

An Assessment of Health Information Resource Center and Supportive Program Needs

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ABSTRACT

Objective: No practical method or assessment tool for identifying patients' and their families' health information resource needs in a resource center exists. We sought to assess the health information and resource preferences of patients and their families to guide the planning of a health information resource center (HIRC). **Methods:** A needs assessment was conducted using convenience sample of patients and families drawn from the National Cancer Centre in Singapore. A survey was conducted to gather data from April 23, 2018, to May 11, 2018, at the Specialist Oncology Clinics (SOCs) and the Ambulatory Treatment Unit. **Results:** A total of 778 surveys were analyzed, and the majority of the respondents were Chinese (79.8%). There were 449 (57.7%) patients and 317 (40.7%) family members. Among the 778 respondents, the overall top item chosen for facilities, resources, and equipment were a quiet and comfortable area for reading and reflection (77.2%), information about education and support services offered by the center (71.6%), and computers

with internet access (63.6%), respectively. The overall top three services needed in the resource center were advice on useful resources (70.6%); announcements on newly received materials, programs, and support services (64.8%); and resource personnel to assist with identifying materials/navigating through resources (53.2%). Written education pamphlets/brochures were rated as the most useful material (74.6%), followed by consumer health books (74.2%) and newsletter (59.6%). The top overall three supportive programs required were nutrition talks and cooking demonstrations (76.7%), counseling (individual, couples, family, and bereavement) (74.3%), and exercise (e.g., Tai Chi, yoga) (68.5%). **Conclusions:** The findings obtained from this assessment provide guidance to the development of a user-friendly, patient- and family-centric HIRC.

Key words: Brochures, cancer, health information resource, printed information materials, resources, supportive programs

Introduction

Cancer and its treatment is a very traumatic event affecting not only the patients but also their caregivers. The nature of the disease requires patients to learn about the illness, make difficult decisions regarding the ensuing treatment, and

cope with the consequences of the illness. For caregivers, information is needed to provide physical, emotional, social, financial, and spiritual support to the cancer patients and help them manage their own physical and emotional needs.

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Studies have revealed that cancer patients have a considerable amount of informational needs, and these needs vary from patients to patients, gender, age, and type and stage of disease.^[1,2] Information needs include illness/disease^[3-6] and treatment,^[3-5] likelihood of cure/prognosis; spread of disease;^[3] recurrence and survival outcomes;^[4] and side effects;^[5,6] including financial concerns.^[7,8] Similarly, research studies have also shown that patient caregivers had a considerable need for information and support as they are becoming more responsible for providing physical and psychosocial care over long period.^[9,10]

However, literature consistently identifies gaps in information delivery; patients and their caregivers have to resort to other information sources to seek information, and the prevalence of information seeking does not diminish over time.^[11-16] Concerns were also raised about the difficulty in obtaining the information they needed, difficulty in comprehending the information obtained,^[17-19] causing confusion,^[20] conflicting information and unreliable sources^[18,21] and the quality of information obtained^[11,15,16] besides being a time-consuming process.^[21]

Lack of information puts both patients and caregivers at risk for negative consequences such as distress^[9,22-24] and increased burden.^[9] Conversely, well-informed patients and caregivers have been reported to have reduced anxiety and increased sense of control, better coping, increased satisfaction with treatment, and improved communication with family.^[25] In order to help them make informed medical decisions and cope with the physical and psychological problems associated with cancer and its treatment, it is important to assess their information and supportive care needs. Failure to identify the information and supportive care needs of the patients and their families may result in spending an inordinate amount of time and resources attempting to deliver information and supportive care that may not be needed by them, resulting in the ineffective use of finite resource.

Health information resource center (HIRC) has an important role to play in improving access to health-related information by patients and their families. Careful planning is important to ensure that the resource center will serve a useful purpose. An understanding of stakeholders' information needs and resource preferences is crucial to guide care planning so that finite resources can then be directed toward developing the needed resources and support programs to supplement the consultation visits and provide support for both patients and family members.

