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# *G*lioma *r*esource *o*utreach *w*ith *s*upport: A program to identify and initiate supportive care interventions for unmet needs among adult lower-grade glioma patients

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## Abstract

**Background**. Lower-grade (WHO grades 2–3) gliomas typically affect young and middle-aged adults and exhibit *isocitrate dehydrogenase* (*IDH*) mutations. For such patients, symptoms related to the tumor and associated treatment contribute to morbidity and erode quality of life. With improved treatment, a better understanding of these effects over time is critically needed. Existing data characterizing unmet needs of lower-grade glioma patients is limited and little consensus exists on addressing these needs in clinical practice.

**Methods**. In order to better identify and address the unmet needs of lower-grade glioma patients, focus groups among patients and caregivers were initially conducted among patients treated at a single academic center. A semi-structured interview guide to comprehensively understand unmet needs was then developed. Each patient-defined unmet need was categorized into domains through qualitative content analysis. In parallel, a database of established local and regional community-based resources was established, and a dedicated resource specialist provided patient-specific referrals and follow-up.

**Results**. Eighty-five patients were interviewed. Median age was 41 years and the median time from tumor diagnosis was 63 months. Approximately 68% had a WHO grade 2 tumor and 60% were off therapy. Qualitative analysis of interview content identified 5 overarching domains of unmet need: Psychosocial; Neurologic/Cognitive; Lifestyle; Financial; and Other Medical. At least one unmet need was identified by 71% of participants and the most common domains were Psychosocial (40.7%) and Lifestyle (34.9%).

**Conclusions**. Our program begins to address frequently unmet survivorship needs of lower-grade glioma patients that spanned 5 major domains. Further research aimed to better define and address unmet needs among these patients is warranted.

## Key Points

- More effective therapies are leading to improved survival for patients with WHO grades 2 and 3 glial tumors yet strategies to define and address unmet needs that evolve from the tumor and its treatment over time for these patients are lacking.
- We conducted patient/caregiver focus groups that allowed us to develop an interview tool that was structured to identify key unmet needs articulated by individual patients and their caregivers during one-on-one interviews.
- Five overarching domains of unmet need were identified.

- A database of existing community-based resources was developed in parallel and individual, patient-specific referrals with follow-up were implemented as an interventional strategy to address these needs.
- Our program may serve as a model for other neuro-oncology centers to better define and address the unmet needs of patients afflicted with lower-grade gliomas.

## Importance of the Study

Novel treatment strategies are improving survival for patients with WHO grades 2 and 3, *IDH*-mutant tumors. Better understanding of the impact of the tumor and its treatment over time on individual patients may translate into better function and quality of life. We implemented a focused approach that includes a novel interview tool to better define the unmet needs of these patients. Five overarching domains of unmet need were defined and a database of existing community-based resources potentially capable of addressing unmet needs was defined and referrals implemented. Our program may serve as a model for other neuro-oncology programs to further improve understanding and interventions aimed at addressing the unmet needs of these patients.

Adapting to a primary brain tumor diagnosis can be challenging for adult patients and their caregivers. The nature and severity of symptoms typically vary over time and can differ from patient to patient depending on tumor pathology, tumor location, treatment, and other factors.[1] Gliomas, the most common primary malignant brain tumor in adults, are categorized by the presence or absence of a mutation in *isocitrate dehydrogenase (IDH)1*, and less commonly*, IDH-2*. Eighty percent of lower-grade gliomas (WHO grades 2 and 3) harbor an *IDH* mutation. In adults under the age of 50, *IDH*-mutant lower-grade gliomas are the most common primary brain tumor and are typically diagnosed during the fourth and fifth decades of life. Due to differences in natural history and response to available treatment options between *IDH*-wild-type and *IDH*-mutant gliomas, patients with *IDH*-wild-type glioma have a 5-year survival rate of less than 6%, while *IDH*-mutant lower-grade glioma patients can live over a decade past their date of initial diagnosis and often experience prolonged periods of progression-free survival.[2–4] Despite a more favorable prognosis, *IDH*-mutant lower-grade gliomas remain incurable, can cause significant morbidity, and may require aggressive multi-modal treatment that can negatively impact brain health and function in the long term. In consideration of their greater life expectancy, longer periods of observation, and younger age at diagnosis, *IDH*-mutant lower-grade glioma patients have survivorship needs distinct from those of *IDH*-wild-type glioma patients.

