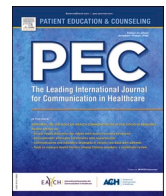




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Patient and family preferences in referral to legal services after a cancer diagnosis

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Incorporating legal support into cancer care is essential in addressing the financial toxicity of a cancer diagnosis [1]. Patients' quality of life is impaired by unmet legal needs regarding healthcare, finances, employment, insurance, and estate planning [2]. As noted by Hastert et al., the optimal method for coordinating these services remains an issue for oncology teams, with perceived barriers and proposed solutions varying by provider type [3]. By surveying individuals who received legal support after cancer a diagnosis, we provide insight into patient and family preferences around referral to legal consultation.

Cancer Legal Care (CLC) is a non-profit organization that provides legal services and education to Minnesotans affected by cancer [4]. A 34-question survey was developed to solicit information about CLC client demographics, financial circumstances, and experiences with CLC. When available, we used validated measures from other large, national surveys to obtain socio-demographic data and measures of financial impact after cancer [5,6]. For items where no validated measures currently exist, survey items were designed based on themes derived from key informant interviews with five CLC clients, representing diverse racial and socio-economic backgrounds, at which point no new themes emerged. Once completed, a draft of the survey instrument underwent cognitive testing among five individuals who had no prior experience with CLC to assess its length, wording, and organization.

From June 2023 through July 2023, 430 surveys were mailed to individuals known to be alive and have received services from CLC in the last two years. Individuals were provided with a return envelope to respond via mail, as well as link to complete the survey online if preferred. Forty-seven surveys were returned as undeliverable. Of the 383 remaining surveys, 120 were completed (31%) and 113 included complete responses for key outcomes.

Respondents were predominantly white (86.7%), female (50.4%), over 50 years old (69.8%), and metropolitan residents (76.1%) (Table 1). Based on data collected by CLC at intake, respondents' demographics were generally representative of CLC's clientele, although slightly more likely to be white and male. Most respondents sought services for themselves alone (74.3%), with others seeking services for a family member instead of (or in addition to) themselves. The most common legal concerns leading clients to CLC were wills, powers of attorney, or health care directives (40.7%); employment issues (31.9%);

Social Security disability insurance (30.1%); insurance issues (20.4%); and dealing with a bill or debt (20.4%).

Most (66.4%) respondents learned about CLC from their medical team, but even more (81.4%) indicated they would like to learn about legal services from their medical team. Comparing respondents' preferred versus actual sources of information about legal services reveals other discrepancies (Fig. 1). While 49.6% of respondents indicated they would like to hear about legal services from their oncologist, only 10.6% actually did. Similarly stark differences were reported regarding information sheets from a doctor (52.2% preferred vs 5.3% actual) and pamphlets in clinic (38.1% preferred vs 6.2% actual).

While respondents desired better access to referrals in clinic, they preferred to receive legal services remotely. Phone (74.3%) and video (40.7%) were the most popular means of working with CLC, especially compared to meeting in clinic (30.1%). Respondents also preferred to learn about CLC's services earlier on in the course of their cancer care. Time of diagnosis was most frequently cited (64.6%) as a useful period to learn about CLC, followed by the start of treatment (34.5%). At the end of treatment and upon request were the least cited times (both at 8%).

Medical-Legal Partnerships represent an emerging effort to mitigate financial impacts of cancer. Various models exist for bundling these services, with differing degrees of integration with the health system [7]. The present survey emphasizes several considerations for patient-centered approaches to structuring such collaborations.

Respondents valued the recommendations of their care team, and many more wished to receive referrals to legal care this way. In their qualitative analysis of interviews with providers, Hastert et al. found that physicians varied in their capacity to engage in these conversations. They revealed that limited time with patients, a lack of familiarity with their financial issues and a need for additional resources all presented barriers for physicians. In the present study, most respondents (52.2%) indicated that information sheets from providers were a desirable form of referral, which may help mitigate these barriers.

From the perspective of social workers and legal practitioners, Hastert et al. reported a need to discuss the financial impact of cancer early on, even if some patients were reluctant at first. Having surveyed patients *after* receiving legal consultation, they ultimately shared these concerns. This confirms the importance of connecting patients to legal

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Table 1
Demographic composition of respondents.