The goal of this assessment was to facilitate the development of a patient- and family-centric HIRC in the new National Cancer Centre Singapore (NCCS) based on

the actual needs of users. Specially, the assessment aims:

- To create an environment that is conducive for learning
- To establish the type of relevant and accessible collection of resource
- To identify the type and range of services needed
- To determine the supportive care needs of the patients and family.

Methods

This assessment employed survey as an evaluation method in order to gather a large number of stakeholders to obtain information about their needs and preferences about the facilities and resources for the planning of a HIRC. The survey was conducted from April 23, 2018, to May 11, 2018, at the SOCs and the Ambulatory Treatment Unit of the NCCS. Anyone who attended NCCS (patient/family member/accompanying personnel) and able to read and write in English or Chinese during the survey period were invited to participate in the self-administered questionnaire. The questionnaire included an open-ended question to ascertain the type of information needed. The questionnaire was developed based on information obtained from the "Resource Centre Manual: How to set up and manage a resource centre"^[26] and prior identified needs of patients and caregivers in the Centre.^[15,27,28] Ethical approval for this evaluation was not obtained because no sensitive or identifiable data of participants were obtained, and it also posed no foreseeable risk/harm to participants in this quality initiative to enhance the delivery of patient- and family-centric care.

Statistical analysis

Descriptive statistics were used to summarize the quantitative data collected in the survey. Categorical variables were reported using frequent counts and percentages. Data were analyzed for the entire cohort of respondents, and by identity of the respondents (i.e., patient, family, or others). Responses in the open-ended question were grouped into categories for reporting purpose.

Results

Demographics

A total of 778 respondents was analyzed. Majority of the respondents were patients (57.7%) and Chinese (79.8%) [Table 1].

Patient and family education resource center

Facilities/resources/equipment

Among the 778 respondents, the overall top item chosen for facilities, resources, and equipment were a quiet and comfortable area for reading and reflection (77.2%),

Table 1: Demographics

| | No. | % |
|-----------------|-----|------|
| Total | 778 | 100 |
| Identity | | |
| A patient | 449 | 57.7 |
| A family member | 317 | 40.7 |
| Others | 11 | 1.4 |
| Missing | 1 | 0.1 |
| Race | | |
| Chinese | 621 | 79.8 |
| Malay | 68 | 8.7 |
| Indian | 39 | 5 |
| Eurasian | 3 | 0.4 |
| Others | 46 | 5.9 |
| Missing | 1 | 0.1 |

information about education and support services offered by the center (71.6%), and computer with Internet access (63.6%), respectively. The results were almost similar across the patients and family members except that the family members preferred to have Internet access (79.8%) than a quiet and comfortable area for reading and reflection (73.8%) [Table 2].

Services needed

Among the 778 respondents, the overall top three services needed in the resource center were advice on useful resources (70.6%); announcements on newly received materials, programs, and support services (64.8%); and resource personnel to assist with identifying materials/navigating through resources (53.2%). The results were consistent with the patients, whereas the family members preferred to have resource lists (49.8%) over having a resource personnel to assist with identifying materials/navigating through resources (46.1%) [Table 3].

Information materials

Among the 778 respondents who rated the materials as useful or very useful, written education pamphlets/brochures were rated as the most useful material (74.6%), followed by consumer health books (74.2%) and newsletter (59.6%) [Figure 1].

Type of information needed

The top three types of information needed by respondents were cancer, treatment, and diet and nutrition. Healthy living, drugs/clinical trials, and survivorship are currently not their focus [Table 4].

Language

Among the 778 respondents, 82.8% wanted the materials to be in English and 54.9% wanted the materials to be in Chinese [Table 5].

