

背景

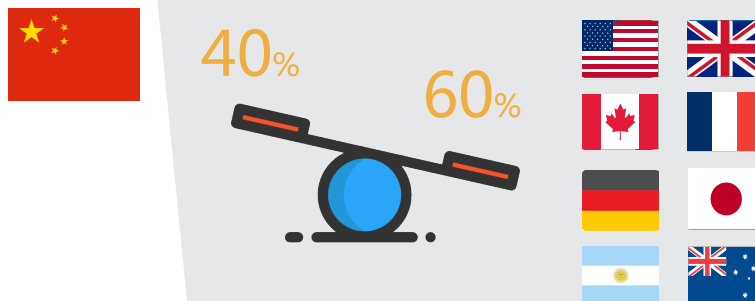
Background

从 2008 年起，国际淋巴瘤联盟确立了每两年开展一次全球淋巴瘤患者调查的传统。通过这项调查，淋巴瘤患者的患病体验以及治疗和护理对其身体的影响能够被更好地理解，国际淋巴瘤联盟通过其全球成员单位传递患者的声音，并呼吁社会提升对患者幸福感和支持性服务的关注。

Since 2008, Lymphoma Coalition (LC) has established the tradition of launching a global patient survey every two years. Though this survey, patient experience in lymphomas as well as the impact of treatment and care can be better understood; meanwhile, LC and its global members bring the patient voice forward, and help raise the awareness on the patients' happiness and their supporting service.

因为有淋巴瘤之家的参与，2018 年全球淋巴瘤患者调查中，首次出现中国患者的数据。

Due to the participation of House086, Chinese patients data, for the first time, appears in the 2018 Global Patient Survey on Lymphomas.



通过 65 个国际淋巴瘤联盟成员单位收集了 6631 份调查问卷，其中由中国受访者贡献了 2611 份数据。

Among 6631 questionnaires from 65 Lymphoma coalition members, Chinese participants contributed 2611 copies of files for data.

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PART ONE

患者信息统计

Basic Information

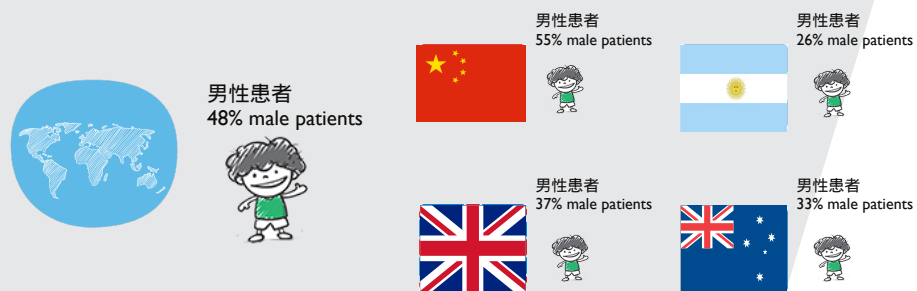
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性别及年龄 Gender / Age

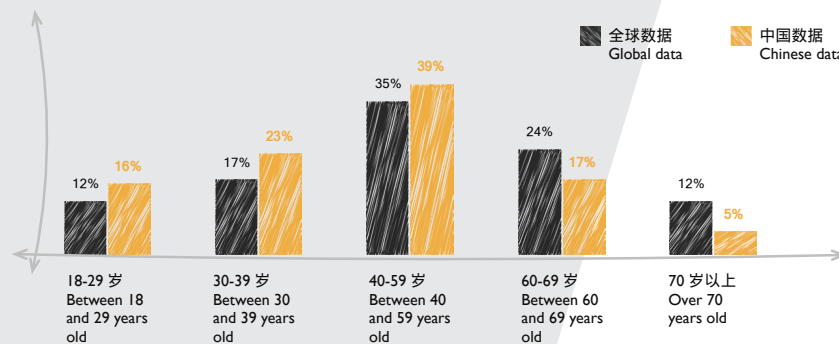
中国是少数男性受访患者比例高于女性受访患者的国家。

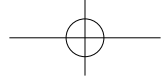
China is one of the minority countries that the ratio of male patients is higher than the female patients.



在所有国家中，至少有一半的受访患者年龄在 40 岁以上。

Among all the countries, there are at least more than half of the patient respondents are over 40 years old.





PART ONE

患者亚型 Lymphoma Subtype

中国受访患者中，惰性淋巴瘤亚型的比例明显低于全球数据，而侵袭性淋巴瘤亚型的比例明显高于全球数据。

The ratio of indolent lymphoma among Chinese patient respondents is lower than that among global patient respondents, while the ratio of aggressive lymphoma among Chinese patient respondents is higher than that among global patient respondents.



