the density of the text, increase the clarity of how the questions are arranged, and create space to add more information as text.

5. Conclusions

Designing and testing the “Cancer and You” patient education materials has confirmed that there is a significant need for cancer patient education in low resource settings. As efforts are being made to bring modern cancer medicine to these locations, public awareness of cancer and its associated treatments is still minimal. Low health literacy poses a significant challenge, and lack of knowledge may contribute to delays in care or loss to follow-up.

This process had also shown that design can play a significant role in addressing these challenges. Improving patient awareness of cancer symptoms and treatment side effects promises to facilitate desired changes in patient behavior and attitudes towards their care. Written patient education materials designed for low-resource, low-literacy settings enhance discussions between patients and providers, and can make a significant difference if they are designed considering specific cultural needs. They can also be a tool for disseminating information beyond the hospital to the family, friends and caregivers of cancer patients.

5.1 Scalable Design Process

The iterative design and research process has proven effective to improve the patient education materials. Incorporating patient and provider feedback has been essential to ensure written materials are culturally and literacy appropriate for the local patient population. To make the design process sustainable and scalable, the experiences in Malawi, Rwanda and Haiti provide a good foundation. In particular, the research process in Haiti provides a framework to develop a base protocol to scale global implementation and research for content evaluation and iterative design in multiple locations.

- **Pre-Pilot**

After the document is translated, a preliminary assessment by medical providers is conducted on content and visual materials. The outcome is a set of recommendations for adjustments to improve cultural relevance that can be tested during implementation.

- **Pilot: Patient and Provider Feedback**

The focus is to collect qualitative and quantitative data on the effectiveness of the booklet design, including clarity of content, layout, and illustrations.

- Patient Evaluations (Interviews / Focus Groups)
- Observations on usage of the materials in context.
- Provider Evaluation and Recommendations

It is advisable to have the support of local practitioners to carry out the pilot in the local language and facilitate patient counseling using the booklet. This also helps to establish ownership and emotional investment in the booklet's value by local medical staff.

- **Post-pilot: Co-creative Re-design**

Sharing the results and preliminary recommendations with local staff to collect ideas for final recommendations and design improvements. Evaluation with the rest of the GO team to assess which recommendations are applicable to a specific context and which ones are relevant to all locations.

5.2 Recommendations for Implementation

Ensuring there is an adequate supply of booklets can be a challenge to implementation.

It is essential to have at least one point person to ensure copies of the booklet are in

stock and there are adequate financial resources locally to do so. However, the booklet can and should be distributed at multiple points of care and by all members of the team—when patients are first diagnosed by a physician, when they meet with a nurse before chemotherapy, or during counseling and support groups conducted by the psychosocial team.

The format of the booklet may also differ place to place. When the materials were brought to Rwanda, the booklet was distributed as a laminated copy on the ward. In Haiti, the laminated copies were rarely used because providers were afraid patients would take them home. Providers preferred to give patients their own paper copy and patients similarly wanted a paper copy all of their own, to take home and share with family and friends.

Making sure providers feel empowered to use the booklets for patient education can also become a barrier to implementation. Engaging in a collaborative, interdisciplinary design process that engages the whole team helps get buy-in from providers and ensures they feel comfortable and confident using the materials with patients. Continuing to follow up and maintain an active collaboration with cancer programs that have implemented the booklet will be essential to monitor the use of the booklets in practice and ensure it continues to meet patients' and providers' needs.

5.3 Adapting to Local Contexts

It becomes fundamental to find the best way to identify opportunities to make the materials culturally relevant. Local providers are an excellent source of information about what will and will not work when adapting the booklet to a new population, including cultural adaptation of text and the effectiveness of illustrations. The concerns that

providers raised about line drawings during the initial feedback stage in Phase 1 were substantiated by data collected from patients during Phase 3, suggesting that future implementation and evaluation can rely more heavily on provider's understanding of what will be culturally effective. This information can be collected early as assumptions that can then be corroborated and expanded upon during implementation and evaluation with patients.

It would also be of significant value to study the way the materials are used outside a clinical context. Understanding the way they are shared in patients' homes and communities may help increase cultural relevance and design quality.

In terms of visual design it is important to identify images that may cause confusion or that may have a specific cultural interpretation that distorts its intended meaning. A rapid development of alternative images to be tested can provide a mechanism for fast evaluation. Over time results from different locations will help identify elements that are uniquely problematic within specific contexts and those that need to be changed for all locations.

This has also implications in terms of future sustainability of the project. As part of a global strategy there needs to be a level of consistency in the content and at the same time the possibility to be flexible and adopt changes required by very different communities. This will require further discussion and research in terms of what part of the content are best served as static modules and what parts can be easily customized. It also presents opportunities to address local topics that are unique and may need different tools for assessment and different ways the materials can be used and shared.

There has already been interest to adapt the materials for radiation therapy, pediatric care and for translation to other languages to include additional countries in Africa, Latin America (e.g. Guatemala), and India. There is also an opportunity to extend the type of education materials that can be developed, including other printed formats (e.g. posters, visual cards, patient diaries) as well as to conduct research on opportunities for the design of content in alternative media (e.g. audio, video, mobile) to support patient education in low resource settings.

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