One challenge associated with the treatment of *IDH*-mutant lower-grade glioma is the negative impact of focal therapies including radiation therapy, which is a standard of care therapy for all gliomas, on global neurologic function over time.[5] A recent phase 3 trial evaluating treatment with the IDH-inhibitor vorasidenib in patients with grade 2 *IDH*-mutant glioma demonstrated superior progression-free survival compared to patients treated with placebo, signifying the beginning of a new era in *IDH*-mutant glioma treatment and patient care.[6] As an alternative to upfront radiation therapy for grade 2 tumors, vorasidenib's anticipated Food and Drug Administration approval holds the promise of effective treatment that might also help delay or avoid the unfavorable effects of radiation therapy on long-term brain health and function. The field of neuro-oncology has long recognized a need for balancing both quality and quantity of life in patient care. It is not surprising that the development of novel therapies for *IDH*-mutant glioma has been accompanied by a broader call by practitioners for the use of quality-of-life outcome measures to inform neuro-oncologic clinical practice.[7,8] One common neurologic sequalae in patients with *IDH*-mutant lower-grade glioma is seizures, due in part to the putative epileptogenic activity of R-2-hydroxyglutarate (2-HG), the oncometabolite produced in excess by mutated IDH enzymes.[9] Seizure activity, physical impairment, changes in cognitive function, and overall worse general health perception have been shown to negatively influence self-reported health-related quality of life (HRQoL) in patients with lower-grade glioma.[10,11]

Measures of HRQoL can decline, even when tumors remain stable.[12] Broader integration of questionnaire assessments along with conventional outcome measures (eg, progression-free survival and overall survival) could provide a more nuanced understanding of the unmet needs in the lower-grade glioma patient population. While questionnaire assessments dominate the available research in the HRQoL space, significant heterogeneity in the methodologies and findings of these investigations have limited their broader usefulness to patient care in neuro-oncology. A 2023 literature review of such studies notes thirteen different HRQoL questionnaire instruments across 29 publications of 22 studies conducted.[13] Some have proposed that a uniform questionnaire be used across all clinical studies looking at HRQoL, but the multi-factorial nature of lower-grade glioma symptomatology and morbidity may limit the ability of a single questionnaire to fully capture the breadth of this disease's impact on patient well-being.[14] Despite available studies characterizing certain aspects of HRQoL in heterogeneous glioma populations, there are few studies specifically assessing unmet needs in the lower-grade glioma population.[11–13] Screening tools for identifying unmet needs for CNS tumor patients have been developed including the Supportive Care Needs Survey (SCNS-SF34) and a brain cancer-specific needs survey (BrTSCNS) and results of their application have been recently reported primarily among high-grade glioma patients.[15] We chose to utilize an interview approach rather than questionnaires because qualitative data from mainly interview questions may allow for a more comprehensive and nuanced understanding of this population's survivorship experience and associated unmet needs. Although questionnaires require less support and analysis of their results may be more straightforward, the interview approach was advantageous for our purposes as it offered the opportunity to acquire unique and broad patient commentary while minimizing potential bias. A recent report utilized semi-structured interviews amongst 28 low-grade glioma patients in the United Kingdom to explore the impact of a low-grade glioma diagnosis on patients as well as potential supportive care needs.[16]

*IDH*-mutant lower-grade glioma patients are typically diagnosed as young- or middle-aged adults.[4] While cognitive and physical functioning are anticipated to be generally worse in *IDH*-wild-type glioma patients, patients with *IDH*-mutant lower-grade glioma often have social obligations as parents, students, or employees—roles that are sensitive to even modest variations in function.[17] As such, these individuals may require specific forms of support to be delivered via targeted supportive services (eg, patient navigation, peer support, cognitive rehabilitation).