惰性淋巴瘤患者
43% Indolent
lymphoma patients



侵袭性淋巴瘤患者
55% Aggressive
lymphomapatients

不知道
2% don't know

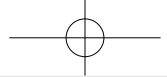


惰性淋巴瘤患者
27% Indolent
lymphoma patients



侵袭性淋巴瘤患者
72% Aggressive
lymphomapatients

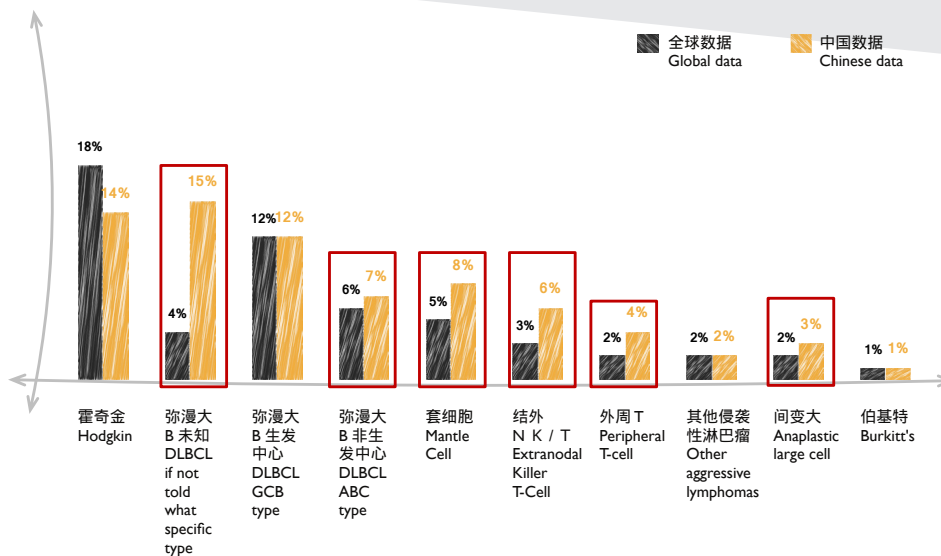
不知道
1% don't know



侵袭性淋巴瘤 Aggressive Lymphomas

侵袭性淋巴瘤亚型中，中国受访患者仅在霍奇金亚型中的比例低于全球数据，在弥漫大 B 和 T 细胞各亚型中的比例均高于全球数据。

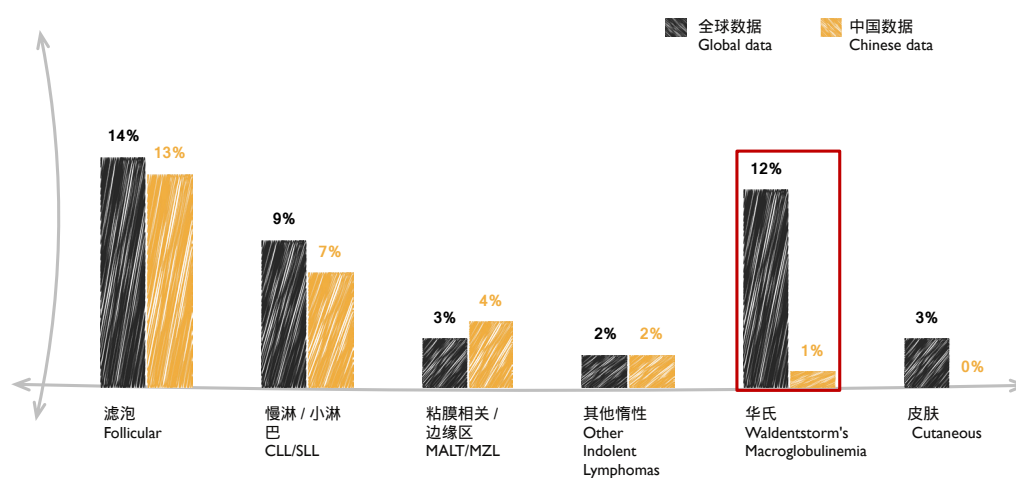
The ratio of Hodgkin among Chinese patient respondents is lower than that among global patient respondents, while the ratio of DLBCL and T-Cells among Chinese patients respondents is higher than that among global patient respondents.



惰性淋巴瘤 Indolent Lymphomas

惰性淋巴瘤亚型中，中国华氏巨球蛋白血症受访患者比例明显低于全球数据。

The ratio of Waldenstrom's Macroglobulinemia among Chinese patient respondents is obviously lower than that among global patient respondents.

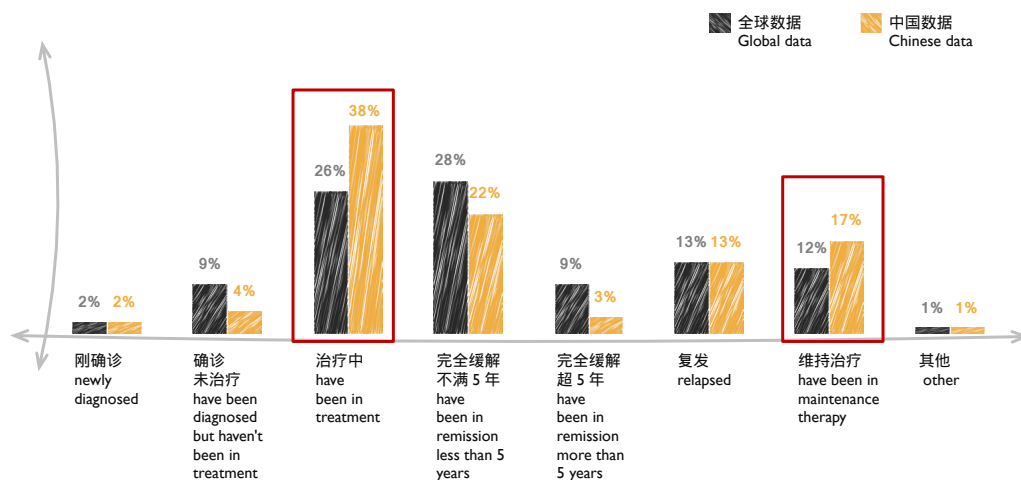




患者目前状态 Current State of the Patients

治疗和维持治疗状态中的中国受访患者比例高于全球数据。

The ratio of Chinese patient respondents interviewed in treatment and maintenance is higher than that among global patient respondents.



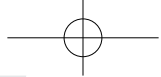
受访患者所处阶段

The stage that best described where the respondent was in their experience.



PART TWO **2**

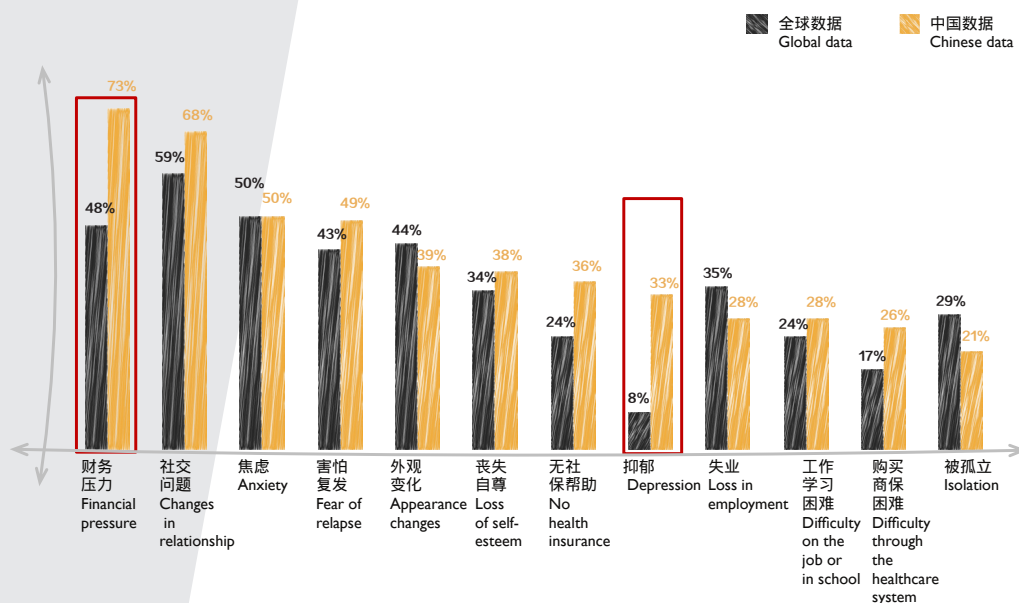
患者心理情况 Psychological Conditions



治疗中影响患者幸福感的心理问题 Psychosocial issues affecting respondents' wellbeing during treatment

财务压力给中国受访患者造成的影响最大，出现抑郁问题的比例也远高于全球数据。

The biggest impact of Chinese patient respondents is financial pressure. And the ratio of depression among Chinese patient respondents is higher than that among global patient respondents.



