

INTEGRATING TECHNOLOGY WITH THE HUMAN TOUCH THROUGH DIALOGUE

The Canadian Cancer Society's Cancer Information Service,
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Manuscript submitted to the American Association for Cancer Education 36th Annual Meeting October 31-
November 3, 2002 Toronto, Canada

ABSTRACT

Since its inception as a national service of the Canadian Cancer Society in 1996, the Cancer Information Service has responded to more than 450,000 inquiries from cancer patients, their relatives and friends, individuals awaiting results, healthcare professionals and the general public. Canadians often need someone to help them understand cancer. Seventy trained information specialists located in four information centres across Canada provide one-on-one discussions tailored to the information needs of the callers on a wide range of topics, from prevention and diagnosis to treatment and supportive care. With the help of Dialogue, a custom web-based software application designed with user input, our specialists have information at their fingertips with on-line access to a database of 54 types of cancer, over 4000 community services and 700 publications and web resources. The type of information and referrals provided on inquiries is compiled and analyzed to identify the information needs of specific groups of callers. Integrating technology with the human touch through Dialogue is a winning combination for tailoring cancer information delivery.

1.0 BACKGROUND

1.1 The Canadian Cancer Society's Cancer Information Service (CIS)

Since its inception as a national service of the Canadian Cancer Society in 1996, the Cancer Information Service (CIS) has responded to more than 450,000 inquiries from cancer patients, their relatives and friends, individuals awaiting results, healthcare professionals and the general public. Canadians often need someone to help them understand cancer. Seventy trained information specialists located in four information centres across Canada (Vancouver, Regina, Hamilton and Montréal) provide one-on-one dialogue tailored to the information needs of the callers on a wide range of topics, from prevention and diagnosis to treatment and supportive care.

1.2 Operating principles of CIS

To ensure high-quality service delivery, the following operating principles are applied:

- Information specialists have a healthcare background and undergo 6-8 week training
- Information specialists provide information, not advice or personal opinion
- Information specialists support the doctor-patient relationship. Callers are encouraged to discuss with their doctors the information they receive from CIS and to obtain their doctor's advice before making a medical decision
- Information specialists are supportive and non-judgmental
- Confidentiality and anonymity of callers are respected
- Information specialists use Dialogue, a software program with comprehensive modules on cancer information, materials for distribution and community service directory.
- Documentation distributed to callers come from sources approved by the Canadian Cancer Society (~25% of inquiries)
- An inquiry record is completed for each inquiry to gather data on client type, type of cancer and topics discussed, age, gender, province of residence and referral to 1-888 number.
- Quality assurance plan is in place.

2.0 CANCER INFORMATION

2.1 Changing environment

In the last decade, we have seen important changes in our healthcare environment and information channels. These have impacted access to cancer information and the information needs of the public, more particularly those of cancer patients. Examples are:

- Patients have become part of their healthcare team and participate in decision making about their care. They need to understand what the options mean for them. (eg. lumpectomy or mastectomy)
- Many clinical studies are reported in the media. The public has difficulty interpreting the significance of the results (which sometimes contradict previous findings) and how it might apply to them. (eg. mammography for women in the 40-49 age group)
- The Internet provides broad access to a multitude of sources on health information - not all sources

are credible, not all information is accurate. When there is too much information, the public looks for synthesis and relevance for their own situation.

The Canadian Cancer Society's information specialists have observed that the complexity of the inquiries is increasing. Their role has shifted from providing and explaining cancer information to interpreting, synthesizing and helping callers understand how the information applies to them.