In 2017, the National Cancer Institute published workshop proceedings emphasizing the need to develop and expand efforts to address the survivorship needs of patients with central nervous system cancers.[18] Aligned with this goal, we established the *GROWS (Glioma Resource Outreach With Support)* program at the Dana-Farber Cancer Institute's Center for Neuro-Oncology (DFCI CNO) to identify and understand the unmet needs of lower-grade glioma patients. Herein we describe the initial effort of our *GROWS* program. First, we conducted focus groups with patients and caregivers. Based on collected feedback, we then developed a semi-structured interview guide to assess the various challenges experienced by individuals living with this diagnosis. Using this guide, we then interviewed 86 patients with histologically confirmed WHO grade 2 or 3 glioma. In parallel, and based on identified categories of unmet need, we generated a database of local, community-based resources and services, and utilized a dedicated *GROWS* resource specialist to guide patients to appropriate, individualized supportive resources. Our report summarizes preliminary and previously unpublished data on the initial implementation of this approach to better address this population's unmet needs.

## Materials and Methods

### Design and Setting

In late 2020, the DFCI CNO received generous financial support from a low-grade glioma patient and family to develop a tailored survivorship program with the goal of better identifying and addressing the unmet needs in lower-grade glioma patients. The program was named *GROWS* (*G*lioma *R*esource *O*utreach *W*ith *S*upport). We assembled a multi-disciplinary team including a dedicated *GROWS* resource specialist, senior and junior neuro-oncologists, a neuro-oncology nurse practitioner, a psychiatrist, social workers, a psychologist, and patients. The team met twice a month to plan the initial development strategy of *GROWS*. Rather than developing specific interventional programs, the team opted to define a strategy to better understand the actual unmet needs as described by lower-grade glioma patients and caregivers. Based on this feedback, our *GROWS* resource specialist began to establish a database that included a detailed listing of available community resources localized regionally and beyond, with the hope of addressing the unmet needs of our patient population. During this process, the resource specialist made contact with local and regional providers in relevant supportive care specialties (eg, neuropsychological testing, cognitive rehabilitation, and survivorship) to promote the program and open lines of communication for possible future referrals. Thereafter, we facilitated referrals to appropriate resources to begin to address unmet needs defined on a patient-specific basis. In addition to the initial referral, our approach included planned follow-up with patients and caregivers to gauge the utility and value of each referral.

First, focus groups were held to identify common themes of unmet needs identified by lower-grade glioma patients and caregivers who received care at our center. The focus groups were led by members of the *GROWS* team including our patient resource specialist, psychologist, and social worker. Based on the analysis of the focus group feedback, a semi-structured interview guide was developed to refine our understanding of patient unmet needs and their frequency. The questions comprising our interview guide probe aspects of the patient experience that fall outside the realm of disease-directed therapies, to identify areas where additional supportive care interventions and resources may be warranted. One-on-one interviews utilizing the guide were conducted during scheduled clinic visits with lower-grade glioma patients who agreed to participate. Patients were invited to participate if they had a histopathologic diagnosis of WHO grade 2 or 3 glioma and were followed at the outpatient clinic of the DFCI CNO and included but were not limited to patients who participated in the initial focus groups. Participants were interviewed during a 13-month period, from August 2022 through August 2023. Initially, only patients in surveillance were approached; however, this was later extended to include patients on active treatment. There were no restrictions based on the degree of treatment or number of tumor recurrences. Caregivers, such as partners, children, relatives, or friends of patients, were encouraged to accompany the patient during the interview, per the patient's preference but only the patient interview responses were tallied. All participants were notified that their participation was voluntary. All data presented herein was deidentified for analyses and presentation. This effort was reviewed and approved as a quality improvement project by the Dana-Farber/Harvard Cancer Center (DF/HCC) Institutional Review Board.

