The Knowledge Age:

‘Better’ Outcomes for the ‘Informed Patient’?

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CHAPTER 1: INTRODUCTION AND OVERVIEW

Across recent health reform research, there is growing advocacy and awareness surrounding the idea that patients should act as more effective managers of their health and healthcare. Much research aims to motivate a shift towards a more empathetic healthcare system culture, wherein patients are both encouraged and enabled to participate, engage, self-direct, become empowered, and so on. Knowledge dissemination is frequently named as the preliminary requirement for this shift in attitude and behaviours. Often times, the Lymphoma Coalition (LC) patient community is told anecdotally that the informed patient is a ‘better’ patient, and has ‘better’ outcomes. Because of this, the LC launched a mixed methods (literature review & qualitative interviews) investigation with a single broad objective: to determine if evidence exists that points to better outcomes for more informed patients. It was hypothesised that the correlation between more patient knowledge and ‘better’ outcomes would be positive; however, the parameters and quantifiability of these outcomes were unknown.

Before outcomes could be investigated, parameters had to be put around a lymphoma-specific definition. An extensive scoping literature review was conducted with the initial research question, ‘What key concepts and terminology underlie published definitions pertaining to ‘informed’ patients?’ Given the lack of the term 'informed patient' across the literature, principal terminology that was referenced and repeated often (i.e. activation, engagement, participation, empowerment) was recorded and qualitatively analysed. Relevant components of each term were added to the LC definition specific to lymphomas:

‘Any patient that is informed on their subtype, has a very good understanding of the diagnosis, and has a say in their course of care (treatment and psycho-social). The patient is engaged with a supportive healthcare delivery system, where they are included in information discussions, and are provided with direction on the best information and support for their subtype. The patient is respected as a person and their questions are listened to, heard, and the response elicits a sense of trust—allowing patients to gain confidence in maintaining an active role throughout their patient experience.’

Following the defining process, the literature review narrowed in on studies whose underlying research definitions captured the majority of concepts represented in the LC definition. Study findings were then systematically clustered. Important to note is that in beginning this project, an initial objective and general research areas were determined; however, outcomes were undefined. The main outcome areas were allowed to take shape as defined by the research available. Further, LC is neither agreeing nor disagreeing with these defined outcome areas. We are rather laying out a body of available data, with some thematic and overarching analysis, to encourage critical thought and discussion.

This paper aims to explore and highlight the latest research in the following areas:

A) Defining ‘informed patient’ in a lymphoma-specific context
B) The process of becoming informed (supports and barriers) at the following levels:
   - Individual: educational, socioeconomic status, health literacy, technology and eHealth literacy, patient initiative
   - Community: culture, doctor-patient communication and where the responsibility lies
   - Region/country: relativity of information
C) Informed vs. uninformed and outcomes:

- Patient knowledge and experience
- Use of services and costs to the healthcare system
- Health behaviours and health status: health related lifestyle/self-care activities, treatment adherence, severity of disease & symptoms, mental and physical functioning

These research areas are used to derive broad themes and conclusions, especially surrounding patient confidence in relation to patient choice, and in relation to risk factors and outcomes throughout the patient experience. These risk factors analyse the patient’s relationship with their healthcare providers (hcps) and the wider healthcare system. The disconnect between a systemic healthcare model and individual patient care and choice is pointed to. This report does not place blame; it is to help us better understand the system in order to support all its pieces to function seamlessly, so that patients can get the care they perceive they need.

CHAPTER 2: METHODOLOGY

2.1 Overview

A mixed methods study was conducted comprising the following steps:

i) A 'scoping' literature review to identify the underpinning components of published terminology surrounding 'informed' patients to:
   a) form the LC definition of 'informed patient'
   b) identify outcome studies

ii) Qualitative interviews with key stakeholders (former/current lymphoma patients, LC members, professors, researchers, physicians, oncologists, and nurses (hematology/lymphoma specific and otherwise))

The initial goal of the literature search was to put parameters around an LC definition of 'informed patient'. Principal terminology that was referenced and repeated often was recorded and qualitatively analysed. Relevant components of each term were added to the LC definition in a way that was sensitive to both comprehensiveness and conciseness.

Given the lack of the term 'informed patient' across the literature, the LC definition was formed with key elements of existing terminology in order to derive outcome data. Studies were then sourced, and results were only included if the underlying research definitions (i.e. activation, engagement, etc.) under investigation were comprehensive of the majority of LC definition elements. Qualitative interviews were conducted throughout the literature review process. Data collected using both methodologies was studied using thematic qualitative analysis. Relevant data was pulled from the LC Global Patient Survey databank (2014-2016) to support themes and add context.

2.2 Literature Search

The literature search was conducted ongoing between June 30th- November 1st, 2017. Search terms/strings have been indexed in tables according to database. Databases searched include; PubMed,
Google Scholar, National Institute for Health and Care Excellence Database (NICE, USA), the LC Resource Library and Global Data Base, and the McMaster University's Health Evidence Database (Hamilton ON, Canada). LC Global Patient Surveys (2014 & 2016) were also used for context. Google, government, and relevant organisation websites were also used to identify applicable grey literature.

Studies and articles were first examined by title and abstract. Final articles included in this review were those that met the scope of the topic and were of sound quality. Where possible, meta-analysis and systematic reviews were chosen. Studies considered for initial review were limited to those which were published in the last five years; those published in peer-reviewed journals; those which were published in English; and those which focused on populations of developed countries. Following the initial review, the study selection process continued as outlined below.

2.2.a Study Selection

A detailed outline of the literature selection process can be found in Figure 1. Of the 173 total studies under initial review, 27 were immediately excluded based on analysis of title and abstract—the excluded articles lacked basic information that was directly relevant to any of the outlined research areas. The abstracts of the remaining 146 publications were screened for explicit references to ‘informed patients’ (in relevant terminology), and for associated outcome studies. From this screening, 64 articles were eliminated based on their focus on variables and concepts outside of the identified areas of interest and relevance. Duplicate articles (same article, different database) were also removed. The last step of the selection process was an independent full text analysis of the remaining 82 publications. Though articles were labelled as more relevant or less relevant, articles were not eliminated immediately based on the initial full text read. This is because as core concepts and themes came to light, many articles proved relevant in supporting sub-sections of the paper. Articles that were not used were discarded at the end of the writing process. In total, 61 final studies and articles were included in this review.

Figure 1. Literature Search Study/Article Selection Process.
2.2.b Analysis and Synthesis of Study Findings

A systematic, scoping literature review was conducted. Meta-analysis was not attempted given the heterogeneity of the articles (both subject and type), as well as the heterogeneity of the populations and outcome measures among included studies. A scoping literature review is a method used for mapping key concepts in literature underpinning a research area (Bravo et al., 2015). It follows a 5-stage framework: 1) identify the research question; 2) identify relevant studies; 3) select studies; 4) chart the data; and 5) collate, summarise and report the results (Bravo et al., 2015). The initial research question was, 'What key concepts and terminology underlie published definitions pertaining to 'informed' patients?’. Findings were clustered according to their relevance in examining the processes of defining an informed patient, becoming an informed patient, and comparative studies examining outcomes pertaining to being informed vs. uninformed (in relevant associated language). Within each of these defined areas, variables were identified and clustered into specific subsections.