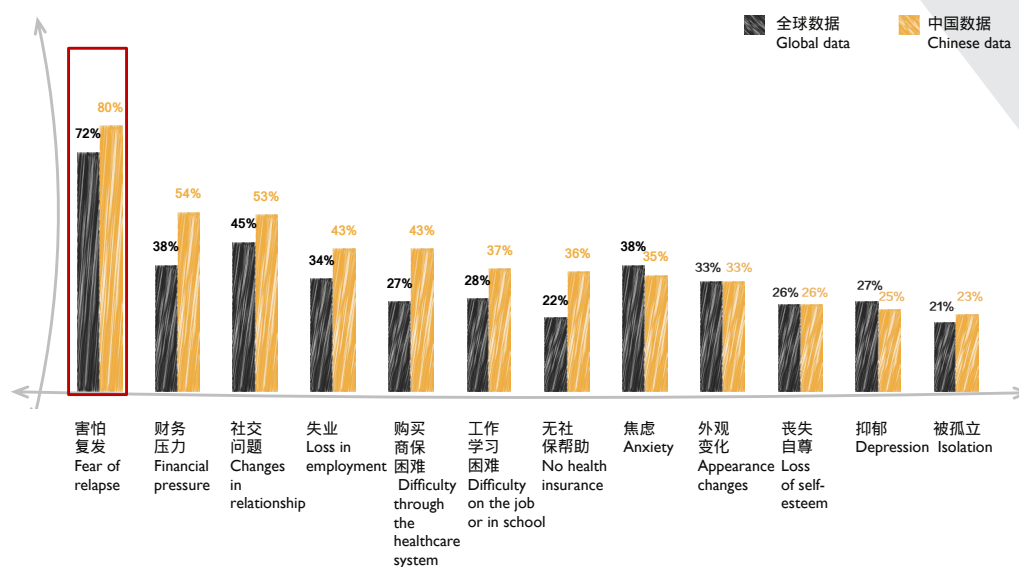
治疗中影响患者幸福感的心理问题
Issues affecting patients' wellbeing during treatment

PART TWO 2

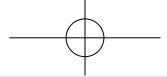
治疗后影响患者幸福感的心理问题 Psychological condition affecting wellbeing after diagnosis

害怕复发是治疗后全球及中国受访患者最常见的影响其幸福感的问题。

Fear of relapse is the most common problem affecting happiness in the global and Chinese respondents after treatment.



治疗后影响患者幸福感的心理问题
Issues affecting patients' wellbeing after treatment

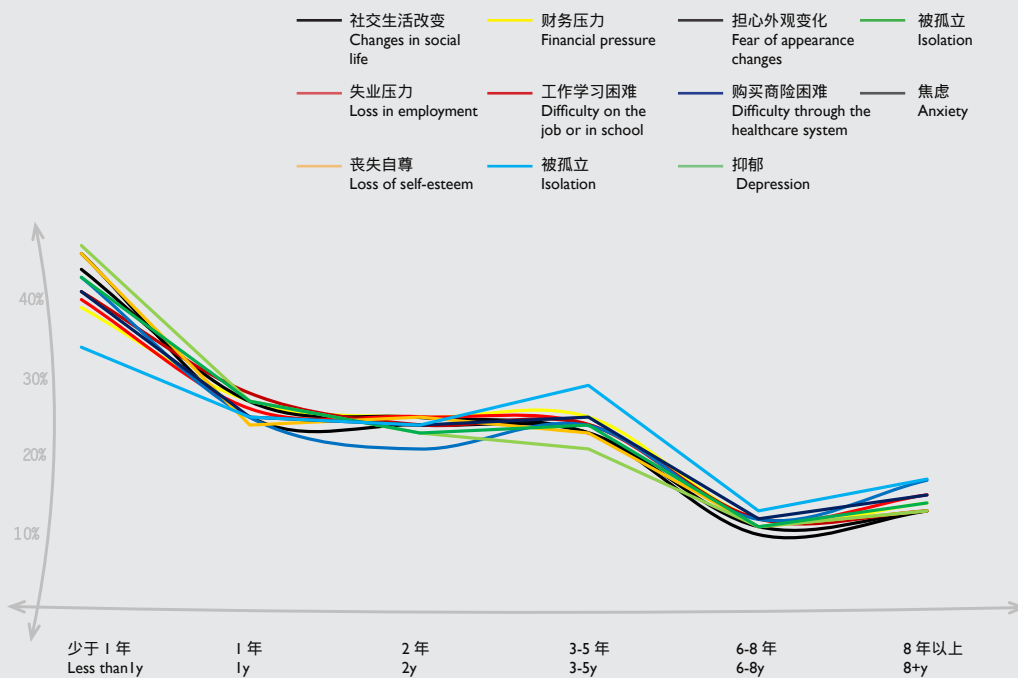


心理问题影响持久

The Long-term Effect of Psychological Problems

一些受访患者表示在接受治疗 8 年后仍不同程度上受到心理状况的影响。

Some of the respondents say they are still suffer from different level of psychological problems to some extent after 8 years of treatment.



影响心理状态的问题持续时间
The duration of psychological problems

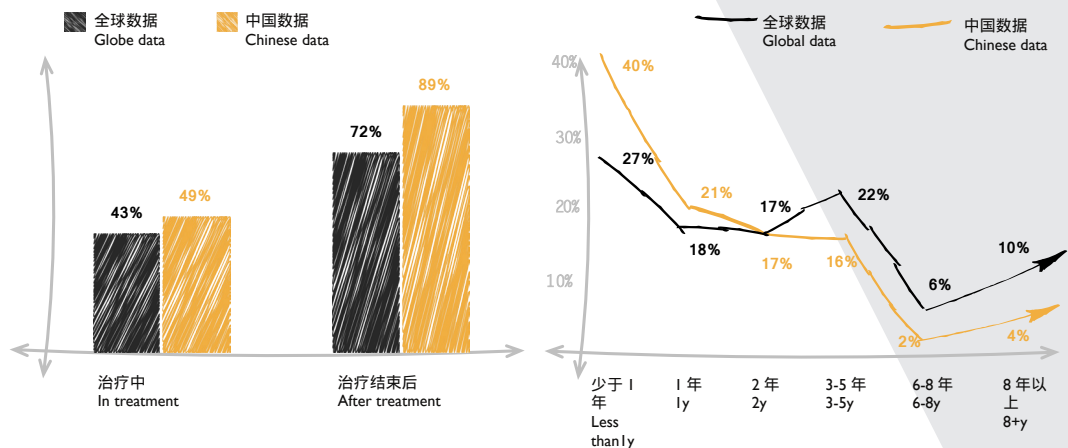
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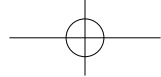
PART TWO 2

害怕复发是治疗后最大的心理问题 Fear of relapse is the biggest psychological problem during post-treatment

害怕复发的恐惧在治疗后达到峰值，而中国受访患者更是在治疗后 2 年内尤其受这种情绪的困扰。

Two years after the treatment, the Chinese patient respondents suffer the most from the fear of relapse.