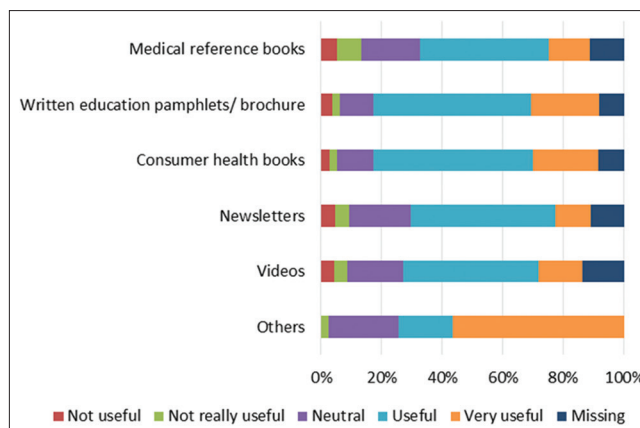


Figure 1: Usefulness of information materials

Support programs

Among the 778 respondents, the top overall three programs wanted were nutrition talks and cooking demonstrations (76.7%), counseling (individual, couples, family, and bereavement) (74.3%), and exercise (e.g., Tai Chi, yoga) (68.5%). Patients rated similarly as the overall cohort, whereas the caregivers preferred to have caregiver support (70.7%) over exercise (67.2%) [Table 6].

Discussion

A HIRC plays a very important role in the continuum of information provision. In order to encourage patients and family members to come to the resource center, it must be equipped with good facilities/resources based on their needs. Needs assessment is a process of directly assessing and identifying specific issues of need of patients, and they are crucial to guide care planning.^[29]

Facilities and resource needs

Overall, patients and family members wanted a “quiet and comfortable area for reading and reflection.” Learning depends on several factors, but the environment plays an important role. Noise can be highly distracting. A distraction-free environment facilitates concentration, resulting in the ability to learn information more quickly and effectively. Besides being distraction free, comfort is also important. Adequate lighting, a cool environment, and comfortable chairs are important for relaxation and good posture. A quiet and comfortable area can play a key role in helping patients and family members concentrate in the most effective way possible. In addition, overall 74.8% of the patients and their family members required Internet access to be available at the resource center including computers with Internet access.

The advent and the rapid growth and development of information technology bring easy access to health-related information. Although 91% of the household have Internet

Table 2: Facilities/ Resources/ Equipment

| | Total | | | | | | | | | | | |
|---------------|---|--|-----------------|--|--|--|---|--|---------------|---------------|-------------------------------|---------------|
| | Facilities | | | | | Resources | | | | Equipment | | |
| Total | A quiet and comfortable area for reading and reflection | Library with reading materials and videos relating to cancer | Internet access | Wheelchair accessible computer station | Posters on latest cancer news and research | Information about education and support services offered by the Centre | Information and description about clinical trials that are open for enrolment | Resources available for children with a family member who has cancer | Video player | Photocopier | Computer with internet access | |
| Total | 778 (100.0) | 601 (77.2) | 489 (62.9) | 582 (74.8) | 319 (41.0) | 458 (58.9) | 557 (71.6) | 427 (54.9) | 484 (62.2) | 264 (33.9) | 259 (33.3) | 495 (63.6) |
| Patient | 449 (100.0) | 357 (79.5) | 302 (67.3) | 321 (71.5) | 196 (43.7) | 280 (62.4) | 326 (72.6) | 257 (57.2) | 289 (64.4) | 157 (35.0) | 158 (35.2) | 281 (62.6) |
| Family member | 317 (100.0) | 234 (73.8) | 184 (58.0) | 253 (79.8) | 118 (37.2) | 172 (54.3) | 223 (70.3) | 163 (51.4) | 187 (59.0) | 105 (33.1) | 97 (30.6) | 204 (64.4) |
| Others | 11 (100.0) | 9 (81.8) | 3 (27.3) | 7 (63.6) | 4 (36.4) | 5 (45.5) | 7 (63.6) | 7 (63.6) | 8 (72.7) | 2 (18.2) | 3 (27.3) | 9 (81.8) |
| Missing | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 1 | 0 | 0 | 1 | 1 |