2.2.c Defining 'Informed Patient'

The LC defines an 'informed patient' as:

'Any patient that is informed on their subtype, has a very good understanding of the diagnosis, and has a say in their course of care (treatment and psycho-social). The patient is engaged with a supportive healthcare delivery system, where they are included in information discussions, and are provided with direction on the best information and support for their subtype. The patient is respected as a person and their questions are listened to, heard, and the response elicits a sense of trust—allowing patients to gain confidence in maintaining an active role throughout their patient experience.'

This definition was framed in consideration of both the literature review results, as well as interview interpretations. There is a multitude of current literature that circulates various terminology relating to being an 'informed patient'. The LC definition aimed to understand, analyse, and blend these existing conceptualisations—combining applicable elements of each. Key terminology employed in forming the LC definition is highlighted in Table 1.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activation</td>
<td>'Patient's willingness and ability to take independent actions to manage their health and healthcare. Understanding one's role in the care process and having the knowledge, skill, and confidence to manage one's health and healthcare'.</td>
<td>(Hibbard &amp; Greene, 2013)</td>
</tr>
<tr>
<td></td>
<td>'The knowledge, skills, and confidence a person has in managing their own health and healthcare.'</td>
<td>(Hibbard &amp; Gilburt, 2014)</td>
</tr>
<tr>
<td></td>
<td>'Those who are activated believe patients have important roles to play in self-managing care, collaborating with providers, and maintaining their health. They know how to manage their condition and maintain functioning to prevent health declines; and they have the skills and behavioural repertoire to manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care.'</td>
<td></td>
</tr>
<tr>
<td>Engagement</td>
<td>‘Acknowledges that patients have a key role to play in their own healthcare. This includes reading, understanding and action on health information (health literacy), working together with clinicians to select appropriate treatments or management options (shared-decision making) and providing feedback on healthcare and processes and outcomes (quality improvement).’</td>
<td>(Coulter, 2012)</td>
</tr>
<tr>
<td>Empowerment</td>
<td>‘Enabling process or outcome arising from communication with the healthcare professional and a mutual sharing of resources of information relating to illness, which enhances the patients feeling of control, self-efficacy, coping abilities, and ability to achieve change over their condition.’</td>
<td>(Small et al., 2013)</td>
</tr>
</tbody>
</table>

> 'Indicators of patient empowerment: self efficacy, knowledge, skills, attitudes and self-awareness necessary to influence their own health behaviour, perceived personal control over health and healthcare, sense of meaning and coherence about their condition, health literacy, feeling respected.' | (Bravo et al., 2015) |
| Participation | ‘An interaction, or series of interactions between a patient and the healthcare system or a healthcare professional in which the patient is active in providing information to aid diagnosis and problem-solving, sharing his/her preferences and priorities for treatment or management, asking questions and/or contributing to the identification of management approaches that best suit his/her needs, preferences or priorities.’ | (Small et al., 2013) |
| Self-Management | ‘The care taken by individuals towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional, and psychological needs; to care for their long-term condition; and to prevent further accidents or illness.' | (Small et al., 2013) |

Following initial brainstorming with key members of the LC team (and wider associated community), a lymphoma-specific working definition was established. This definition was inclusive of critical patient qualities essential for understanding a lymphoma diagnosis and next steps.

From here, the literature search and review were conducted. In analysing the literature surrounding this topic, principal terminology that was seen to be referenced and repeated often was recorded (see Table 1). Each of these principal terms was further researched and compared to our initial definition. Similarities and differences were identified. It was determined that ‘patient activation’ was the concept that aligned most closely; it provides a unique measure of engagement and empowerment. It is measured using the Patient Activation Measure (PAM), a 22-item instrument (or the scaled 13-item short form) that assesses patient self-reported knowledge, skills, and confidence for self-management of one’s health or chronic condition (Rademakers et al., 2012). The PAM divides patients into one of four progressively higher activation levels, which are associated with specific health and self-care behaviours (Rademakers et al., 2012). Though ‘patient activation’ was made a focus, relevant components of each term were added to the LC definition in a way that was sensitive to both comprehensiveness and conciseness.

Given the general lack of the term ‘informed patient’ across studies and peer reviewed articles, it was crucial to form the LC definition with key elements of existing terminology in order to derive outcome data. Study results were only included if the underlying research definitions (i.e. activation,
engagement, etc.) under investigation captured the majority of concepts represented in the LC definition.

2.3 Qualitative Interviews

Interviews were conducted, ongoing, from August 1st to October 30th, 2017. Following the initial literature search, topics of interest and main themes were identified. These themes were used to develop a comprehensive qualitative interview guide. The questions used in the interview guide aimed to prompt discussions surrounding the principal areas targeted by the original research questions. The questions provided opportunities for the participant to narrate stories, and to reflect upon lived experiences. The questions in the guide were modified depending on the interviewee, allowing them to speak best to their area of expertise/knowledge. Individuals targeted for interview discussions included: former lymphoma patients, LC members, professors, researchers, physicians, oncologists, and nurses (hematology/lymphoma specific and otherwise). These interviews were conducted via phone, or using such online platforms as Skype and Join Me. Interviewees were located around the world (i.e. Canada, USA, UK, Europe, India, Israel, China). Interviews were recorded (when possible) and transcribed (in Microsoft Word).

2.3.a Description of Methods Analysis

In qualitative research, data analysis entails preparing and organising the data to reduce it into themes (Creswell, 2013). Themes are derived through coding processes, wherein codes are identified and can be subsequently condensed and combined.

In analysing the interview transcripts, data management was the first step in the process. The data was organised into PDF files by interviewee type and chronology. Next, each transcript was read in its entirety. General memoing was used in the first read through of each transcript. These recorded memos were short phrases, ideas, and key concepts that initially came to light (i.e. striking statements, potential themes, etc.). Looking over these initial notes allowed for reflection on larger thoughts presented in the data, which allowed for initial category ideas to be formed.

The next step was to move towards describing, classifying, and interpreting the data. This was achieved through developing a coding system. Classifying began with deciding on a breakdown strategy for the transcripts. Given the loaded nature of many statements throughout the transcripts, doing a 'selective/highlighting' analysis was the most advantageous. Based on the initial review of transcripts, 'lean coding' was implemented; 3 main categories (corresponding to the literature search) were identified and numbered 1-3. In applying the strategy to the first transcript, 'significant statements' were coded with appropriate categories (1-3) to group them into 'meaning units' or themes. Categories were also expanded and coded when strong subcategories were noticed, for example, 1 a/b/c. These subthemes were added to the initial 3-code list, and then this master code list was applied to the other transcripts, with modifications as necessary.

Interpreting the data was achieved through analysing both textual descriptions (what the participants experienced) and structural descriptions (how the participants experienced the phenomena). Using the coding system and resulting interpretations, key statements and ideas could be applied as supports to the literature.
CHAPTER 3: BECOMING INFORMED

This section will discuss individual, community, and region/country level factors that support or prevent the patient process of becoming informed.

3.1 Individual Level Factors

At the individual level, social determinants of health can either support or hinder a person’s ability to seek, understand, and apply health information. These social determinants refer to the set of environmental conditions in which people are born, live, learn, work, play, worship, and age (Braveman & Gottlieb, 2014). Determinants of relevance include:

- Access to educational/economic/job opportunities, quality of education, language and (health) literacy
- Access to emerging technologies, culture/religion, socioeconomic status, and
- Social norms/support

3.1.a Education, Socioeconomic Status, and Health Literacy

In examining the literature, it appears education, socioeconomic status, and health literacy function in dynamic interplay with such behaviours as health information-seeking, evaluating, and applying. Critical to understanding these relationships is first an understanding of the term ‘health literacy’. Over the past 2 decades, health literacy has been increasingly recognised as having influence on the exchange and application of information among patients, their providers, social networks, and wider health systems (Dageforde & Cavanaugh, 2013; Smith et al., 2013). A commonly circulated definition explains health literacy as the capacity to seek, process, and understand basic health information and services to make appropriate health decisions (McCaffery et al., 2013). However, definitions encompassing a wider range of cognitive and social skills are increasing in popularity.