## Data Collection

Three preliminary focus groups with participating patients, their caregivers, and *GROWS* team staff were convened in person. Focus groups were exploratory and unstructured in nature, with minimal moderator input, in order to encourage patients and caregivers to drive the conversation. Participants were encouraged to discuss their experiences with their brain tumor diagnosis, challenges they have faced both on and off treatment, and provide reflections on medical or supportive care they received or needed. The *GROWS* team reviewed and discussed the content of the focus groups via multiple, sequential sessions. Common categories and related needs raised by patients and caregivers during the focus groups were identified. The feedback was used in parallel with a review of the existing neuro-oncology literature around survivorship in brain tumor patients, to develop an interview guide aimed at better defining and characterizing unmet needs of lower-grade glioma patients (Table 1).

Semi-structured interviews utilizing our guide were then conducted by the *GROWS* resource specialist to further probe the general categories or themes of unmet needs uncovered in the focus groups. Interviews occurred on an individual basis in person in a private consultation room at the outpatient neuro-oncology clinic, over video call, or via telephone. Caregivers were again encouraged to participate pending patient preference. Detailed notes were taken by the interviewer during each encounter, generally lasting 1 hour (range of 20–90 minutes in duration). Demographic and clinical information were collected by electronic medical record review.

Based on the initial general categories of needs identified by the focus groups, our patient resource specialist also simultaneously developed a database of local and regional community-based resource programs and practitioners who could receive referrals to address our patients' unmet needs. Each entry included detailed contact information including names of support staff as well as address, phone and facsimile numbers as well as email when available.

## Data Analysis

We employed a directed approach to content analysis, using focus group participant feedback as a framework to help guide the analysis and coding of one-on-one interview data. All interview records were subjected to inductive content analysis, which generated a list of codes with each code defining a specified area of unmet need.[19] As analysis proceeded, additional themes emerged and additional codes were developed, leading to the revision, refinement, and extension of the initial coding scheme (Table 2, Supplementary Table 1). This process of revision was undertaken by the *GROWS* multidisciplinary team, as defined above to streamline the collection and interpretation of data. Our team met monthly to review the coding scheme employed in interview data analysis, ensuring that codes were generated to comprehensively capture participant feedback. To increase the trustworthiness of our analyses, we created new codes where participant feedback could not be categorized into existing codes. Proceeding in this way, all instances of the phenomenon of interest—unmet needs—were identified and coded. Codes were examined, and those corresponding to similar topics were grouped together to form broader categories or domains.

In collaboration with the DFCI informatics systems team, we designed a database, hosted on a secure, HIPAA-compliant electronic platform, to enable the cataloging of unmet needs identified during patient interviews. Each code corresponding to an instance of unmet need was recorded as a "Program Activity Record" (PAR) in our database. Each PAR was linked in the database to the applicable patient.

Our study population's baseline characteristics were reported using descriptive statistics. We summarized the final list of codes representing instances of unmet needs identified during patient interviews, and we described the 5 overarching domains into which each code was grouped. By analyzing all PARs, we calculated the frequency of codes corresponding to each domain.

# Results

A total of 3 focus groups were conducted over a 6-month period. Each focus group included 3–8 patients/caregivers and at least 1 member of the *GROWS* team staff. All patients involved in the focus groups participated in the subsequent interviews. Each focus group lasted 1–3 hours and each participating patient was encouraged to discuss key aspects of the impact of their brain tumor diagnosis on their life and to provide input on how their neuro-oncology team helped or failed to address their needs beyond those associated with directed tumor therapy. A detailed review of comments provided in these sessions identified 4 broad categories of participant concern: (1) psychosocial status and support, (2) daily activities and habits, (3) disease-specific symptoms, and (4) care-related feedback and goals (Supplementary Table 1). These categories became the basis for developing an initial coding scheme and informed the creation of a semi-structured interview guide (Table 1).[20]