2.2 Why is cancer information complex?

Cancer information is complex because:

- It is about many different diseases
- The spectrum is broad, from risk reduction to palliative care
- It can strike at any age
- It is feared and life-threatening
- Treatments are invasive and painful
- Cancer care is fragmented and confusing to navigate
- Cancer affects a large population; patients as well as family and friends
- There are many myths about its causes and cures
- Several aspects of the disease are still unknown

2.3 Communicating about cancer

Communicating about cancer is more than providing accurate cancer information. It is about understanding where people are in their journey, what motivates their search for information, how much they already know and what they need at this time. This makes every inquiry unique and emphasizes the importance of the needs assessment skills of information specialists. Information specialists consider that they have met some or all of the information needs of the callers when:

- The caller is satisfied
- Explanations to complex questions were clear and understood by the caller
- New information or options were presented to the caller
- The mood of the caller improved
- The fear of the caller was reduced
- The caller was referred to an appropriate service in the community.

Conversely, components of a "difficult call" are when:

- There is little information or help available
- There is difficulty being understood (by caller or information specialist)
- The caller expresses deep sadness, loneliness or distress
- Anger or frustration is directed at the information specialist
- Caller's convictions are founded on inaccurate information (eg. conspiracy for cure).

Effective communication about cancer means "making a connection" with the caller. This requires knowledge, expertise, intuition and judgment on the part of the information specialists.

2.4 Profile and information needs of CIS callers

Information specialists respond to an average of 75,000 inquiries per year. During the period January 1, 2002 and August 31, 2002, data was gathered from the total of 47,605 inquiries received. The inquiries came from:

Client Type Number of inquiries Percentage of total

General Public	17,088	35.9%
Friends and Relatives	13,005	27.3%

Diagnosed Cancer Patient	8,295	17.4%
Health Professional	3,265	6.86%
CCS Representative	1,152	2.4%
Community Organization	1,063	2.2%
Student	974	2.1%
Undiagnosed Person	944	2.0%
Media	179	0.4%
Not recorded	1,640	3.5%
Total	47,605	100%

Approximately 80% of inquiries came from cancer patients, their friends and family and the general public. When assessing their profile and information needs, we observe the following:

Cancer Patients

- Cancer patients who contacted CIS were mostly women (70.9%), English speaking (81.4%), in the 40-69 age group (51.8%) .
- The inquiries were made primarily by phone (94.9%) or email (4.4%).
- The types of cancer most often discussed included breast cancer (26.4%), prostate cancer (7.7%), colorectal cancer (4.6%), lung cancer (2.9%) and Non-Hodgkin's Lymphoma (2.7%).
- The focus of the inquiries was on supportive care (51.3%), treatments (42.7%) and pathology and staging (19.0%).
- Under the supportive care topic, cancer patients were interested in emotional support (14.0%), transportation (5.2%) and financial support (5.1%).
- 46.3% of cancer patients received a referral to a community service.
- Cancer patients found out about CIS from the Canadian Cancer Society (27.7%), telephone directories (19.1%), healthcare sources (12.9%) or had used the service before (17.3%)

Friends and relatives of cancer patients

- Friends and relatives who contacted CIS were women (78.0%), English speaking (85.2%), in the 30-59 age group (42.9%) .
- The inquiries were made primarily by phone (91.6%) or email (8.0%).
- The types of cancer most often discussed were breast cancer (9.8%), lung cancer (6.2%), colorectal cancer (5.5%), prostate cancer (4.7%), Non-Hodgkin's Lymphoma (2.7%) and leukemia (2.6%).
- The focus of the inquiries was on supportive care (51.0%), treatments (36.2%) and pathology and staging (21.2%).
- Under the supportive care topic, friends and relatives of cancer patients were interested in emotional support (12.5%), financial support (4.8%) and transportation (4.0%).
- 46.4% of relatives and friends of cancer patients received a referral to a community service.
- They found out about CIS either from the Canadian Cancer Society (29.1%), a telephone directory (28.0%), healthcare sources (7.9%) or had used the service before (11.1%).