For example, Nutbeam’s model of health literacy delineates three levels:

1. Functional health literacy: basic reading, writing, and comprehension skills to understand health information, conditions, services and systems

2. Communicative/interactive health literacy: higher level communicative and social skills necessary to source, extract, and discuss information with others

3. Critical health literacy: advanced cognitive and social skills necessary for analysing information and applying it in making informed decisions (McCaffery et al., 2013)

Note: Though the concept of health literacy is widely accepted, universal agreement on a definition has yet to be established. When considered globally, measures and proxies vary immensely. Much research on health literacy and associated outcomes is specific to the ‘Western world’.

Studies suggest significant correlations between education level and health literacy, and between ethnicity/race/socioeconomic status and health literacy. Low health literacy is observed more frequently among those with fewer years of formal education (or lower quality education), minority ethnic groups, older adults, those who lack internet access, and those in a lower income bracket.
The population reach of limited health literacy is significant. In 2013, it was estimated that 36% (80 million adults) of the population had ‘basic’ or ‘below basic’ healthy literacy in the United States (McCaffery et al., 2013). Many studies explain that limited health literacy persists even among those with adequate, or above adequate general literacy and comprehension skills (Al Sayah et al., 2013; Henrich, 2012; Eckman et al., 2012). These statistics are striking given the implications of health literacy levels. A person’s level of health literacy affects their ability to source, understand, and apply health information towards interacting with and navigating key health services (McCaffery et al., 2013). Having low health literacy is associated with poor outcomes in the following areas: engagement with health services, health knowledge, concordance with prescriptions, self management of illness, overall health status, and survival (Greenhalgh, 2015).

Additionally, patients with low health literacy ask fewer medical questions and are less able to respond to physician communication (Aboumatar et al., 2013). Some studies explain shame or embarrassment as reasoning behind this; people with lower health literacy may feel the need to conceal their health comprehension level from hcp s—and so refrain from asking questions or requesting further explanations (McCaffery et al., 2013). Conversely, some study results indicate patients with low and adequate health literacy express similar interest in participating in medical decision-making; however, are less likely to experience participatory decision making in their visits (Omachi et al., 2013). In either case, barriers are presented against patients becoming fully informed.

### 3.1.b Technology and eHealth Literacy

Access to technology, coupled with technological proficiency, can provide patients with access to a hub of informative online resources. According to the LC 2016 Global Patient Survey (GPS) report, 60% of respondents reported using ‘online’ sources as their primary information channel throughout their patient experience. Additionally, as seen Table 2 below, patients were more interested in receiving a referral from a hcp for website links than interested in physical or emotional professional support (Lymphoma Coalition, 2016).

**Table 2:** Interest in Potential Referrals from Healthcare Professionals (LC 2016 GPS Report).

<table>
<thead>
<tr>
<th>POTENTIAL SERVICE</th>
<th>% of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Website links about lymphoma type &amp; treatment suggestions</td>
<td>70% 20%</td>
</tr>
<tr>
<td>Patient organisation support</td>
<td>61% 23%</td>
</tr>
<tr>
<td>Professional emotional support</td>
<td>45% 37%</td>
</tr>
<tr>
<td>Professional physical support</td>
<td>44% 37%</td>
</tr>
</tbody>
</table>

**LEGEND**

Most negative

Most positive
The concept of ‘eHealth’ is relatively new, and refers to the utilisation of information and communications technology to improve or enable health and health care (Neter & Brainin, 2012). Systematic analyses of online health communities and patient portals suggest that participation in online health communities leads to benefits in the form of information utility and social support (Kruse, Bolton & Freriks, 2015; Johnston et al., 2013; Kuijpers et al., 2013). Further, informed by online resources, individuals may feel empowered and enabled to participate fully in health decisions (Goldzweig et al., 2013; Neter & Brainin, 2012). However, extending digital and multimedia resources into the health domain has created new gaps in healthcare consumption relating to ‘eHealth literacy’ (Diviani et al., 2015). eHealth literacy is the ability to seek, locate, understand, evaluate and apply health information from electronic sources towards addressing a health problem (Neter & Brainin, 2012). Though the gap in technological access is narrowing in developed countries, the issue appears to stem from population gaps in eHealth literacy (Diviani et al., 2015).

Notable divides in eHealth literacy include age and education. Studies analysing trends in eHealth literacy suggest that younger (i.e. $F_{1,1284} = 35.56, P < .000$; mean 38.87, SD 14.40 years (high eHealth literacy group) vs. mean 44.12, SD 17.00, years (low eHealth literacy group)), more educated individuals tend to be more eHealth literate (Neter & Brainin, 2013). Due to their greater digital knowledge, this population group (or those with higher eHealth literacy generally) consumes more electronic information in various forms. They also employ more search strategies, evaluation techniques, and are more scrutinising of information (Diviani et al., 2015). Repeated use of digital resources is also associated with an improved ability to recognise the quality of information, as well as potential gaps and inaccuracies (Neter & Brainin, 2013).

Correspondingly, many studies suggest that older adults often lack the sufficient technological skills to maximise benefits from online information resources and portals (Watkins & Xie, 2014; Kruse, Bolton & Freriks, 2015; Kuijpers et al., 2013). This is problematic in lymphomas, as many subtypes affect older adults. However, studies comparatively analysing print and multimedia health information sources have failed to prove significant differences in their effectiveness in practice (Wilson et al., 2012). Therefore, the effect of the source of information on patient understanding remains relatively undefined.

3.1.3 Patient Initiative

Patients can also possess varying levels of individual drive to become informed, influenced by the specificities of their condition and personal preferences. For each individual, the capacity and desire to learn will be different. In lymphomas for example, Hodgkin’s lymphoma (HL) typically has a long-term remission rate that is relatively high compared to such less aggressive lymphomas as Mantle Cell (MCL) or Follicular (FL). It is possible that someone with HL will be given a standard chemotherapy treatment (information for which is readily available), go into long-term remission following treatment, and never relapse. For someone with a lymphoma of a more chronic and relapsing nature (MCL, FL), there may be a greater sense of urgency to remain informed, as survivorship will be a persistent theme.

Further, the extent of what a patient desires to know is highly individualised. Anecdottally and throughout the literature, a common theme among newly diagnosed patients is fear. Patients are reluctant to seek in-depth information about their condition in fear of what they may discover.
According to the testimonial of a former lymphoma patient in qualitative interview, 'it is often acceptance and support that prompts someone to pursue information-seeking behaviours following their initial 'fight or flight' reaction'. However, research indicates the existence of a spectrum of patient activation, wherein a patient’s choice to seek and understand information ranges from allowing the doctor/caregiver/family member complete control, to baseline understanding, to full comprehensive knowledge (Smith et al., 2013; Greene & Hibbard, 2012). Studies specific to patient activation have divided patients into one of four progressively higher activation levels, which are associated with specific health and self-care behaviours (see Figure 2 below) (Rademakers et al., 2012).

Figure 2: Four levels of patient activation defined by the Patient Activation Measure (PAM). Adapted from Insignia Health 2016 PAM Survey Levels schematic.