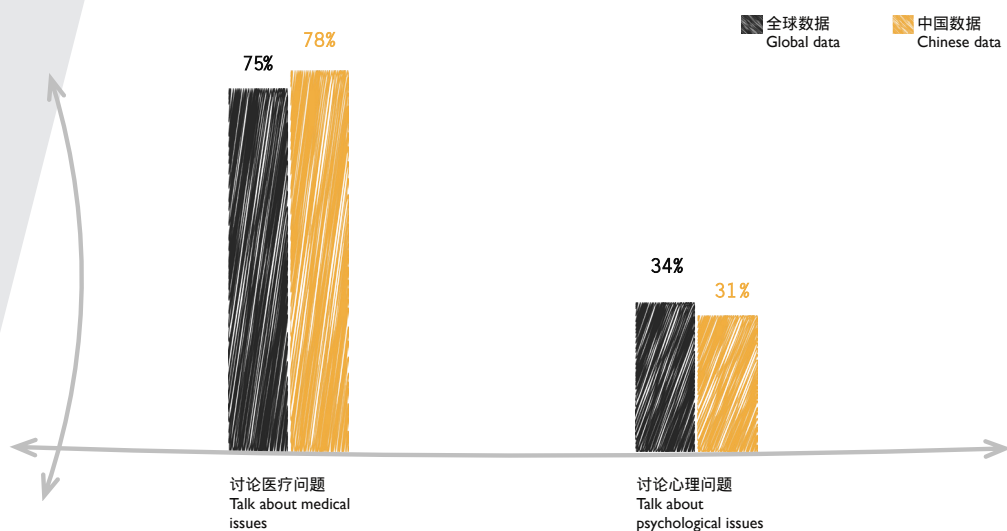


很少与医生讨论心理问题

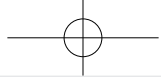
Rarely discussing psychological problems with doctors

受访患者与医生讨论心理问题的比例远低于与医生讨论医疗问题的比例。

The ration of patients discussing with doctors about psychological problems is far lower than that of discussing with doctors about medical problems.



与医生讨论问题的情况
The situation about communication with the doctor



PART THREE

患者应对副作用情况

Living with Side Effects

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淋巴瘤患者可能遇到的身体问题

Possible health problems of lymphoma patient

体液潴留
Fluid retention

性功能变差
Change in sexual function

味觉和嗅觉改变
Changes in taste and smell

呼吸短促
Shortness of breath

手臂和腿部肿胀
Swelling of arms and legs

灼烧感
Burning

疲劳
Fatigue



口腔溃疡
Mouth ulcers

失禁
Incontinence



抽筋
Cramps

睡眠规律改变
Changes in sleep patterns

夜间盗汗
Night sweats



食欲不振
Loss of appetite

皮肤过敏
Skin allergy

记忆力变差
Memory loss



瘙痒
Itching



肌无力
Muscle weakness

生育能力丧失
Loss of fertility



脱发
Hair loss



抵抗感染能力变弱
Problems fighting infections

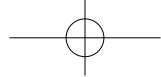
注意力完全无法集中
Problems concentrating

病毒再活化
Viral reactivations

恶心呕吐
Nausea and vomiting

体重下降
Weight loss

排便习惯改变
Bowel changes

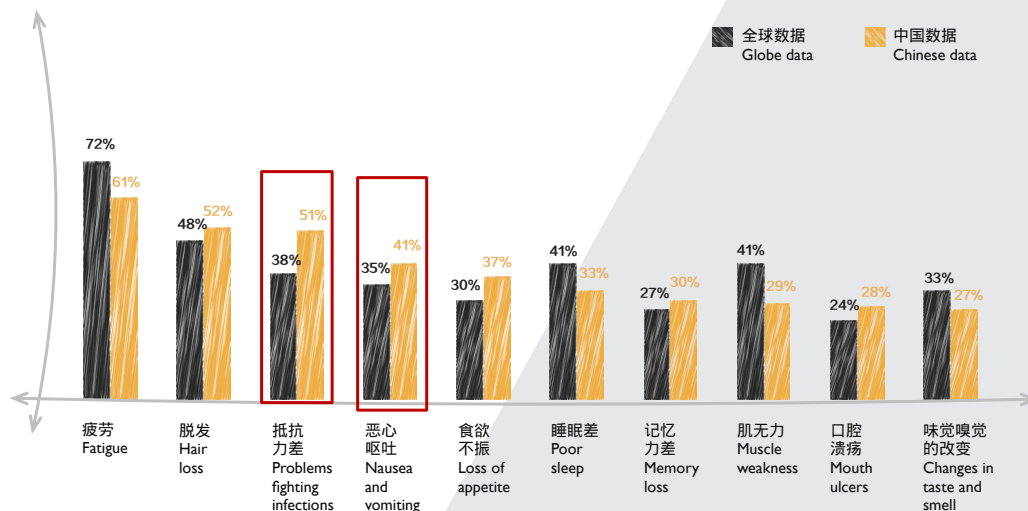


PART THREE 3

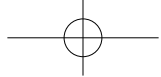
发生比例最高的十大副作用 Ten most common side-effects

除全球受访患者最常报告的疲劳和脱发这两个问题之外，中国受访患者反应在治疗过程中最常见的身体问题还有中性粒细胞减少和与胃相关的问题。

Besides the two most common problems fatigue and hair loss, the common side-effects experienced by Chinese patient respondents during the treatment are neutropenia and stomach-related issues.



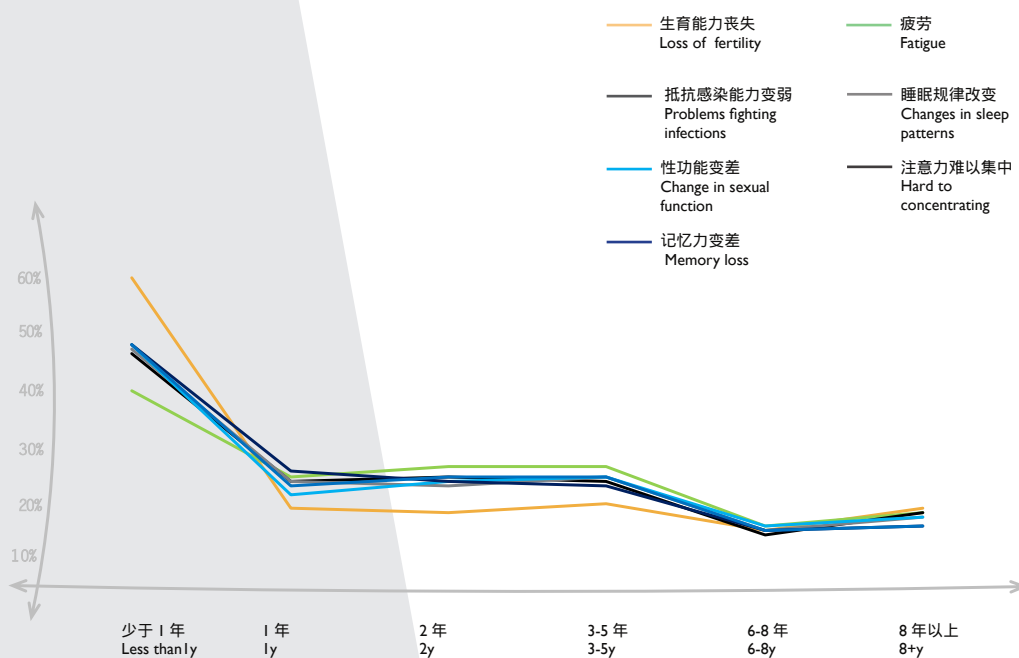
治疗副作用
Side effects of therapies



副作用持续时间长 The Long Term Side-effects

一定比例的受访患者报告说,他们经历的每一种身体问题在治疗后仍持续了8年以上,其中疲劳、生育、睡眠、记忆等方面的影响最为持久。

A certain percentage of patients say that every physical problem they experience lasted more than eight years after treatment, with fatigue, fertility, sleep, memory and other effects being the most persistent.