Patient/caregiver interviews utilizing our guide were then conducted during a 13-month period, between August 2022 through August 2023. A total of 115 patients were approached, introduced to the project, and offered an interview (Figure 1). Most participants (77%) were identified through a review of the clinic schedule and electronic medical record system, while 20% were referred by clinical providers at the DFCI CNO. A total of 85 patients (74%) were interested in the project and completed an interview. Six patients (5%) declined an interview. Twenty-four patients (21%) expressed interest in the project at the time of the initial contact but opted to defer the timing of the conversation and ultimately did not complete an interview. The reasons for this varied and for all these patients, at least one additional approach was attempted, via phone call, message, or in-person visit.

The final sample of 85 participants (Table 3) consisted of 41 patients (48%) with astrocytoma and 44 patients (52%) with oligodendroglioma. All participants were diagnosed

**Table 1.** Interview Guide

| Domain | Question/probe |
|---|---|
| (Ice breaker) | Where did you drive in from today (in-person interview)? |
| | Where are you calling in from today (virtual interview)? |
| Psychosocial status and support | Do you live with anyone or any pets? |
| | What is your relationship like with (this person)? |
| | Do you have (additional) family that lives nearby? |
| | Do you spend time with your family on a regular basis? |
| | Is your family a support to you? |
| | Has your family been a support to you in the past? |
| | Do you have friends that you consider close friends? |
| | Do you spend time with your friends on a regular basis? |
| | Are your friends a support to you? |
| | Have friends been a support to you in the past? |
| | Are you religious or spiritual? |
| | Did you grow up in a religious home? |
| | Has your religion or spirituality been helpful to you recently or in the past? |
| | From your perspective, how is your mental health? |
| | Have you ever seen a therapist for counseling? |
| | Are you interested in a referral for counseling? |
| Daily activities and habits | Are you currently employed and working? |
| | Does your spouse/partner work? |
| | From your perspective, does your diet contribute to your overall health? |
| | Are you interested in resources that can help you to improve your diet? |
| | Do you have an exercise routine? |
| | Are you interested in resources that can help you to exercise safely or meet your fitness goals? |
| | Have you ever meditated or practiced mindfulness before? |
| | Do you have a meditation or mindfulness routine? |
| | Are you interested in trying meditation or mindfulness as a stress-reduction technique? |
| Disease-specific symptoms | Do you currently or in the past have you experienced uncontrolled seizures? |
| | What is your experience of the seizures when one is occurring? |
| | Are you on anti-seizure medications? |
| | Do you experience any bothersome side effects from your anti-seizure medications? |
| | Do you currently or have you in the past experienced any neurological symptoms? |
| | Do these symptoms impact your ability to function and if so, how? |
| | Have you addressed these concerns with your Neuro-Oncology care team? |
| | Do you currently experience any cognitive symptoms? |
| | Do these symptoms impact your ability to function and if so, how? |
| | Have you addressed these concerns with your care team? |
| | Have you been referred for or completed neuropsychological testing? |
| | Are you interested in a referral for neuropsychological testing? |
| | Are you interested in seeing a specialist that can help you understand and address these symptoms? |
| Care-related feedback and goals | Since your initial diagnosis is there anything that has been especially challenging? |
| | Since your initial diagnosis, is there anything that has been especially helpful to you? |
| | Do you have any concerns about your diagnosis or care that you would like to bring up? |
| | Do you have any feedback regarding your care you would like to share with us? |
| | Is there anything you need help with regarding your medical or supportive care here or elsewhere? |
| | Are you in need of any additional resources? |

