PERSPECTIVES OF LGBT CANCER PATIENTS AND THEIR CAREGIVERS ON
SEXUAL ORIENTATION AND GENDER IDENTITY DISCLOSURE

C. Kamen¹, A. Alpert², N. Murray¹, M. Flannery³, M. Janelins¹,
S. Mohile¹, K. Mustian¹, L. Peppone¹, S. Norton³.
¹University of Rochester, Surgery, Rochester, USA.
²University of Rochester, Medicine, Rochester, USA.
³University of Rochester, School of Nursing, Rochester, USA

BACKGROUND

- Competent care for sexual and gender minority (SGM) patients should involve:
 - helping patients feel safe disclosing their sexual orientation and gender identity (SOGI)
 - including SGM patients’ caregivers in care.
- It is unclear whether care providers are assessing SOGI, and whether this has improved the care of SGM patients and caregivers.

METHODS AND MEASURES

- We conducted semi-structured interviews with 24 SGM patients with cancer in upstate New York, their 24 caregivers and 12 of their providers (N=60 participants).
- Interview topics included SOGI data collection, inclusion of SGM patients’ caregivers, and recommendations for improving cancer care.
- Interviews were recorded, transcribed, and analyzed using an inductive coding strategy by two coders.
- Codes were then refined to establish themes within and across patient/caregiver dyads.

RESULTS

- Four themes emerged from coding of responses:
 - SOGI disclosure is inconsistent in cancer care
 - SOGI disclosure carries with it anticipation of stigma
 - Providers and patients struggle to discuss sexuality
 - SGM patients want to be treated with equity

CONCLUSION

- Despite efforts to collect SOGI data, SGM patients often disclose identities themselves.
- Facilitating disclosures could improve cancer care for SGM patients, enhance the visibility of caregivers, and improve provider competence in general.
- Interventions to increase provider comfort are needed to implement these recommendations.

REFERENCES

Kamen CS, Alpert A, Margolies L, et al. "Treat us with dignity": a qualitative study of the experiences and recommendations of lesbian, gay, bisexual, transgender, and queer (LGBTQ) patients with cancer. *Supportive care in cancer*. 2018.

Institute of Medicine. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Washington (DC): National Academies Press; 2011.

Haider A, Adler RR, Schneider E, et al. Assessment of Patient-Centered Approaches to Collect Sexual Orientation and Gender Identity Information in the Emergency Department: The EQUALITY Study. *JAMA Netw Open*. 2018;1(8).

	Patient (n=24)	Caregiver (n=24)		Patient (n=24)	Caregiver (n=24)		Patient (n=24)
Age (Range)	58 (32-80)	57 (40-70)	Marital status			Cancer type	
Gender identity			Married	19	18	Breast	10
Female	16	15	Partnered	5	6	Prostate	4
Male	8	9	Employment			Colorectal	4
Sex assigned at birth			Employed	12	17	Ovarian	2
Female	15	15	Unemployed	3	1	Kidney	2
Male	9	9	Retired	8	5	Lung	1
Sexual orientation			Disability	1	1	Thyroid	1
Lesbian/Gay	23	23	Education			Time since dx	46 mo.
Heterosexual	1	1	Graduate+	7	7	(Range)	(4-140)
Race/Ethnicity			4 year college	8	10		
Non-Hispanic White	23	24	<4 year college	4	4		
Hispanic/Latino	1	0	High school	5	3		

1. SOGI disclosure is inconsistent and patient-driven in cancer care.	2. SOGI disclosure can cause anticipation of stigma.	3. Providers and patients struggle to discuss same-sex sexuality.	4. SGM patients and caregivers want to be treated with equity.
"I don't think they really got the picture...because when we went back, even though [the provider] knew us, I was with someone different ...and they would not let [my wife] in. I literally went through everything, and she was furious... We were like, how do you not have her in our records?" (cis white lesbian, 56, breast cancer)	"One of the concerns I had is that Dr. J, particularly, happens to have a Haitian or Jamaican background and culture, and in those cultures, gay men, um, are literally killed on the streets." (cis white gay man, 68, prostate cancer)	"I never asked my doctors, you know, is it okay to still have sex. I love [my providers] and I would ask them, but I mean... They're both straight men... So its a little uncomfortable to ask...If my doctors were more versed in those things, would they be able to bring them up...versus me having to ask?" (cis white gay man, 40, colon cancer)	"[The provider] had a meeting with us before the surgery, it was 3 heterosexual couples and me and [my husband] and we felt as comfortable as comfortable can be. [He said] "What are your questions? How about you guy's significant others, spouses, wives, girlfriends, boyfriends, husbands, let me know."" (cis white gay man, 61)
"We don't...ask unless the patient is offering. I'm embarrassed to say, we really didn't even know their support person was their [same-sex] partner." (cis white heterosexual woman, 52, nurse practitioner)	"We discussed it, you know and she's like...it's probably not going to be a good experience. We're probably going to get looks, you know. We might be asked questions like well why is she in here with you? You know only family members can be in here." (cis white lesbian, 59, breast cancer)	"They didn't really have all the answers...so then it's like, all right, time to go to Google. Wow, that wasn't the search I wanted." (cis white gay man, 42)	"You get this 25-year-old who is going through cancer and afraid to come out, now what do you do? How do you make that person feel welcome or feel safe enough to come out?"(cis white lesbian, 54)

Funding provided by the Lesbian Health Fund of the Gay and Lesbian Medical Association and by NCI grants K07 CA190529 and UG1 CA189961