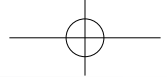


副作用影响时长
The lasting time of side effects



PART FOUR **4**

患者的治疗障碍 Treatment obstacles for patients

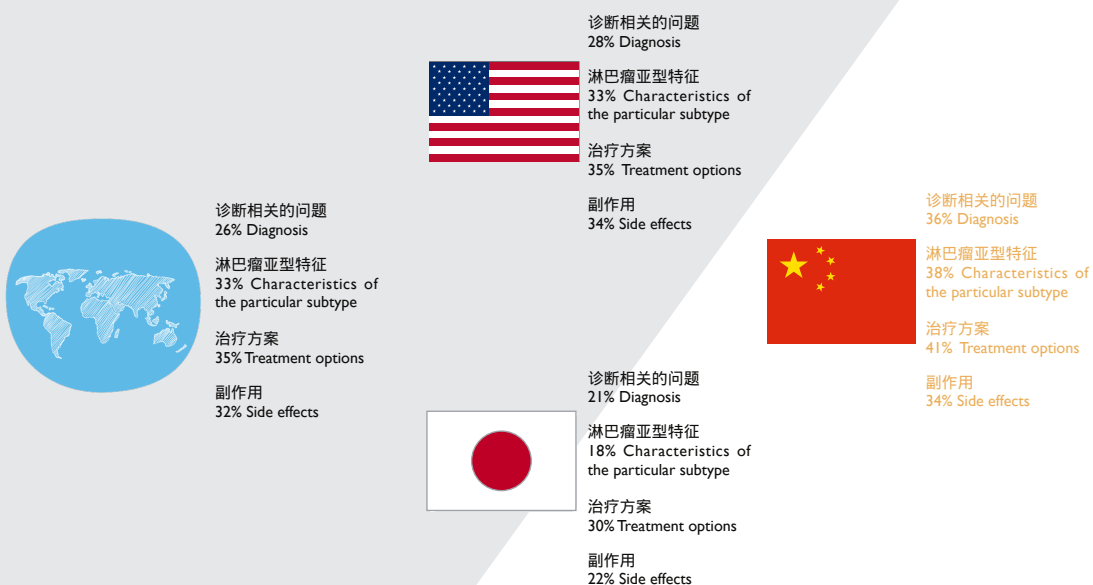


对诊断和护理存在理解障碍

Misunderstanding on Diagnosis and Nursing Process

首次确诊后，中国受访患者在诊断和护理方面的理解困难高于全球平均水平。

After the first diagnosis, Chinese patient respondents has much higher difficulty of understanding the diagnosis and nursing process than the world average.



对诊断和护理存在的理解困难

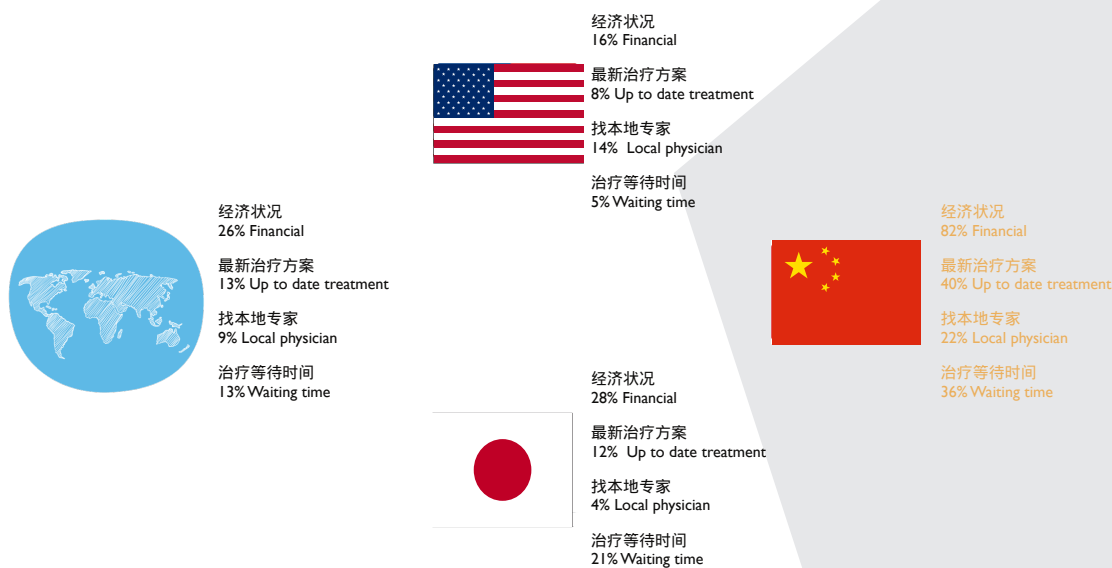
Hard to understand the diagnosis and nursing process

PART FOUR 4

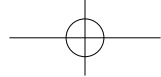
治疗中遇到的障碍 Difficulties during Treatment

中国受访患者遇到各项障碍的频率远高于全球平均值，尤其是在经济状况方面。

The frequency of obstacles encountered by Chinese respondents is significantly higher than the global average, especially financially.



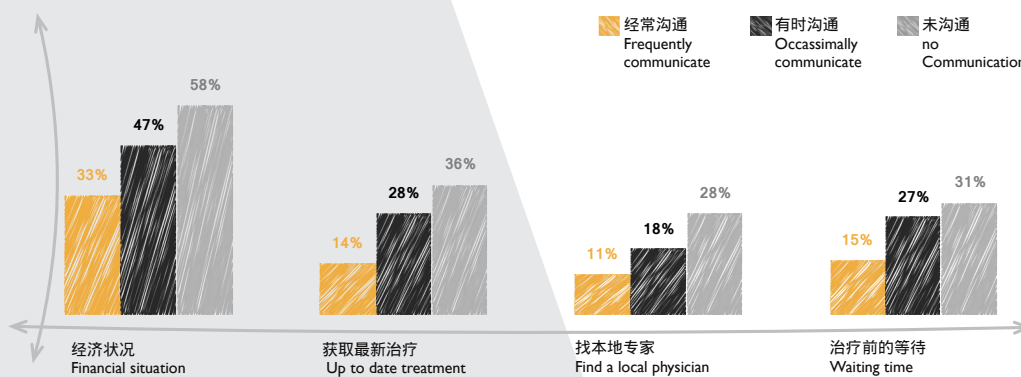
治疗中遇到的障碍
Difficulties during Treatment



可降低治疗障碍的方法 Methods to reduce obstacles in treatment

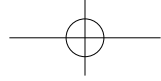
经常与医生沟通的患者遇到的障碍更少。

Patients who often communicate with doctors have fewer obstacles.



与医生的沟通质量对治疗障碍的影响

Barriers to treatment based on the quality of respondent communication with the doctor.