Depending on where a patient falls on this scale, and on their level of engagement and understanding more generally, the amount and type of information they will seek will vary immensely. For some, attempting to navigate through a multitude of constantly evolving information can become a source of stress and despair. For others, failing to remain comprehensively informed will elicit this same response. It cannot be assumed that every patient will want to know everything about their disease, the subjectivities of this are evident. Important to note is that the activation scale is not fixed. Patients can move up or down in activation throughout their patient experience (Greene & Hibbard, 2012). Susan Thornton of the Cutaneous Lymphoma Foundation, US, equates the ‘stages of grief’ with ‘stages of capacity’. She stated (in qualitative interview) that following the initial shock, fear, and denial that comes with a lymphoma diagnosis, many patients are seen to become ‘experts’ in their disease over time. She was careful to mention that this is not the case for all patients, and the level a patient chooses to engage can not be deemed right nor wrong.

For some, attempting to navigate through a multitude of constantly evolving information can become a source of stress and despair. For others, failing to remain comprehensively informed will elicit this same response.

Further, there are many information types available (i.e. condition specific, biology/physiology, treatment, side-effects, clinical trials, emotional/social support, physical support, financial support, patient organisation information, etc.). Which information is prioritised is highly subjective, often dependent upon a patient’s condition and the specificities of their values and beliefs.
3.2 Community Level Factors

3.2.a Culture

Racial, cultural, and ethnic disparities in healthcare have been well described. The emerging field of 'cultural competence' explains that barriers to health information-seeking, accessibility and understanding can occur at the organisational (leadership/workforce), structural (processes of care), and clinical (provider-patient) levels (Betancourt et al., 2016). Culture can greatly affect one's ability, or even willingness to seek information. This is illustrated in the case studies below, as described (in qualitative interview) by lymphoma patient organisations:

Vandana Gupta, founder of V Care Cancer, India:

*In India, there are generally three main classes: very poor, middle class, and upper class. This class system perpetuates many cultural divides, most of which prevent individuals from seeking or understanding health information. To the very poor, doctors are equated with gods, and so to ask questions of them or seek further information is disrespectful. The middle class has better access to technology and resources, but still feel as though they should not 'annoy' the doctor with questions. The upper-class desires to know everything and has access to boundless information and resources (financial and otherwise); however, they refrain from asking questions or seeking support because having cancer is conversational and societal taboo. There are cultural associations wherein a cancer diagnosis is a karmic manifestation of a familial wrongdoing in the past. Further, using the word 'cancer' is perceived as stressful for the oncologist and the patient. The diagnosis is often withheld from the patient and explained rather to the family to prevent patient stress and depression.*

Guy Tavori of Flute of Light, Israel:

*In Israel, disease can be coupled with shame—though the prevalence of this has decreased significantly. For example, if a couple wants to marry, and someone in either of the potential spouse's family is ill or has a disability, it can serve as a reason to not marry into that family. This can prevent someone from seeking medical attention or information even if they intuitively sense something is wrong.*

Hong Fei, Founder of House 086, China:

*In China, the patient’s family members will be generally informed of the condition. The doctor will only tell the patient directly if the patient is young and the condition is not serious. Once the information is with the family, the family will typically disclose the information if the patient is young, and conceal the information if the patient is elderly.*

3.2.b Doctor-Patient Communication

For many patients, doctors and other hcps remain as primary information sources throughout their patient experience. As such, dialogue and information sharing behaviours are important to analyse as they pertain to enabling or preventing patients from becoming informed.

The patient-clinician relationship has both emotional and informational components. Emotional care involves mutual trust, respect, empathy, acceptance and warmth (Kelley et al., 2014). Cognitive care involves information gathering, sharing medical information, patient education, and expectation management (Kelley et al., 2014). Communication will often indirectly affect one's ability to become/
remained informed via its influence on such intervening variables as: patient understanding, patient-clinician agreement on treatment, adherence to treatment, etc. (Street, 2013).

A recent article in the New York Times, written by two oncologists, describes a sort of collusion that takes place in the doctor-patient relationship—one which prevents patients from understanding the full scope of information necessary (Sekeres & Gilligan, 2017). Clinical factors often drive doctor-patient communication. To quote one doctor, ‘unfortunately, it’s often not really about informing you.’ (Sekeres & Gilligan, 2017). They describe a relationship influenced by social norms, and characterised by complicacy. Over time, patients are conditioned to expect that doctors may be annoyed or concerned should they not understand information, or ask for it to be repeated (Sekeres & Gilligan, 2017). This may prevent patients from asking beneficial questions, or from seeking clarifications should they feel their questions are not answered. For example, the LC 2016 GPS report indicated that on a global basis, 61% of respondents said that patient’s physical and emotional issues had been communicated to their doctors. However, only 30% said they had been definitely helped by them (doctors), while 18% said they had not been helped, and as many as 50% said that their doctors had only been of ‘some help’ (Lymphoma Coalition, 2016).

This disconnect is noted throughout the literature; there can be major discrepancies between what a physician communicates, and what a patient takes away or understands. Dr. Jessica Greene, a lead researcher in ‘patient activation’ notes (in qualitative interview) that in mediating these discrepancies, there is a tremendous lack of patient confidence in persistent information seeking, or challenging/ disagreeing with a physician in a non-confrontational way. For example, an observational study was conducted by Martin et al. analysing the perceptions of both patients and physicians following consultations. It was found that patients reported much of the consult focus to be on prescribing and referring, while physicians reported the focus to be active listening, supporting, and giving advice (Verlinde et al., 2012). Additionally, limits on physician’s time can discourage these behaviours. Hong Fei of House 086, China, indicated (in qualitative interview) that lymphoma doctors in China will face dozens to hundreds of patients a day—making it systematically difficult to get comprehensive disease information from them. Vandana Gupta of V Care Cancer, India, outlined (in qualitative interview) a similar systematic barrier. Physicians in India are often only able to spend roughly 5 minutes with each patient, during which time they will give, in medical language, the diagnosis and treatment options. The patient will not ask questions.

A recent study out of Centre For Research and Technology (CERTH), Hellas (Greece), examined the research question, ‘Do physicians need help to better support their Chronic Lymphocytic Leukemia (CLL) patients?’ Semi-structured interviews were conducted with hematologists (n=30) from all over Greece (Karamanidou, 2017). The study results indicated that physicians experienced great uncertainty surrounding communicating information to patients, and felt uncomfortable delivering ‘bad news’ (i.e. initial diagnosis, relapse, and poor prognosis) (Karamanidou, 2017). It was found that none of the participants had ever received formal communication training, causing them to frequently doubt their approaches (40%) (Karamanidou, 2017). Some physician-reported communication techniques included: using caregivers as mediators when communicating difficult issues (80%), balancing realism with hope (70%), choosing words carefully (60%), disclosing information gradually (56.7%), and using pictorial...
representations or metaphors in descriptions (53%) (Karamanidou, 2017). However, the most common technique reported was adapting the quality and quantity of information provided according to each patient's characteristics (96.7%) (Karamanidou, 2017) – the subjectivity of these 'patient characteristic' judgements can prove both beneficial and problematic.

There are many studies examining the 'social gradient' in doctor-patient communication. Several reviews have found that patients from a lower social class (measured by income, education, occupation) receive less socio-emotional talk and a more directive/less participatory consulting style (less involvement in treatment decisions, more biomedical talk and physician question asking, less patient control over communication, less diagnostic/treatment information, more physical examination) (Street, 2013; Verlinde et al., 2012; Weiner, 2012; Dy & Purnell, 2012). Conversely, patients from a higher social class receive more information, more explanation, more emotional support, and more often a shared decision-making style (Street, 2013; Verlinde et al., 2012; Weiner, 2012; Dy & Purnell, 2012). In a social system, how does a physician know this information about a patient? Is it judgmentally determined?