Variable	Categories	N (%)
Age	≤ 50	31 (27.4)
	51-60	36 (31.8)
	61+	43 (38)
	Missing	3 (2.6)
Gender	Male	52 (46)
	Female	57 (50.4)
	Other/missing	4 (3.5)
Race	Non-White	12 (10.6)
	White	98 (86.7)
	Missing	3 (2.6)
Monthly Household Income	\$0-\$2000	20 (17.6)
	\$2001 to \$6000	49 (43.3)
	\$6001 to \$10,000	19 (16.8)
	\$10,001 or more	16 (14.1)
	Missing	9 (7.9)
Educational Degree	Less than college	44 (38.9)
	2- or 4- year college	51 (45.1)
	Graduate or doctoral	15 (13.2)
	Missing	3 (2.6)
Occupational Status	Student	3 (2.6)
	Unemployed	4 (3.5)
	Medical Leave/Long Term Disability	7 (6.1)
	Employed part-time	14 (12.3)
	Employed full-time	24 (21.2)
	Retired	26 (23)
	Disabled	29 (25.6)
	Other/missing	6 (5.3)
	Widowed	6 (5.3)
	Single, never married	16 (14.1)
Marital Status	Divorced or separated	28 (24.7)
	Married or living as married	60 (53)
	Missing	3 (2.6)
	1	29 (25.6)
	2	41 (36.2)
Household Size	3+	39 (34.5)
	Missing	4 (3.5)
	Non-Metropolitan	25 (22.1)
	Metropolitan	86 (76.1)
Metropolitan Status	Missing	2 (1.7)
	Tricare, V A, Military	1 (0.8)
	Private, Individual	4 (3.5)
	COBRA	4 (3.5)
	No coverage	6 (5.3)
	Medical Assistance (Medicaid)	13 (11.5)
	Medicare	22 (19.4)
	Private, Employer	60 (53)
	Missing	3 (2.6)
	Poor/fair	46 (40.7)
Overall Health	Good	48 (42.4)
	Very good/excellent	14 (12.4)
	Missing	5 (4.4)
	Pancreatic	5 (4.4)
Cancer Type	Gynecologic	7 (6.1)
	Colorectal	9 (7.9)
	Lung	10 (8.8)
	Leukemia/lymphoma	12 (10.6)
	Breast	20 (17.6)
	Other/missing	50 (44.2)
	Stage I	6 (5.3)
Cancer Stage	Stage II	11 (9.7)
	Stage III	11 (9.7)
	Stage IV	48 (42.4)
	Remission	16 (14.1)
	Other/missing	21 (18.6)

Abbreviations: VA, Veterans Affairs; COBRA, Consolidated Omnibus Budget Reconciliation Act.

and financial services at diagnosis, even if it may not initially seem necessary.

Finally, our survey found a strong preference for receiving legal consultation remotely, via phone or video call, as opposed to in clinic. This aligns with recent research about the time toxicity of a cancer diagnosis, with patients desiring to spend less time in healthcare environments [8]. In seeking to lessen the burdens placed on cancer patients

and their families, medical-legal services may be more effectively implemented when tailored to accommodate these concerns.

While the present study provides valuable insight, it is subject to several limitations. First, while we achieved a relatively low response rate of 31%, this is in line with response rates of other large, national surveys [5,6] and our respondents were socio-demographically similar to the broader CLC clientele. Furthermore, these findings come from a