**Table 2.** Domains of Unmet Need

| Domain | Subcategory/codes |
|---|---|
| Financial | Medical bills |
| | Tuition cost |
| | Basic needs cost |
| | Disability benefits navigation |
| | Transportation |
| | Household maintenance |
| | Finding employment |
| | Maintaining employment |
| | Temporary housing |
| | Permanent housing |
| Lifestyle | Nutrition |
| | Exercise |
| | Meditation/mindfulness |
| Neurologic/cognitive | Refractory seizure disorder |
| | Subjective cognitive deficit |
| | Expressive dysphasia |
| | Subjective speech changes |
| | Impaired balance |
| | Fatigue |
| | Pain (neurological) |
| Other medical | Insomnia |
| | Fertility and family planning |
| | Primary care |
| | Gynecologic care |
| | Long-term steroid use sequalae |
| | Arthritis |
| | Allergies |
| | Excessive muscle pain/soreness |
| Psychosocial | Depression |
| | Marital tension |
| | Existential despair |
| | Social isolation |
| | Emotional distress |
| | Mood changes |

with WHO grade 2 or 3 *IDH-mutant* gliomas. Sixty percent of participants were under radiographic surveillance and not actively receiving tumor-directed treatment at the time of their interview. For those who were receiving tumor-directed therapy at the time of the interview, approximately 47% were receiving an IDH inhibitor, either off-label or in the context of a clinical trial. The median time from the initial histological glioma diagnosis to the time of the interview was 63 months, with a wide range from 12 days to 10 229 days (>28 years). The median age of the participants was 41, with ages ranging from 20 to 70 years old. About half the participants (48.2%) were female. Most (88.2%) of the participants were Caucasian and non-Hispanic. Just over 54% of participants were married or in a civil union, and 47% had dependent children. Approximately 59% of the participants were working full or part-time, taking temporary leave from work, or were full-time students, while 27% of patients were unemployed and did not have plans to return to school or work.

Using a directed approach to qualitative content analysis, we identified 5 domains of unmet needs reported by participants during interviews: Psychosocial; Neurologic/Cognitive; Lifestyle; Financial; and Other Medical (Table 2).[21] In the Psychosocial domain, participants not only reported experiencing neuropsychiatric symptoms including anxiety and depression, but also frequently expressed a desire for additional mental health care and emotional support. Regarding concerns pertaining to Lifestyle, participants frequently sought additional advice from their care team on healthy habits, exercise, and nutrition. In the Neurologic/Cognitive domain, participants reported ongoing difficulty with persistent symptoms related to their tumor or associated treatment, especially cognitive dysfunction. Financial concerns reported by participants consisted of, among other issues, worries about paying for medical bills and affording basic necessities of daily living. Lastly, participants expressed concerns regarding Other Medical issues and comorbidities, including what exactly they should disclose or discuss with their primary care provider.

By summing all the PARs in our database, we counted a total of 176 distinct instances of unmet needs among the 85 participants in the study. Instances of unmet Psychosocial need occurred at a frequency of 36% of all PARs and were ranked, by frequency, either first or second for all patient subgroups. Lifestyle and Financial needs comprised 24% and 21% of the total PARs, respectively. Neurologic/Cognitive issues comprised 12% of the documented instances of need. Based on frequency of occurrence, Lifestyle concerns were ranked in the upper half of all categories by most subgroups of patients, except for those who were 10+ years from initial diagnosis or on IDH-inhibitor treatment, for whom Lifestyle needs were ranked 4 of 5. The relatively small sample size limited formal statistical comparisons between subgroups of various domains, but a trend to higher rank for Lifestyle needs was identified among males versus females. Of interest, rank across domains did not appear different based on age. Table 4 and Figure 2A detail the frequency of patient-reported unmet needs across the 5 major domains.