PART FIVE 5

患者需要的支持 Support Needed By The Patients

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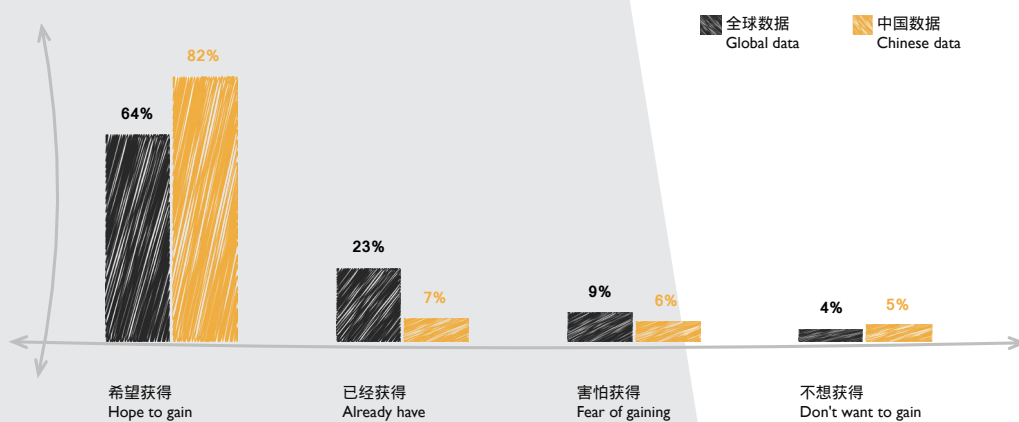


绝大多数淋巴瘤患者希望获得相关医疗信息

Most lymphoma patients want to gain medical-related information

全球受访患者报告显示，患者对于相关医疗信息的需求是显而易见的，其中中国受访患者的需求更为迫切。

Global patient report shows that patients' needs for relevant medical information are obvious, especially in China.



初诊与医生交谈时，对诊断结果相关信息的需求情况

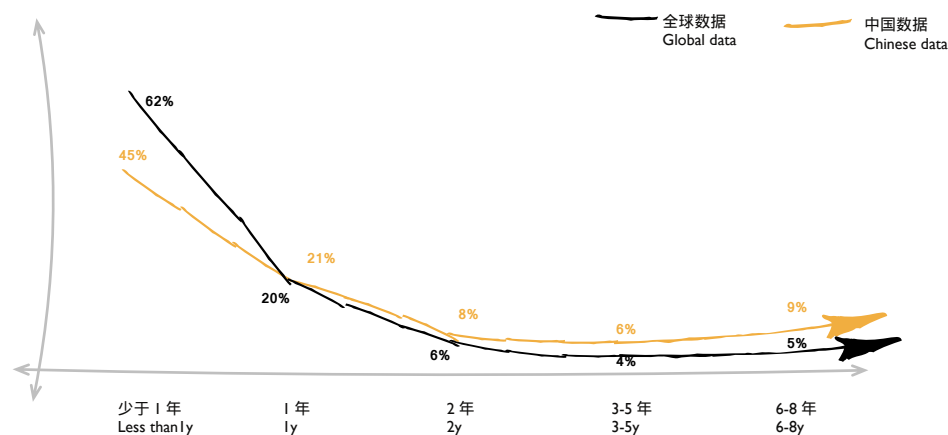
The need for receiving additional medical information at their initial diagnosis meeting with the doctor

PART FIVE 5

患者更倾向于于一确诊便立即寻找信息 Patients are more likely to seek information immediately after diagnosis

62% 的全球受访患者会在确诊后立即主动寻求信息，这种情况在中国受访患者中的比例为 45%。

62% of the global patient respondents will immediately seek information after the diagnosis, and the percentage for Chinese patient respondents is 45%.



不同时间段寻求信息的情况

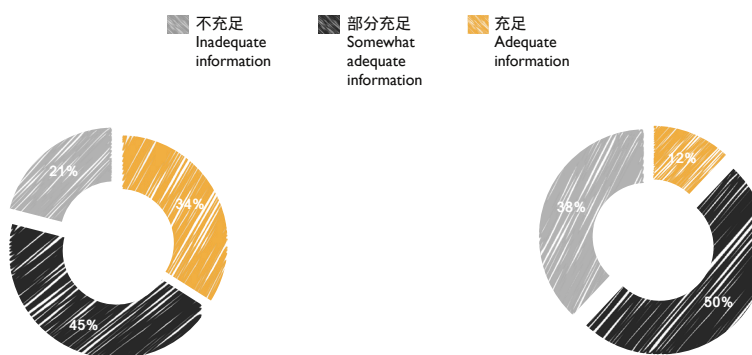
The need of information of different time



患者的信息需求未被充分满足 Patients' information needs are not fully met.

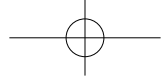
只有 12% 的中国受访患者感觉自己拥有“充足的信息量水平”，比全球受访者 34% 的数据还要低。

Only 12% of Chinese patient respondents feel that they have enough information, which is much less than the global average 34%.



全球受访患者对自身所拥有信息量的感觉
The feeling about perceiving level of information overall

中国受访患者对自身所拥有信息量的感觉
The feeling about perceiving level of information among Chinese patients

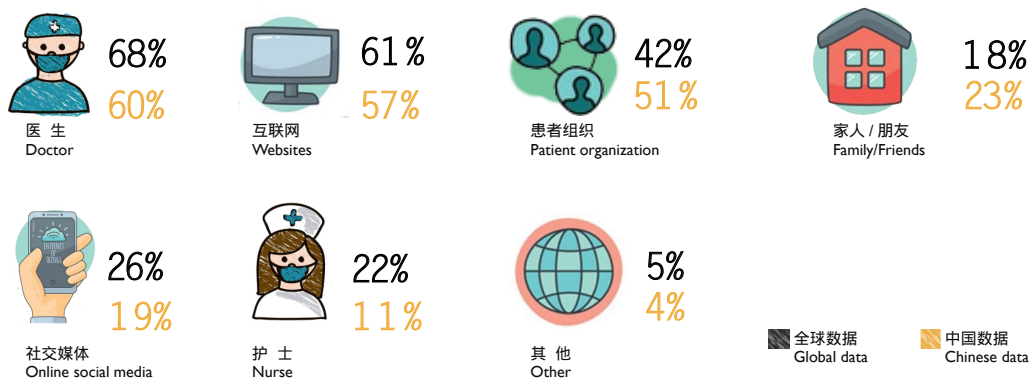


PART FIVE 5

医生和互联网是患者的主要信息来源 Doctors and the Internet are the main source of information for patients

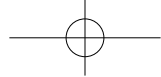
在大多数国家，患者的信息需求都未被充分满足的情况下，患者组织可以填补这个信息的缺口。

In most countries, if the patients' needs for information are not satisfied, patients' organization can fill the gap.