General Public

- Members of the general public who contacted CIS were women (71.1%), English speaking (82.8%) and in the 20-59 age group (36.8%) .
- The inquiries were made primarily by phone (92.3%) or email (7.5%).
- When the general public discussed a type of cancer , it was on breast cancer (5.5%), prostate cancer (2.2%), colorectal cancer (1.8%) and cervical cancer (1.1%).
- The focus of the inquiries was on risk reduction (19.0%), especially tobacco, screening and signs/symptoms (8.9%), financial donations (19.9%) and hair donations (13.5%).
- 57.4% of inquiries by the general public received a referral to a community service.
- General public found out about CIS either from the Canadian Cancer Society (33.6%), telephone directory (26.6%), healthcare sources (3.5%) or had used the service before (6.0%).

The data suggest that the information needs of cancer patients, and their family and friends, focus on supportive care, treatment and pathology and staging. For the general public, the topics of interest risk reduction, screening, signs and symptoms and making donations. Overall, the types of cancer discussed reflect the incidence of the most common types of cancer in Canada.

The data on information needs of cancer patients, their family and friends and the general public help the Canadian Cancer Society direct the development of its information products and ensure that information specialists have the resources required to meet the needs of CIS callers.

3.0 INTEGRATING TECHNOLOGY WITH THE HUMAN TOUCH THROUGH DIALOGUE

To meet to information needs of our callers, information specialists must integrate knowledge, communications skills, call management, resources and use of the technology. Through Dialogue, a custom web-based bilingual software application designed with user input, our information specialists have information at their fingertips with on-line access to a database of 54 types of cancer, over 4000 community services and 700 publications and web resources. They can link to a comprehensive range of cancer information or conduct a search tailored to the questions of the caller. Dialogue allows the information specialist to focus on the caller while the system does the work of searching and recording.

Based on the information needs of our callers, the following are examples are of issues related to supportive care, treatment, pathology and staging that are difficult to find, or understand, without the assistance of an information specialist:

- How to navigate the cancer system: Having an information specialist explain the details of the cancer system is invaluable at a time when one feels confused and vulnerable.
- Medical tests and procedures: Many questions arise a few days before an appointment for a test or treatment. Asking an information specialist how to prepare and what will happen can reduce anxiety.
- Looking for help: Cancer is overwhelming and not knowing where to turn for help makes one feel powerless. An information specialist can provide referrals to a wide-range of services in the community, including home care, emotional support, financial assistance etc...
- Clinical trials: Searching for a clinical trial is not accessible to all. An information specialist can help identify what is available, the eligibility criteria and how to contact the cancer centres.
- Staging: Different staging systems can be confusing...An information specialist can explain what staging means for a specific type of cancer and how it might relate to treatment options.
- Statistics and prognosis: Relative risk and prognosis need to be put in context. An information specialist can help someone understand the meaning behind the numbers.
- Latest research findings: Understanding the risk and benefits of early detection and screening can

- be a challenge. An information specialist can bring clarity to clinical practice.
- Complementary and alternative therapies: Do they work? Where can I get it? Do you know a good clinic? An information specialist can provide a list of important considerations when a caller is contemplating the use of complementary or alternative therapies.

With access to resources and technology at their fingertips, information specialists bring context and clarity to complex cancer issues.

4.0 CONCLUSION

Given the important changes in our healthcare environment and new information channels, communicating about cancer has become more than providing accurate information. Cancer patients are asked to make decisions, the general public needs to make sense of media coverage, and the information overload begs for interpretation and relevance. Communicating about cancer is about understanding where people are in their journey, what motivates their search for information, how much they already know and what they need at this time.

The role of the Canadian Cancer Society's Cancer Information Service has shifted from providing and explaining cancer information to interpreting, synthesizing and helping callers understand what information means and how it applies to them. Cancer patients, their family and friends, and the general public ask about risk reduction, screening, early detection, supportive care, treatment, pathology and staging. With access to resources and technology at their fingertips, information specialists bring context and clarity to complex cancer issues. Integrating technology with the human touch through Dialogue is a winning combination for tailoring cancer information delivery.