Table 3: Services needed

| | Total | | | | | | | |
|---------------|----------------|-------------------|--|----------------|---------------|----------------------------|---|---|
| | Total | Loan of materials | Announcements on newly received materials, programs and support services | Resource lists | Photocopying | Advice on useful resources | Resource personnel to assist with identifying materials/ navigating through resources | Assistance with patient education classes' registration |
| Total | 778 (100.0) | 335 (43.1) | 504 (64.8) | 391 (50.3) | 274 (35.2) | 549 (70.6) | 414 (53.2) | 397 (51.0) |
| Patient | 449 (100.0) | 198 (44.1) | 293 (65.3) | 227 (50.6) | 167 (37.2) | 318 (70.8) | 262 (58.4) | 247 (55.0) |
| Family member | 317 (100.0) | 134 (42.3) | 204 (64.4) | 158 (49.8) | 105 (33.1) | 221 (69.7) | 146 (46.1) | 146 (46.1) |
| Others | 11 (100.0) | 3 (27.3) | 6 (54.5) | 5 (45.5) | 2 (18.2) | 9 (81.8) | 5 (45.5) | 4 (36.4) |
| Missing | 1 | 0 | 1 | 1 | 0 | 1 | 1 | 0 |

access in Singapore,^[30] it is not unexpected that computers with Internet access topped the overall equipment needs. Literature indicates that cancer patients and their caregivers have many information needs^[1-5,27] and are active online information seekers^[13-15] due to its convenience, the amount of information available, immediacy of access,^[12,31] and privacy and anonymity.^[31] However, concerns were raised regarding the quality and quantity of information and its credibility and impact on patients' well-being and

decision-making.^[21,32] In addition, negative feelings, such as confusion or nervousness/anxiety, were also reported.^[20,21] As there is no regulatory oversight on the posting of medical and health information on the Internet, the information posted may be incomplete, inaccurate, inappropriate, or erroneous.^[18,21,31] Although there is little evidence that much harm has been done, there was a reported case of death directly reported from misinformation from the Internet.^[31] As information on the Internet can vary widely

Table 4: Type of information needed

| Topics | Total |
|-----------------------|-------|
| Cancer | 107 |
| Treatment | 99 |
| Diet and nutrition | 85 |
| Coping | 54 |
| Support | 42 |
| Research | 28 |
| Caregivers | 22 |
| Drugs/clinical trials | 19 |
| Survivorship | 19 |
| Healthy living | 17 |
| Others | 16 |

Table 5: Language preferred

| | Total | | | |
|---------------|-------------|------------|------------|-----------|
| | Total | English | Chinese | Others |
| Total | 778 (100.0) | 644 (82.8) | 427 (54.9) | 96 (12.3) |
| Patient | 449 (100.0) | 348 (77.5) | 228 (50.8) | 52 (11.6) |
| Family member | 317 (100.0) | 285 (89.9) | 192 (60.6) | 42 (13.2) |
| Others | 11 (100.0) | 10 (90.9) | 6 (54.5) | 2 (18.2) |
| Missing | 1 | 1 | 1 | 0 |

in quality and there is the potential risk of misinformation and confusion, patients and their families also need advice on useful resources (identified as top resource needs by both patients and families) and assistance with identifying materials/navigating through resources (identified as top three service needs) including information on useful web links to high-quality and reliable health-related information websites based on their needs and assistance in accessing them.

Health information needs

Information needs about cancer and treatment topped the types of information needed. The importance of such information is well reported in the literature.^[3-6] Information about the disease and its treatments and potential outcomes is important in decision-making regarding the ensuing treatment and coping with the consequences of the illness and treatment, both physically and emotionally and to be an active participant in the care process.

Overall, 74.6% rated written educational materials/brochures as useful/very useful. The preference for written information materials is supported by literature.^[13,15,20,33,34] The benefits of written education materials/brochures are the ability for learners to control their own rate of learning, the order in which they choose to pay attention

to information, and they are easy to physically carry and interact with as needed without the necessity of further equipment.^[35] A systematic review by Sherlock and Brownie^[36] found that patients' recollection and understanding of the medical procedure, risks, and complications is often low, particularly among older individuals and the use of education materials delivered in written form or embedded in an interactive multimedia process led to improvements in patients' understanding. However, written information materials may be ineffective unless they are written based on health and language literacy.^[37] As English (82.8%) and Chinese (54.9%) languages and almost 75% of Singaporeans are Chinese,^[38] this provides impetus for the need to provide information materials are not only in English but also in the Chinese language.