患病期间主要信息来源

Where respondents sourced their information

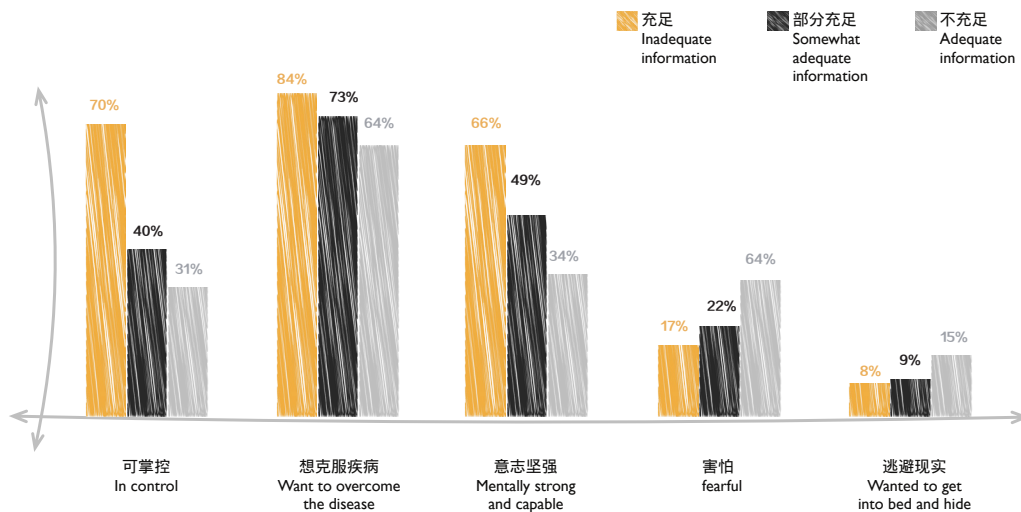


信息充足的患者心态更好

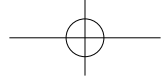
Patients with sufficient information are better at mentality

信息量充足的受访患者，不仅感觉自己更有力量，而且大多数时候很少有负面情绪。

The informative respondents not only feel more powerful, but also rarely have negative emotions most of the time.



不同信息水平受访患者在“大多数时候”的感受情况
Feelings experienced by respondents in Most Days

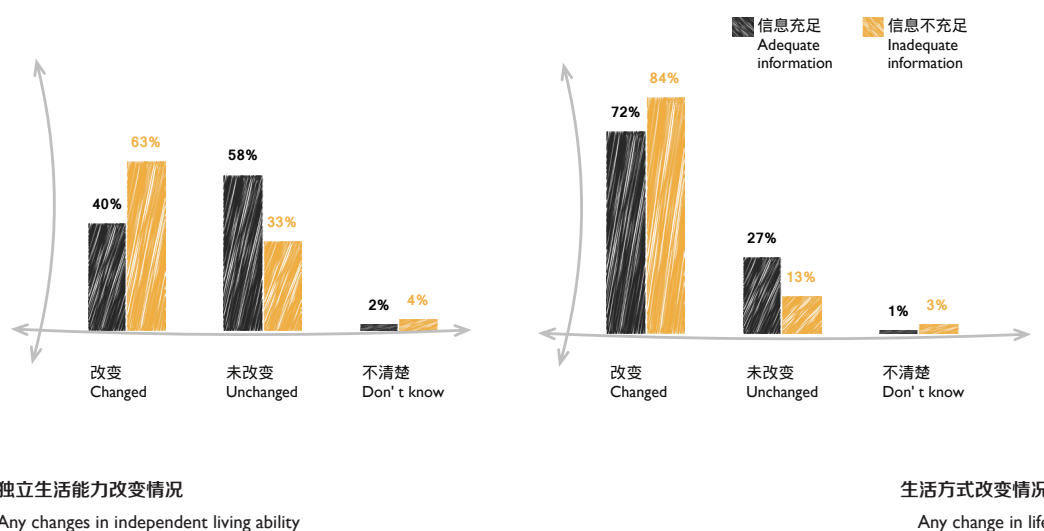


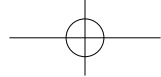
PART FIVE 5

信息充足的患者生活所受影响较小 Sufficient information allow patients to be less negatively influenced by their disease

虽然患病会在一定程度上改变患者的独立生活能力及生活方式，但信息充足的受访患者所受影响相对较小。

Although the disease may change the independent ability and lifestyle of patients to a certain extent, well informed respondents are less affected.

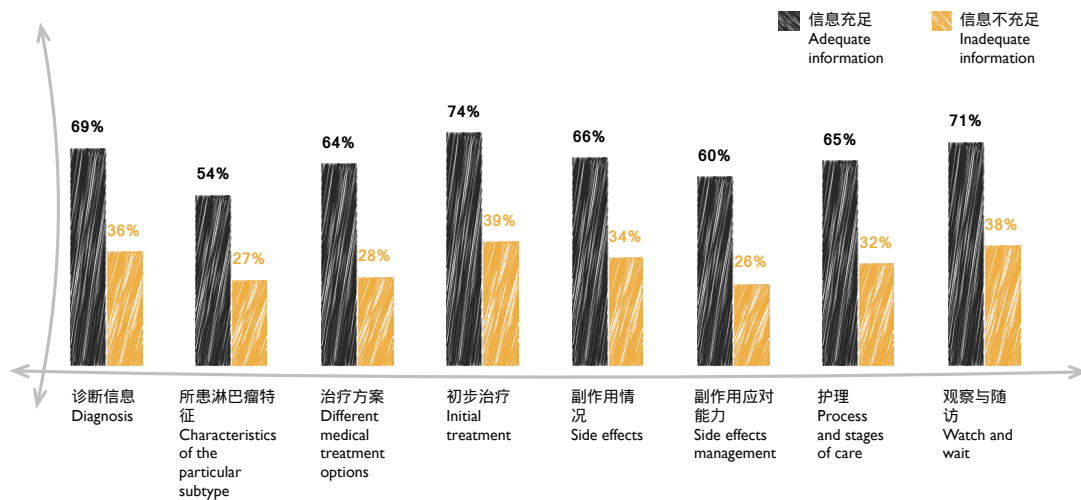




信息充足的患者更理解诊断和护理问题

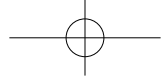
Patients with sufficient information have better understanding of the diagnosis and nursing process

信息充足的受访患者对诊断信息和护理的理解程度都高于信息不充足的受访患者。
Patients with sufficient information understand the diagnosis and nursing process better than the patient with less information.



不同信息水平的受访患者首诊后的信息理解程度

Respondents' understanding after the initial visit with the doctor based on their perceived level of information.

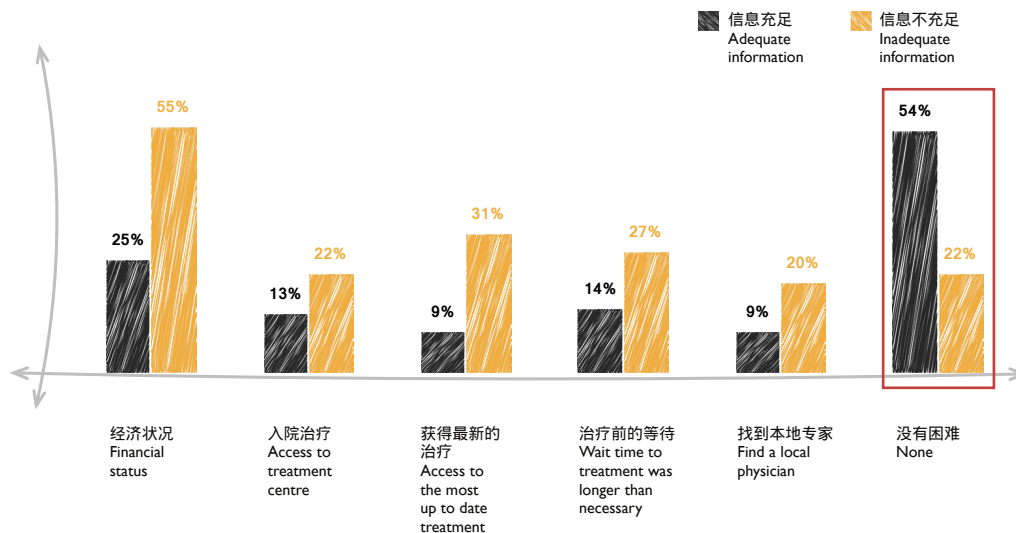


PART FIVE 5

信息充足的患者治疗期间遇到的困难更少 Well-informed patients encounter fewer difficulties

一半以上信息充足的受访患者认为自己在接受治疗期间没有困难，而只有 22% 的信息不充足的受访患者这么认为。

More than half of the well-informed patient respondents think that they encountered no difficulties during the treatment; however only 22% of the less-informed patient respondents think the same.