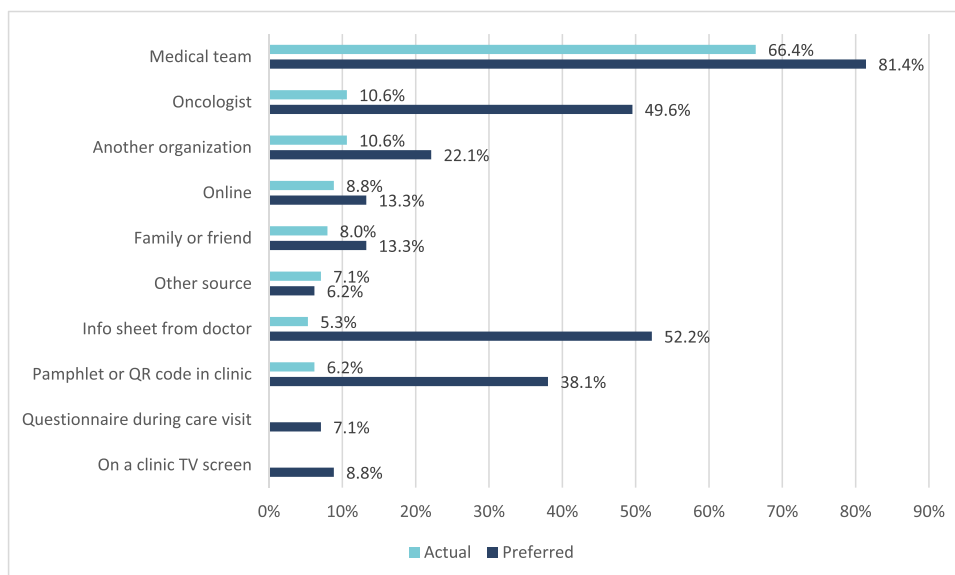


Fig. 1. Preferred vs. actual sources of information about services offered by Cancer Legal Care.

single organization and so may not be generalizable to other models for structuring medical-legal partnerships. Future research may build on our findings by examining preferences for referral to a broader range of social support services (e.g., financial support, food and housing benefits) or within a broader network of medical-legal partnerships. Additionally, future research may benefit from employing qualitative methods to better understand the complexity of patients' experiences with legal consultation after a cancer diagnosis.

Overall, these findings provide a first step in understanding who receives legal services after a cancer diagnosis and provides actionable insights for coordinating these services in the context of healthcare delivery in a patient-centered manner.

Ethics

The IRB of the University of Minnesota determined this study did not constitute human subjects research.

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CRediT authorship contribution statement

Helen M. Parsons: Writing – review & editing, Supervision, Project administration, Methodology, Funding acquisition, Data curation, Conceptualization. **Rachel Kourelis:** Writing – review & editing, Conceptualization. **Lindy Yokanovich:** Writing – review & editing, Funding acquisition, Conceptualization. **Samuel J. Greenwald:** Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal

relationships which may be considered as potential competing interests: LY and RK are employed by Cancer Legal Care but were not directly involved in data collection.

Data availability

The data used in this project will be shared upon request.

References

- [1] Hussaini SMQ, Gupta A, Dusetzina SB. Financial toxicity of cancer treatment. *JAMA Oncol* 2022;8(5):788. <https://doi.org/10.1001/jamaoncol.2021.7987>.
- [2] Zevon MA, Schwabish S, Donnelly JP, Rodabaugh KJ. Medically related legal needs and quality of life in cancer care. *Cancer* 2007;109(12):2600–6. <https://doi.org/10.1002/cncr.22682>.
- [3] Hastert TA, Nair M, Egly S. Providers' communication-related concerns in helping patients address the financial impact of cancer. *Patient Educ Couns* 2023;114:107860. <https://doi.org/10.1016/j.pec.2023.107860>.
- [4] Overview: what we do: cancer legal care. (www.cancerlegalcare.org); (<https://www.cancerlegalcare.org/what-we-do>) [Accessed October 26, 2023].
- [5] National Health Interview Survey: NHIS data, questionnaires and related documentation. (<https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm>) [Accessed January 2, 2024].
- [6] Behavioral Risk Factor Surveillance System: BRFSS Questionnaires. (<https://www.cdc.gov/brfss/questionnaires/index.htm>) [Accessed January 2, 2024].
- [7] Bednar T, Antoniadis D. Medical-legal partnerships in cancer care. In: Hopewood P, Milroy MJ, editors. *Quality cancer care*. Springer; 2018. p. 161–97. https://doi.org/10.1007/978-3-319-78649-0_11.
- [8] Johnson WV, Blaes AH, Booth CM, Ganguli I, Gupta A. The unequal burden of time toxicity. *Trends Cancer* 2023;9(5):373–5. <https://doi.org/10.1016/j.trecan.2023.01.006>.

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