Supportive programs needs

Nutrition talks and cooking demonstration topped the list of support services desired by both patients and family members (76.7%). The need for dietary information and advice has been well reported in the literature.^[27,39,40] Cancer and its treatment such as chemotherapy and radiation therapy can cause many side effects such as mucositis, alteration in taste, dyspepsia, dysphagia, nausea, vomiting, diarrhea, and constipation^[41-43] and adversely affect the nutritional intake and compromise the general health of the patients. Restrictions of specific foods in children (<18 years old) undergoing cancer treatment was practiced by 57% of mothers and misconceptions regarding diet are prevalent.^[44] Food avoidance is very prevalent in the Asian, especially the Chinese. The Chinese believed that the body is kept in the harmony (Yin and Yang) by the type of food that one eats. It can also be either more Yin or more Yang depending on the methods used in cooking. There are also many foods that are considered taboo when a patient has a diagnosis of cancer. These beliefs can include that patients should avoid protein from animal sources, such as chicken, pork, eggs, seafood, not drinking milk, and not eating sugar.^[45] This is supported by studies^[46,47] that the majority of patients reported a reduction in the consumption of red meat, seafood, and poultry. As good nutrition is important in recovery and literature indicates a lack of basic information and dietary advices, this is an area that will probably be well received by many patients and family members.

Limitations

Sampling by convenience limits the generalizability of these findings and the questionnaire was only available in English and Chinese, therefore, a limitation of this assessment was that participants had to be proficient in English or Chinese. However, English is our first language

Table 6: Support programs

| | Total | | | | | | | | | | | | | |
|------------------|---|--|--|---------------|------------------------------|------------------|---------------|----------------|---|-------------------|---|----------------------|---------------|-------------|
| Total | Counselling (individual, couples, family and bereavement) | Exercise (e.g. Tai Chi, yoga) | Nutrition talks and cooking demonstrations | Creative art | Journaling and sharing | Music therapy | Knitting | Pet therapy | Look Good... Feel Better (Beauty care and styling) | Spiritual care | Support groups (disease specific, adolescents, family or friends [caregivers]) | Caregiver support | Others | |
| Total | 778 (100.0) | 578 (74.3) | 533 (68.5) | 597 (76.7) | 197 (25.3) | 217 (27.9) | 382 (49.1) | 147 (18.9) | 155 (19.9) | 341 (43.8) | 376 (48.3) | 486 (62.5) | 516 (66.3) | 35 (4.5) |
| Patient | 449 (100.0) | 331 (73.7) | 312 (69.5) | 343 (76.4) | 117 (26.1) | 123 (27.4) | 216 (48.1) | 87 (19.4) | 86 (19.2) | 203 (45.2) | 217 (48.3) | 273 (60.8) | 284 (63.3) | 19 (4.2) |
| Family member | 317 (100.0) | 237 (74.8) | 213 (67.2) | 243 (76.7) | 78 (24.6) | 92 (29.0) | 160 (50.5) | 59 (18.6) | 68 (21.5) | 131 (41.3) | 155 (48.9) | 206 (65.0) | 224 (70.7) | 15 (4.7) |
| Others | 11 (100.0) | 9 (81.8) | 7 (63.6) | 10 (90.9) | 1 (9.1) | 2 (18.2) | 6 (54.5) | 1 (9.1) | 1 (9.1) | 6 (54.5) | 3 (27.3) | 6 (54.5) | 7 (63.6) | 1 (9.1) |
| Missing | 1 | 1 | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 0 |

and there were representations from other races in this assessment. In addition, the assessment was conducted using a nonvalidated questionnaire. Nevertheless, we were able to gather a large sample of both patients and family members to provide the needed data to assist us in our planning of our HIRC.

Conclusions

HIRC plays a very important role in the continuum of information provision by improving access to health-related information to patients and families. Careful planning is important to ensure that the HIRC will serve its useful purpose in meeting this important need. This assessment has identified the facilities, resources, and supportive care needs of patients and families. We hope that the assessment will help guide the development of a patient- and family-centric HIRC. Our findings would also help health-care professionals to better understand the support programs desired by patients and families so that finite resources can then be directed toward developing the needed support for them. To ensure that the HIRC and support programs remain relevant and patient and family centric, it is important to monitor and assess its performance and service needs continuously.

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Conflicts of interest

There are no conflicts of interest.

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