信息水平不同的受访者治疗期间遇到困难的情况

Barriers in receiving treatment based on the respondents' perceived level of information



患者掌握信息的程度及其积极性对治疗的影响

The influence of patients' information level and their enthusiasm on treatment

态度积极的患者和医生的沟通质量更高，需要与护理协调的事情更少。

1

Higher-quality interpersonal exchanges with physicians, greater fairness, increased out-of-office contact with HCPs, and fewer issues with care coordination.

(结论出自 : Hibbard & Greene, 2013; Alexander et al., 2012; Maeng et al., 2012)

态度积极的患者在拜访医生前更有可能提前准备好需要向医生提出的问题，更具备获取自己所需信息的能力和信心。

2

More-activated patients like 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.

(结论出自 : Hibbard & Greene, 2013)

态度积极的患者住院率更低，出意外和遇到紧急情况的可能性更低，因而医疗花费更少。

3

More-activated patients have lower rates of hospitalization, and fewer visits to accident and emergency departments.

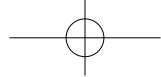
(结论出自 : Hibbard & Gilbert, 2014; Shively et al., 2013; Greene & Hibbard, 2012)

态度不积极的患者非常有可能在出院后的 30 天内再次回来住院。

4

Less-activated patients are significantly more likely to be re-admitted to hospital within 30 days of discharge.

(结论出自 : Mitchell et al, 2014; Kirby, 2012)



PART FIVE 5

患者掌握信息越多获益越多

The more information the patients have, the more benefit they gain

住院率低

Lower rates of hospitalization

积极配合

Actively cooperate with the doctor

能与医生有效沟通

Have good conversation with the doctor

乐观

Optimistic

易回归社会
Easy to return to society



自理能力强

Self-care ability

有信心
Confident

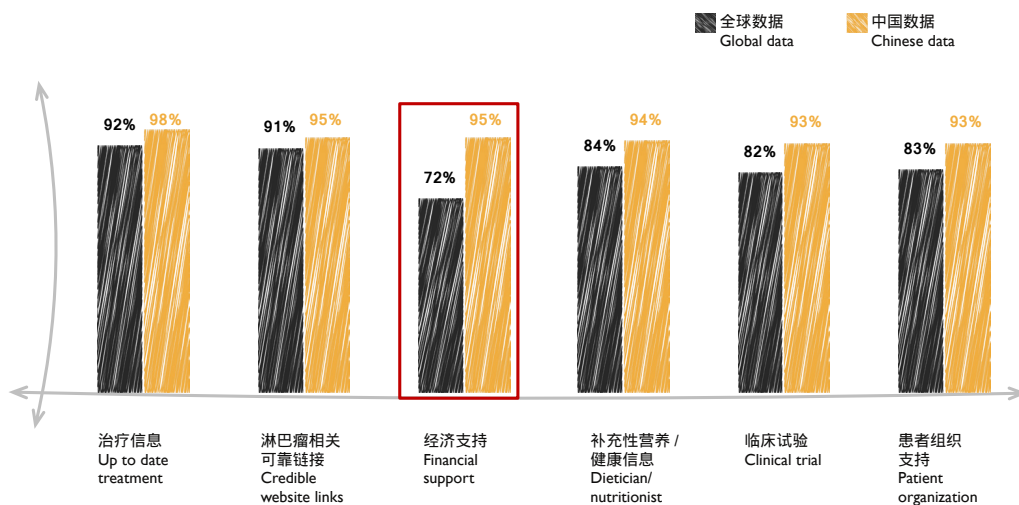


患者感兴趣的服务类型

Types of services that patients are interested in

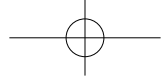
全球受访患者最感兴趣的前三位服务类型是治疗信息、治疗相关可靠网站链接、补充性营养信息，只有中国受访患者将经济支持评为最感兴趣的三大服务类型之一。

The top three types of services most interested to patients around the world are treatment information, treatment-related reliable website links, and supplementary nutrition information. Only Chinese patients rated economic support as the three most interested types of services.



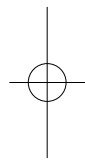
感兴趣的服务类型

The service that the patients most interested in

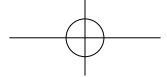


PART SIX **6**

主要发现
Key Findings



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在全球受访患者数据中，惰性淋巴瘤亚型患者更多；
在中国受访患者数据中，侵袭性淋巴瘤亚型患者更多。

1

The ratio of indolent lymphoma subtypes among global patient respondents is much higher than that in Chinese patient respondents, especially the ratio of Waldenstrom's macroglobulinemia. The ratio of aggressive lymphoma subtypes among Chinese patient respondents is higher than that among global patient respondents.

成功治愈可能取决于在正确的时间掌握正确的信息。患者掌握的信息越充足，会感觉自己越有力量，并且会与医生进行更加有效的交流沟通，治疗期间遇到的障碍也越少。而且中国受访患者对信息的渴求程度远高于全球其他国家，需要引起医生及患者组织等相关方面的重视。

2

The patients' recovery may depend on the information they gain and the time they gain the information. The more information they have, the more powerful they feel, which can facilitate effective communication between patients and doctors. Consequently, they can reduce the obstacles in the period of treatment. Around the world, Chinese patient respondents have stronger desire to gain information, which requires the attention from doctors and patient organizations.

疾病及其所带来的心理问题和治疗副作用一直影响着患者的幸福感，但心理问题和治疗副作用的影响会蔓延至治疗之后的8年甚至更久。

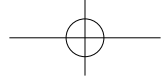
3

The psychological problems and treatments' side-effects continue to affect the patient's happiness, even after 8 years of post-treatment.

与遇到疾病问题大部分患者有意愿主动与医生交流不同，当遇到心理及副作用的问题时主动寻求医生帮助的患者并不多。

4

In comparison to patients who are willing to discuss their medical conditions with the doctors, only a few patients seek help for psychological and side-effect problems on their own initiative.



中国受访患者遇到与治疗相关障碍的频率远高于全球平均值，尤其是经济状况方面，患者遇到的障碍最多，并因此产生了极大的心理压力。



The frequency of treatment-related disorders encountered by Chinese patients is far higher than the global average, especially in terms of economic conditions, and the most common obstacles encountered by patients, resulting in tremendous psychological stress.

与医生进行良好的沟通，不仅可以帮助患者掌握信息，还能降低患者遇到障碍的频率，是需要向患者倡导的。



Good communication should be advocated to patients, because it can not only help patients acquire information but also reduce the chances of encountering obstacles.