Illuminating the Distinct Information Needs of Brain Cancer Patients and Their Caretakers During Routine Clinical Care

Jennifer A. Lyon¹, MS, MLIS, AHIP, Dr. Jessica Schumacher², PhD, Dr. Erin Dunbar³, MD, Jennifer West³, RM, BSN, CCRP, Mary Edwards¹, EdD, MLIS, AHIP

¹Health Science Center Libraries
²Department of Health Services Research, Management and Policy, College of Public Health and Health Professions
³Department of Neurosurgery, College of Medicine
University of Florida
Brain Cancer Patients (BCPs) are unique even among cancer patients because brain functions are disrupted
- Damage to personality, memory, cognitive, motor & sensory function
- Shocking and serious nature of the diagnosis

Difficulties surround providing appropriate information while accommodating the uncertainty surrounding outcomes
- Patients unable to process information immediately after diagnosis
- Information presentation must be done in short ‘bites’
- Information must be repeated and well-timed
- Information must be high quality, understandable, and reliable

Providing high quality health information to brain cancer patients in a timely and effective manner is a significant unmet need.
Objectives

• Establish an interdisciplinary collaboration to investigate the health information needs of brain cancer patients, their providers, and caregivers

• Obtain feedback on the potential usefulness of
  – an online resource guide tailored for brain cancer patients
  – an information prescription form
Methods

• Subjects
  – Brain Cancer Patients and Health Care Providers, aged 18-89 years who are able to speak English and consent for self
  – Recruited from the Preston Wells Brain Tumor Therapy Center, UF&Shands, Gainesville, FL

• Logistics
  – 30-60 minute focus group sessions held in a quiet conference room
  – Semi-structured interview, open-ended questions

• Data Analysis
  – De-identified transcripts subjected to qualitative thematic analysis
  – Themes compared and discussed until consensus reached
# Focus Groups – Round 1

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**Total HCP: 3**  **Total BCP: 11**
Key Finding

Caregivers are vitally important!

- Patients are seriously ill and shocked
- Caregivers take on much of the information gathering and assessment
- Caregivers often speak on behalf of the patients

Given these findings the IRB Protocol was rewritten to allow inclusion of caregivers in focus groups and further investigate the caregiver’s role.
## Focus Groups – Round 2

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<td>12/13/11</td>
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**Total Caregivers**: 6  
**Total BCP**: 4  
**Total HCPs**: 3
Health care professionals know that there are unique information needs at each stage.

“...once the person hears the word ‘cancer’ it doesn’t matter what [the HCPs] say for the next 20 minutes. It’s not going to be absorbed. So [the HCPs] have to be prepared to come back and talk about it in more detail.”
Providers: Themes

• Important time periods are:
  – first 24-48 hours post-diagnosis (determining the plan of care)
  – 7-10 days post-diagnosis (diagnosis has ‘sunk in’ and questions formulated)

• Importance of providing info on what to expect and how to prepare

• Importance of providing info that can be reflected on later and shared with others (caregivers)

• Importance of talking face-to-face with provider team, patient and caregivers
Providers: Themes

• Acknowledgement that each individual has unique set of questions and needs
  – Pre-made (cancer society, etc) info is often too generic/general
• Take time to allow patients/caregivers to write down verbal information
• Use of the Internet: pluses and minuses
• Acknowledgement that both short-term and long-term information needs exist
• Important to repeat information in different modes at separate times
“I went to [hospital] and they took me into emergency and they did a CAT scan thing. And they come out with a little picture with a little dot... He said, ‘Well you have [a] tumor.’ What’s happening? You know, to me, it don’t mean squat other than something’s there that shouldn’t be there.”

**Question:** When you first learned about your cancer... what types of questions did you have about it?
**Patient:** Where do I go to get it treated?

**Question:** Did you ever feel, uh, confused by the information that you were getting from these different doctors?
**Patient:** I kind of let my wife worry about that... I just let her deal with getting me to where I needed to go.

I go to appointments with both of them after I had this radiation done... and then one of them is saying “Don’t ever bend forward.” The other one says: “Don’t ever bend backwards.”
Patients: Themes

• Focus on the rarity/lethality of their brain cancer and are proud of “beating the odds”

• Value experience, quality, and personal attention in physicians
  – They will search for the best physicians, best hospitals, best technologies
  – Willing to travel or be inconvenienced to get better care

• Want real-time information - knowledge is power/control
  – Can have serious problems understanding what providers are saying

• Want honesty, frankness, even guesses/opinions from providers & value their opinions
Patients: Themes

• Seek out clinical trials, new treatments, new technologies, more options
• Want **timely** information from providers to relieve anxiety and facilitate preparation
• Want **practical** information about where events take place, how to get there, park, etc.
• Get lost searching the internet & have limited time and energy to spend on it
• High utilization of social networking sites for contact with family/friends and other patients
  – A support network is essential for providing information and filtering out the scary and inaccurate or dangerous.
Focus Groups - Caregivers

“I took what they [gave] us and went to WebMD and pulled up some information and I read what I could about it, but it was very minimal and most of it was too medical for me to understand and I’m not a medical person, but I got the gist of it that we’re on a limited time frame here.”