Studies suggest a few ways that physicians make these discernments (verbal, non-verbal, education level, employment). For example, patient's verbal behaviours have been seen to influence physician's communication style. In a study by Street et al., physician's information giving was positively influenced by patient's question asking, affective expressiveness, and opinion-giving—behaviors which were associated with patients with higher education levels (Verlinde et al., 2012). According to a study by Siminoff et al., patients who attempted to build interpersonal relationships with their physicians were met with more effort from the physician to reciprocate. This behavior is significantly associated with educational level as an independent factor (Levit, Balogh & Nass, 2013). Though tailoring medicine towards individual patient characteristics can be beneficial for information comprehension, it can also be problematic given the subjectivity of the physician's judgement. For example, for a patient of perceived higher socio-economic status, it can be assumed that they know more than they do. Conversely, for a patient of perceived lower status, a specific treatment may not even be disclosed should the physician assume they cannot afford it.

Cultural, community, and linguistic competence are also important to consider. Studies indicate that patients consider their providers ability to understand their cultural or ethnic background important (Blue Shield California, 2012). ‘Continuity' and ‘connectedness' are also notable themes from the literature. Continuity and connectedness do not directly guide patient engagement, rather indirectly increase health information, confidence, comfort, and comprehension (Blue Shield California, 2012).

Studies indicate that patients are more comfortable asking questions, and providers usually explain things in a way that patients can understand if:

a) patients see the same provider on a regular basis (continuity)

b) there is a sense that someone at their care facility knows them well (connectedness)

(Blue Shield California, 2012).

3.2.c Responsibility

Each participant in the LC qualitative interview process was asked ‘Whose responsibility is it to be informed?', referring to the patient in the context of the healthcare system. There was consensus across most interviews that the patient bears the largest responsibility in becoming and remaining 'informed'. Exceptions to this were cultural-specific, for example in China, where the information is
intentionally concealed from the patient and given to the family.

There were many underlying ideals behind this consensus, but a main theme was accountability. This meaning that the doctor-patient relationship is not unidirectional, the patient should be ‘giving back’. Many interviewees spoke to the idea that in the end, no one is as invested in your health and well being as you are. There was also consensus that a patient’s process of becoming informed and confident must come from not only actions they are taking, but also from the healthcare system and how their physicians (and other hcps) are engaging with and supporting them. Patients, after all, do not know what they do not know.

Though interviewees deferred the principal responsibility away from physicians (due to time, taxing workload, disease parameters of lymphoma specifically, etc.), they did indicate a necessity for physicians to refer patients on to those who can support the information dissemination process. Guy Tavori of Flute of Lite (patient organisation), Israel, provided some insight on how ‘personalised medicine’ could be better applied in physician’s language. For example, asking ‘how can I best support you?’ or ‘what type of information would you find most beneficial?’ (i.e. medical info, social/emotional support info, be connected to patients like you, etc.) instead of bombarding patients with information that they may not want or understand. Shawn Sajkowski of the LC, and former lymphoma patient, suggested that hcps be trained to encourage information-seeking via various information channels (i.e. support groups, patient organisations, social workers, etc.), while remaining the broker for medical information pertaining to the patient’s case.

3.3 Region/Country Level Factors

3.3.a Relativity of Information

Important to discuss is relativity of information. In many instances, information that is immediately accessible to a patient is context specific. Hcps cannot possibly remain informed on every evolving parameter of every disease, condition, subtype etc. However, a patient’s primary healthcare provider is often their main source of information. The LC 2016 GPS indicated that 80% of respondents had used doctors as their primary information source throughout their patient experience (Lymphoma Coalition, 2016). This can be problematic in terms of comprehensiveness given that in many regions/countries, doctors simply do not have time to exhaust researching treatments and therapies available globally. The information they will possess may be relative to their country or region. Further, as was mentioned earlier, it is not uncommon for physicians in certain countries to intentionally withhold information from the patient.

It then becomes the patient’s responsibility to seek out further information; however, if even the doctor does not possess the information, it becomes difficult to discern an honest broker for all sources gathered. Additionally, patients can run into translation issues when seeking further information. For example, if patients in Israel are seeking information regarding lymphomas through such common search engines as Google, information will be relatively non-existent in Hebrew (as reported by Guy Tavori, qualitative interview). To get search hits, they may have to search in English—problematic for those not proficient in English. Though translators do exist, they are certainly not error free, complicating an already daunting health literature search. This is true not only for the patient, but also for physicians, clinicians, and researchers around the world given the predominance of the English language across the scientific community. These are all implications to consider in someone’s desire and capacity to become informed. Further, depending on the model of a country’s healthcare system, a patient’s ability to use
the information gathered could be limited. In China for example (as reported by Hong Fei, qualitative interview), in lymphoma treatment, patients have no other opportunity for input other than choosing to determine the hospital in which they receive it—unless they choose to leave the country.

CHAPTER 4 : INFORMED VS. UNINFORMED AND OUTCOMES

This section will examine the implications of being 'informed' vs. 'uninformed' in the following outcome areas: patient knowledge and experience, use of services and cost to the healthcare system, and health behaviours/health status.

The statistics and studies presented build on the initial findings of the 2002 Cambridge University (Cambridge, UK) 'Informed Patient Study', which suggested that better informed patients: are less anxious, more satisfied, follow advice better, select lower risk treatments, begin treatment earlier, and help healthcare costs drop though more self-management and more efficient use of resources (Detmer et al., 2003). Though much of the evidence presented may seem intuitive, research has aimed to build systematic, quantitative data behind the patient knowledge-outcome relationship. Understanding this relationship, among other factors, is an effective tool for improving public health across a range of different populations and health conditions.

Disclaimer

Much of the sourced data that met the criteria of the LC literature search (published in the last five years; those published in peer-reviewed journals; those which were published in English; focused on populations of developed countries) was US-centric—especially studies surrounding 'patient activation' (developed in Oregon, USA). There was some concern that outside of the US healthcare model, use of the Patient Activation Measure (PAM) and its results could be irrelevant. However, in recent years, the PAM-13 (short form 13-item PAM version) has been translated, adapted (healthcare system, cultural, psychometric properties), and validated as a reliable instrument for measuring activation in patients with chronic disease in Spanish, Italian, Dutch, and Danish versions (Moreno-Chico et al., 2017; Verlinde et al., 2012). Further, information from studies beyond the US was incorporated wherever and as often as possible.

4.1 Value of Information in a Patient Outcome Context

Throughout the literature review process, a series of qualitative interviews were conducted with hcp's, researchers, patient organisation representatives, and former lymphoma patients from around the world. Each interview participant was asked, 'What does information give to a patient, what is the value of it?'. Table 3 below notes some responses to this question.
When asked this question, interview participants were not given background on specifics of the literature search findings or themes that had been determined. Further, this question was asked at the beginning of the interview. Interesting to note is that with no probing, most respondents used some form of the word 'confidence' in their explanation of what information gives to a patient. The theme of patient confidence will be further explored throughout the succeeding sections.