“It takes both of us to put all this together to begin with, we take notes and notes and notes, it happens that we both have notebooks full of information where we jotted down every word [HCP] said to us then we go back and try to decipher it.”

“What does that mean, where do we go, what should we expect…how does this affect a person, what signs should we be seeing…what should we be looking for, are there certain things that happen…his behavior, or things that will indicate to us that we’re moving, that we’re doing ok or that we’re moving into the next phase.”

“…do they have a video? Let us sit and watch a video that shows us what it looks like for a person to have seizure, if he was to have a seizure and what…it looks when someone has a seizure and this is what you should do...”
Caregiver Themes

• Heavy responsibilities: calling providers, transportation, collecting medical records, searching Internet, informing others, making plans
• Concerned about maintaining family life
• Want to know what to expect and how to respond
• Level of medical knowledge directly related to satisfaction with provided information
  – Issue with understanding medical terminology
• Want clear information on progression and prognosis
Caregiver Themes

• Want information useful for planning the future
• Frustration with online sources (combined with lack of knowledge of available sources)
• Issues with getting too much or too little information
• Varying level of satisfaction with HCP communication
• Experienced communication problems with HCPs
• Desire to communicate with others sharing the same experience
• Conflict between protecting patient’s positive outlook while preparing for the worst
Tailored Online Resource

“Informed Cancer Patients” website, utilizing the “Campus Guides” software platform

http://guides.uflib.ufl.edu/Patients

• Disease, Treatment, Prognosis, Clinical Trials
• Assistance programs and services for patients and caregivers
• Counseling, support, and treatment options
Informed Cancer Patients
Consumer Information, Local Resources, Forms
Last update: Jul 5th, 2011
URL: http://guides.uflib.ufl.edu/Patients

Cleaning Assistance
- Cleaning for a Reason: A nonprofit organization offers free professional housecleaning to women undergoing treatment for any kind of cancer.

Elderly
- Catholic Charities Bureau: 352.372.0294
- Central Florida Community Action Agency: 352.373.7667
- Elder Helpline: 800-262-2243
- Elder Options: 800-863.5337
- Eldercare of Alachua County: 352.265.9040
- Florida Respite Coalition
- Shands HomeCare: 352.265.9276

Disabilities
- ARC of Alachua County: 352.334.4060
- Blind Services: 352.955.2075
- Center for Independent Living of North Central Florida: 800.266.5724
- Parking Permits for Disabled Persons (Alachua County, FL): 352.374.5326

Hospice
- Haven Hospice: 352.378.2121

Wigs & Things
- Especially for Women: 352.332.9005
- K-Beauty Mart: 352.378.6788
- Mirrilee Boutique and Wigwam (Bellevue, FL): 352.245.2433
Response to Resource

• Patients think we should be advertising the website and the clinic itself
• Patients perceive value of website resource for future use, but not at initial diagnosis
• Some patients don’t feel computer literate

“I don’t know how to work none of that stuff.”

• Patients believe that caregivers will make more use of it.

“My wife will spend hours and hours on there...She’ll scour all that stuff up.”
### Information Prescription Form

**DRAFT to be generally discussed with participants**

**Information Prescription**
A service generously provided by the UF Health Science Library

**Phone, website**

| Name: ____________________________ | Today's date: ____________________ |
| Phone #: __________________________ | e-mail address: __________________ |

Circle one: a patient: ___ Caregiver/Family member: ___ Interested person: ___

### Description of information request:

**Disease:**

- □ Risk factors
- □ diagnosis
- □ staging
- □ treatment at diagnosis
- □ treatment at recurrence
- □ monitoring

**Patient or caregiver questions about:**

- □ Talking to relatives (children, others) or health care provider
- □ Memory and personality, Changes in self-perception or how others perceive you, Emotional wellbeing, coping
- □ Energy/Fatigue
- □ Nutrition while receiving treatment, changes in taste

- □ prognosis
- □ Specific medicines or treatments (uses, risks/benefits, results)
- □ other:

- □ Comfort and quality of life
- □ Use of alternative medicines
- □ Exercises and Rehabilitation
- □ Home care, rehab care, and hospice care
- □ End of life issues and care:
- □ Other:

### Additional information that should be considered in filling this prescription:
Response to Form

Information prescription idea perceived as highly valuable because “there’s a lot of people that aren’t Internet savvy.”

“A prescription to go to a librarian service would be great for a lot of people.”

“If it don’t say [this month] on it, it’s already out of date.”

“Be careful of using of the phrase ‘alternative medicine’ on the form versus the phrase ‘complimentary therapies’.”
Future Directions

• Data from second round of focus groups still under analysis
• Interventional studies based on needs assessment will be considered
• Web resource will continue to be developed and updated
• Sharing information with providers to help them meet these needs
Thank you!

Any Questions?

Contact me at: jalyon@ufl.edu