4.2 Patient's Knowledge & Experience

The literature indicates an inherent connectedness of patient knowledge with patient confidence—which functions in a type of positive feedback loop (or negative, in the case of ‘uninformed’ patients). This same connection was acknowledged throughout the interview process. When a patient has knowledge surrounding their condition, treatment options, and self-care practices, doctor-patient communication is more fluid, patient experience is improved, and patients are more inclined to be confident in taking a sustained active role in managing their health and condition. This theme is echoed in study results across a wide range of patient and condition groups.

The Blue Shield of California Foundation ran a telephone survey from March to April 2012, with the intent of exploring trends in patient empowerment and engagement. Survey findings suggest that

<table>
<thead>
<tr>
<th>Title/ Affiliations</th>
<th>Response</th>
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<tbody>
<tr>
<td>Dr. Judith Hibbard Research Professor University of Oregon</td>
<td>'Information is necessary but not sufficient, must also develop a certain competence to carry and use the information with confidence.'</td>
</tr>
<tr>
<td>Vandana Gupta Founder V Care Cancer India, Cancer Survivor</td>
<td>'Information gives a patient confidence, especially to poor and uneducated. If you speak to them in a way they understand with terminology they will understand, they will have the confidence to ask more questions, seek more information, and then present this to the doctor.'</td>
</tr>
<tr>
<td>Shawn Sajkowski Lymphoma Coalition Lymphoma Survivor</td>
<td>'Information gives patients reassurance, allows them to feel more in control of their health, and confident in making the best-informed healthcare decision.'</td>
</tr>
<tr>
<td>Dr. Jessica Greene Research Professor Baruch College Marxe School of Public &amp; International Affairs</td>
<td>'Information helps patients to see their role in their healthcare, and helps them to be confident in being proactive in that role.'</td>
</tr>
<tr>
<td>Susan Thornton VP Cutaneous Lymphoma Foundation</td>
<td>'Information gives a patient the emotional capacity and strength to deal with wherever they are in the patient experience. Being informed allows patients to be confident in making the right choices for themselves.'</td>
</tr>
<tr>
<td>Hong Fei Founder House 086 China</td>
<td>'Information can soothe the psychological pressure of patients, and ease confusion about disease and treatment, allowing patients to more confidently communicate with healthcare providers and understand treatment options.'</td>
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Table 3. Views on the Value of Information for Patients as Shared by LC Qualitative Interview Participants.
'well informed patients' are much more likely to be confident about taking an active role in their care decisions, to feel comfortable asking questions of their care provider, and to report understanding their providers explanations (Blue Shield California, 2012). The report generated put numbers behind this equation, marking significant differences between the 'informed' and 'uninformed' patient. Some results to note:

- Nearly 7 in 10 who feel very informed about their health also feel very confident in their ability to make healthcare decisions. This confidence drops to roughly 44% among those who feel less than very-well informed.

- 67% of respondents who feel informed about their health report being comfortable asking questions of their hcp, this drops to 33% among those who feel less informed.

- 61% of respondents who feel informed report always understanding their hcp's advice and treatment plans, this drops to 34% among those who feel 'somewhat informed', and to 18% among those who feel less informed.

- 83% of those who feel like they have enough information report actively engaging in their healthcare decisions, this drops to 55% among those who feel like they lack information about their health.

(Blue Shield California, 2012)

Regression modelling in this study showed that the most important predictors of self-confidence in making healthcare decisions were: feeling informed, receiving clear explanations from healthcare providers, and taking responsibility for one’s own health (Blue Shield California, 2012). It was concluded that even when other factors were absent (continuity, connectedness, etc.), information remained a primary driver of empowerment and engagement (Blue Shield California, 2012). Beyond this study, numerous studies examining empowerment have linked the concept to such patient outcomes as adaptation to chronic illness, improved sense of well-being, and better maintained independence (Bravo et al., 2015; Camerini et al., 2012).

Many studies surrounding patient activation present similar outcome data pertaining to patient knowledge and experience. Studies and reviews document that self-reported rates of positive care experiences are consistently higher among more activated patients (Hibbard & Greene, 2013). Scoring higher on the Patient Activation Measure (PAM) scale is associated with: higher-quality interpersonal exchanges with physicians, greater fairness, increased out-of-office contact with hcp's, and fewer issues with care coordination (Hibbard & Greene, 2013; Alexander et al., 2012; Maeng et al., 2012). Patients who are more activated are also significantly more likely to prepare questions for doctor-visits, and to possess the skills and confidence required to elicit the care and information they require from their providers (Hibbard & Greene, 2013). For example, one study indicated that highly activated patients reported better care experiences than did less activated patients, even when seeing the same doctor (Greene et al., 2013). This was hypothesised as attributable to an activated patient’s ability to be confident in using their knowledge to shape more productive interactions with their clinicians—getting what they feel they need (Greene et al., 2013). Another study
found that highly activated patients were 2-3 times more likely to be knowledgeable about treatment guidelines specific to their condition, to seek out further health information, and to draw meaningful comparisons of the quality of healthcare providers (Hibbard & Greene, 2013).

By contrast, throughout the literature, less activated patients (estimated to be between 25 and 40% of the population) are proven to be more likely to: misunderstand their role in the care process, feel overwhelmed by managing their healthcare, have limited problem solving skills, and have little confidence in their ability to positively impact their health (Hibbard & Gilburt, 2014; Hibbard & Greene, 2013). Further, it is common for less activated patients to have had a substantial experience in failing to manage their health, causing them to become passive in their healthcare, or to avoid thinking about it all-together (Hibbard & Gilburt, 2014). Correspondingly, people who are less activated are less likely to seek help when they need it, to be knowledgeable about treatment guidelines for their condition, to follow their doctor’s advice closely, to be persistent in seeking clarification, and to manage their health when they are no longer being treated (Hibbard & Gilburt, 2014).

A contextual illustration:

A study assessing the relationship between patient activation and behaviours/experiences of people with cancer found that, compared to less activated patients, higher activated patients were: 9 times more likely to feel as though their treatment plans reflect their values, 4.5 times more likely to cope well with side-effects, and roughly 3.3 times more likely to initiate a healthier diet post diagnosis (Hibbard, Mahoney & Sonet, 2017). Less activated patients were less likely to understand their diagnosis, follow treatment regiments, and to be satisfied with their care (Hibbard, Mahoney & Sonet, 2017). The study used multivariate analysis in assessing survey data from 6 surveys, each including 500 cancer survivors (Hibbard, Mahoney & Sonet, 2017).

4.2.a Too Much Information?

Though much evidence links being better informed to better patient experiences, when considered on a broader global scale, it is important to identify some potential burdening outcomes. For example, if information is uncovered regarding an available treatment or clinical trial that is not accessible to the patient (i.e. financially, in the region, not approved in that country, etc.), it may induce anxiety and stress, or decrease the patient’s quality of life. Even in such developed areas as Canada and Europe, there is evidence that taking a ‘generic’ brand drug rather than a name brand can induce patient stress (as explained in LC qualitative interviews). Further, remaining continually informed can be onerous for patients. So to can be the process of understanding the information itself and how to best apply it. Patients cannot spend 24 hours a day in the space of their cancer, there is a need to be able to separate from it.

4.3 Use of Healthcare Services and Costs to the Healthcare System

Though healthcare reform [in the USA] has made patient ‘engagement’ a major focus, evidence linking lower healthcare costs to increases in patient engagement is limited (Greene et al., 2015). The relationship to patient ‘activation’ is proven more concretely across the literature.

After controlling for disease severity and demographic characteristics, several studies describe connections between patient activation and healthcare service utilisation. A group of researchers from
George Washington University, University of Oregon, and Fairview Medical group recently concluded the largest longitudinal investigation to date (2-year time span) assessing the relationship between activation level and changes in health outcomes and costs (Greene et al., 2015). Using the PAM scale, they examined more than 32,000 adult patients (Greene et al., 2015). The study found that when participants remained at the highest level of activation over the entire study period, their projected costs were 31% lower than for those who remained at the lowest levels (Greene et al., 2015). Similarly, costs were seen to move in the same direction as changes in activation level. For example, participants who moved from the highest levels (4 and 3) down to lower levels (2 and 1) had projected costs that were 27% higher than those who remained at high levels for both years (Greene et al., 2015).

These trends are replicated throughout the literature. Many studies have demonstrated that more-activated patients have lower rates of hospitalisation, and fewer visits to accident and emergency departments—likely leading to lower healthcare costs (Hibbard & Gilburt, 2014; Shively et al., 2013; Greene & Hibbard, 2012). Further, less-activated patients are significantly more likely to be re-admitted to hospital within 30 days of discharge (Mitchell et al., 2014; Kirby, 2012). This adds to the cost of care. Patient activation scores have also been assessed temporally in relation to healthcare costs. PAM scores have been proven predictors of a patient's billed care costs, for both the current and the subsequent year (USA focused studies). One study showed that less activated patients had costs roughly 8% higher than more activated patients in the baseline year, and 21% higher in the subsequent year (Hibbard et al., 2013).

Many empirical studies suggest that people who score higher on the PAM scale are significantly more likely to:

- Engage in preventative behaviours (attend regular check-ups, screenings, immunisations)
- Engage in healthy behaviours (diet, exercise)
- Avoid health-damaging behaviour (smoking, drugs, alcohol)

(Hibbard & Gilburt, 2014; Hibbard & Greene, 2013).

### 4.4 Health Behaviours and Health Status

#### 4.4.a Health Related Lifestyle/ Self Care Activities

In a multivariate modelling study examining patient activation and health outcomes/utilisation, every 10 points in patient activation lowered the predicted probability of having an emergency department visit, obesity, and smoking by 1% (Greene & Hibbard, 2012). The 10-point increase also increased the likelihood of having a regular breast cancer screen by 1% (Greene & Hibbard, 2012). Further, after controlling for such factors as income, education, and access to care, patients who are less activated are 2-3 times more likely to have unmet medical needs and to delay medical care (Hibbard & Gilburt, 2014; Hibbard & Greene, 2013).

#### 4.4.b Treatment Adherence/ Severity of Disease & Symptoms

Studies examining the management of long-term conditions have positively correlated higher activation scores with adherence to treatment and condition monitoring, as well as with seeking and
obtaining regular care associated with the condition (Greene & Hibbard 2012; Rogvi et al., 2012; Schiøtz et al., 2012). Further, empirical studies have found that chronically ill patients who are more activated are more likely to perform self-monitoring at home, obtain regular chronic care, and adhere to treatment (Hibbard & Greene, 2013).

4.4.c Mental and Physical Functioning (Clinical Indicators)

Studies have linked patient activation with specific clinical health outcomes among both healthy patients, as well as outcomes among patients with various physical health conditions. Some of these health conditions include: HIV, multiple sclerosis, arthritis, asthma, chronic obstructive pulmonary disease (COPD), congestive heart failure, cardiovascular disease, osteoporosis, Parkinson’s disease, cancers, and other long-term conditions (Hibbard & Gilburt, 2014; Marshall et al., 2013; Rogvi et al., 2012). Additionally, patient activation scores have been highly relevant in assessing outcomes among people with mental health disorders such as depression, bipolar disorder, anxiety, and schizophrenia (Hibbard & Gilburt, 2014; Cabassa et al., 2013; Kukla et al., 2013). Among this group of disorders, higher activation scores are correlated with positive attitudes towards recovery, healthier coping strategies, higher levels of hope, reduced mental health symptoms, lower levels of substance abuse, positive self-management of illness, and more consistent adherence to treatment regimens (Hibbard & Gilburt, 2014; Kukla et al., 2013).

A cross-sectional study at Fairview Health Services in Minnesota, US, examined 13 patient outcomes across 4 areas: prevention, unhealthy behaviours, clinical indicators, and healthcare utilisation (Hibbard & Greene, 2012). This study analysed 25,047 adult patients, all of whom had a primary care visit in the prior 6 months and completed the PAM as part of their office visit (Hibbard & Greene, 2012). The study results indicated that for every 10 points in patient activation, the likelihood of having clinical indicators in a normal range (A1c, HDL, and triglycerides) was one percent higher (Hibbard & Greene, 2012). This finding has been replicated in numerous studies spanning across patients with a range of conditions and economic backgrounds, with results indicating that highly activated patients are more likely to have biometrics (BMI, hemoglobin, blood pressure, cholesterol) in the normal range (Hibbard & Greene, 2013).

There has also been research specific to indicators associated with specific diseases and conditions. For example, a study analysing HIV patients and PAM scores found that for every 5-point increase in activation score, there was significant improvement in CD4 counts, viral suppression, and adherence to drug regimen (Marshall et al., 2013). A recent study surveyed 551 orthopedic patients on their understanding of their condition and available treatments, and conducted a 6 month follow up to assess outcomes and quality of life (Sepucha et al., 2017). This study found that being less than ‘well informed’ can lead to unwanted treatments and poorer outcomes. Patients who were informed and received their preferred treatment tended to ‘do better’—although the reasons for this were unclear. It is thought that patients had more realistic expectations, or were more motivated to follow through with their treatments (Sepucha et al., 2017).

CHAPTER 5: DISCUSSION AND CONCLUSION

5.1 Discussion

The Lymphoma Coalition began this project with a broad research objective: to determine if evidence exists that points to better outcomes for a patient who is more informed. We sought to
identify key concepts and terminology underlying published definitions surrounding 'informed patients' in order to:

i) Create a lymphoma-specific definition,

ii) Examine the patient process of becoming 'informed'

iii) Assess outcome variability

It was hypothesised that the correlation between more patient knowledge and better outcomes would be positive. While the data analysed failed to nullify the initial hypothesis (as evidence supporting this correlation is available across various outcome areas), the complexity of attempting to measure subjectivity does not allow for one straightforward concluding statement. Based on this literature review and accompanying interviews, it is perhaps more accurate to state that 'positive outcomes' will look different for each patient depending upon what they perceive to be important. Further, it cannot be assumed that every patient’s desire and capacity to be informed will or should be equal; patients will translate their level of knowledge and understanding in a way that directs them towards the outcome they want—which varies along a complicated and subjective scale. It is also possible that a patient will not want to translate their knowledge at all, or seek information or engagement to begin with, and would rather be passive within the system.

This led the LC to question who exactly wants patients to be informed? Is it the healthcare system and associated organisations, or patients themselves? And how does one categorically quantify outcomes that are so individual by nature? For instance, most of the research aiming to correlate patient activation/engagement/empowerment etc. with improved physical outcomes focuses on treatment adherence, self-management, and clinical indicators. However, to illustrate: if a lymphoma patient highly values a physically active lifestyle, yet is suffering from ongoing debilitating fatigue, will they care that their clinical indicators are in a normal range? Will they consider this a good outcome?

Though outcome measurements and definitions varied throughout the literature, one theme remained fairly consistent: When a patient has knowledge surrounding their condition, treatment options, and self-care practices, patients ask more questions, patient experience is improved, and they are more inclined to be confident in taking a sustained active role in managing their health and condition. This was mirrored throughout the qualitative interviews; the majority of participants reiterated that confidence plays a key role in allowing patients to manage where they are, or excel throughout their patient experience. They also noted that it is often information, leading to improved interaction with the healthcare system, that fosters this confidence. Important to understand is that having confidence as a patient does not necessarily mean that a patient will experience a better ‘health outcome’ as defined by clinical research. However, it may mean that they are confident in making the right choice for him/herself—leading them towards ‘their good outcome’. Alternatively, feeling confident in your ability to make the right choice for yourself, or to ask questions and get answers from your doctor could be considered a good outcome in itself. So, is how the patient ‘feels’ the prime motivator? And what is the scientific measurability of this? Some potential measurements to consider: emotional strength/stability, quality of life measures, physical outcomes and clinical indicators, self-care/treatment adherence, confidence/comfort communicating with healthcare providers, etc.
5.2 Future Directions

Moving forward, it would be beneficial to implement more standardised measures to facilitate outcome analysis, especially surrounding patient confidence level. One of such measure, growing in recent popularity, are Patient Reported Outcomes.

Patient Reported Outcomes (PROs) are any report on the status of the patient’s health condition (and its therapy) that come directly from the patient—without any interpretation by another party (clinician, family member, caregiver, etc.) (Dobrozsi & Panepinto, 2015). PROs can be collected in many ways and for several reasons: disease-specific (severity, symptoms, functional limitations specific to a particular disease state), condition-specific (patient experiences related to a specific condition or problem, or related to particular interventions or treatments), drug-development specific (treatment risk/benefit, endpoint or secondary endpoints in clinical trials, HRQoL data in clinical trials) (Acquadro & Regnault, 2015; Black 2013). Patient Reported Outcome measures (PROMs) are the tools and/or instruments used to report PROs (often patient self-completed questionnaires, interviews, diaries, web-based forums) (Weldring & Smith, 2013). These measures provide composite scores from a series of questions, all pertaining to a central concept, to quantify levels of distress or impairment caused by a patients disease/symptoms/treatment (physical, social, emotional) (Weldring & Smith, 2013). Over the past few years, there has been increasing interest in PROs among drug developers, clinicians, payers, regulators, and patients (regarding both development and application of PROs in drug development process) (Engelberg Center for Healthcare Reform, 2014). There is, however, some controversy stemming from the suggestion that this interest largely surrounds the ability of PROs to support labelling claims.

Despite this controversy, there is potential for PROs to help both clinicians and patients make better decisions (Black, 2013). In recent reviews, it is suggested that patient participation must be made an integral part of the PRO development and validation process. Including patients enriches discussions, and illuminates new concepts and ideas that are relevant for the validity of the instrument (Aboumatar et al., 2013). LC views PROs as an avenue through which patient organisations can make a significant and immediate positive impact. Through establishing key partnerships (i.e. with clinicians, clinical trials, pharma, patients), PROMs can be modified and enriched, the right patient-centred questions can be asked, and crucial outcome data (both clinically and individually focused) can be derived and utilised.

5.3 Closing Statements

In closing, this review has served to highlight both quantitative and qualitative research surrounding ‘informed’ vs. ‘uninformed’ patients. Beyond defining what it means to be an informed patient and how patients get there, the main objective of this review was to research and identify the differences, if any, between outcomes for informed vs. uninformed patients. In all of these areas, it is clear that recent research has aimed to build a quantitative data bank to support implicit qualitative concepts. In analysing outcome-specific research surrounding informed patients (activated, engaged, empowered, etc.), it can be concluded that outcomes can be quantified only so far as research has
defined them. Currently, research has defined these principal outcome areas: patient experience, use of services and cost to the healthcare system, and health behaviours and health status. Within each of these categorised research areas, quantitative data is presented to support the idea that positive outcomes are more associated with being a more informed patient. However, many of these ‘positive outcomes’ can be considered subjective.

Regardless of apparent subjectivities, most of these named positive outcomes either contribute to, or are a by-product of patient confidence. Research indicates that confidence, stemming from information and support among many other factors, plays a significant role in positive healthcare experiences and resulting outcomes. So, if how the patient feels is to be the prime motivator, conceivably confidence should be named a primary outcome.

Moving forward, a way this understanding can be applied is towards identifying and remedying ‘risk factors’. This meaning, specific points along the patient experience (diagnosis, treatment, doctor-patient interactions, navigating the system) where not being informed or not being confident, risks a patient’s relationship with the healthcare system (and vice versa), and potential outcomes. The current healthcare system employs language that can be unsupportive of patient inquiry or information-seeking. There is often a sense among patients that if you are in the system, you are being ‘taken care of’—unfortunately this does not always hold true. If a patient does not posses the knowledge or confidence in their ability and right to inquire, to ask questions of a physician, to take a certain therapy or not, to request further clarification when they do not understand, to feel like they have the right to take up more of the doctor’s time, to bring up emotional issues and so on, then they are at risk for poor ‘outcomes’ throughout their patient experience.

Confidence in terms of what it means to patients was not examined from their perspective, rather derived as an overarching theme. There is a psychosocial research piece to be further investigated here. However, based on the presented evidence and collective anecdotal patient experience, it would appear that patients need not only information, but also support to acquire, maintain and employ this confidence throughout their experience. In other words, it cannot stem solely from the actions they are taking. Actions must be reciprocated on the healthcare system side.

The system works well for those who are confident and assertive; these patients are better able to interact with healthcare providers and the healthcare system in a way that allows them to derive what they feel they need from it. Bottom line, they are better able to both recognise and ask the questions they feel are important. So how do we support these recognitions and individual choice within the current healthcare system configuration? In many developed countries, all the system pieces are in place to foster patient understanding, self-direction, and individual choice. However, both doctors and patients must be better supported in understanding how to communicate and use all the system pieces together rather than as independent entities. In the underdeveloped countries, it is time we supported the patient organisations who step in and support the patients throughout their experience at all levels of the existing social structures.
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APPENDIX A: LITERATURE SEARCH STRATEGY DESCRIPTION

We searched for observational studies, randomised studies, systematic reviews, and meta-analyses that highlighted and evaluated the association between 'informed' patients and outcomes—or provided information descriptions of relevant terminologies. Because of the heterogeneity of database information and structure (i.e. different information accessible, different 'limitation tools' for searching), independent literature searches were carried out across the following databases: PubMed, Google Scholar, National Institute for Health and Care Excellence Database (NICE, USA), the Lymphoma Coalition Resource Library, Global Data Base and Global Patient Surveys (2014-2016), and the McMaster University's Health Evidence Database (Hamilton ON, Canada). The search terms and limitations applied are listed in the tables below. Initially, PubMed was used to broadly explore the research available surrounding 'informed patients'. Very general terminology (informed patient, uninformed patient) was used to generate a larger number of hits, this way, abstracts could be analysed for more specific terminologies and themes. As more relevant terminology was discovered, these terms were employed as search terms and combined to draw out specific study areas. This process continued as more terms were identified. 'lymphoma' was then combined with existing search terms to bring in context.

Because PubMed is a strictly scientific database, this broad to narrow process was repeated in the remaining databases (besides the LC information sources) to identify additional studies (i.e. psycho-social, SW), statistics, public health sector reports, government reports, and other pertinent grey literature. In order to be included, grey literature had to be recent, relevant, and published by a governmental or recognized public health organisation. LC sites were searched in a less systematic way because of the nature of the information available, thus search techniques are not recorded in table form. Information was pulled when it was relevant to a specific theme or study.

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