Sixty-one participants (72%) reported at least one unmet need, in any category. Among these participants, the median number of total unmet needs per participant was 2 (range of 1 to 18 instances of need). The largest number of unmet needs reported by a single participant in one single category was 9, in the category of Financial needs. A total of 40.7% of all participants reported needs in the Psychosocial domain, while 34.9% of participants reported needs in the Lifestyle domain (Figure 2B). Fifteen patients reported unmet needs exclusively in the Psychosocial category. Just under half (49.2%) of participants with unmet needs ($N = 61$) reported at least 1 need in the domain of Lifestyle, and 13 of these patients had unmet needs exclusively in this domain. Only 11.6% of all patients had unmet medical needs that fell outside the realm of routine neuro-oncologic care, making the Other Medical category the

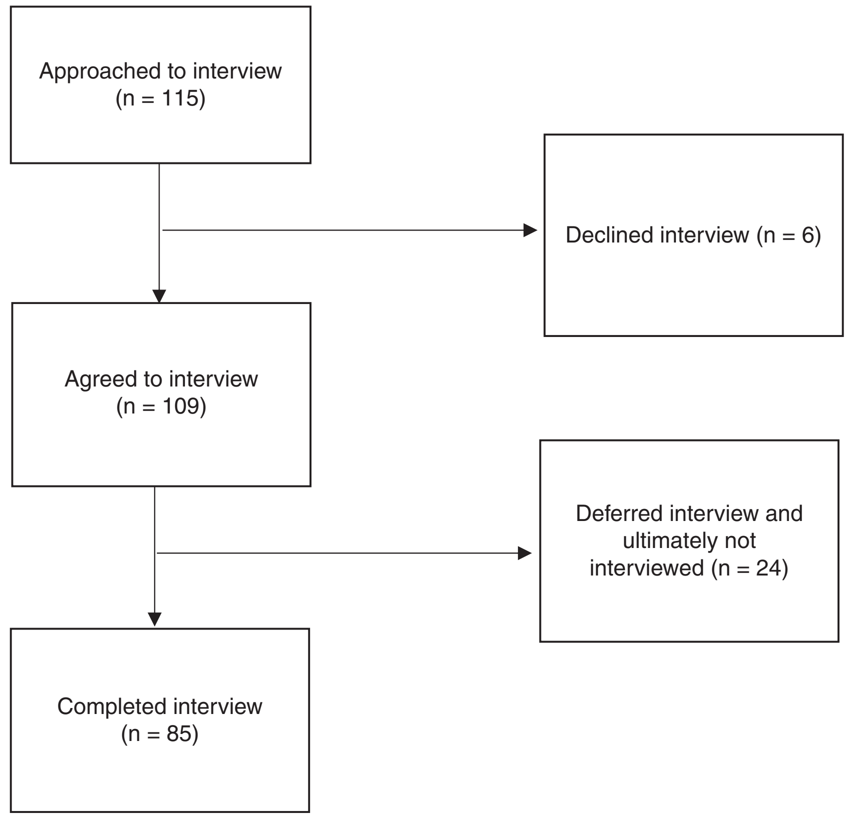

**Figure 1.** Project Recruitment and Participation

least frequently reported category of unmet need. All individuals who reported unmet needs in this domain also reported unmet needs in at least one additional domain.

The database of resources maintained by the resource specialist falls into one of the following resource categories: Supportive Care; Financial; or Patient-Centered. Within the Supportive Care category, there are resource records for medical doctors in specialties such as sleep medicine, neurology, and palliative care, rehabilitation therapists such as speech-language pathologists, occupational and physical therapists, mental health providers such as licensed mental health counselors, licensed independent social workers and doctors of psychology and integrative therapy or healthy living providers such as nutritionists, exercise physiologists, and massage therapists. Financial resource records are comprised of programs and organizations that help to support participants financially, either by providing navigation services related to finances or material resources or by offering financial relief, transportation, and other material support to eligible individuals. The financial resource records are largely providing benefits that are institution or state-specific. Patient-centered resources include nonprofit organizations, peer support groups, and case management programs that may provide educational support, advocacy, or navigation services. While most of the resources in our database are in the local metropolitan and state area, others are located out of state and reflect the demographics of our participating patients. Given changes made in the past 5 years due to the COVID-19 pandemic, many resources that were previously only accessible in-person are now available for virtual use by patients. A significant portion of resource records fall into this category.

## Discussion

Following the discovery of *IDH* driver mutations in a subset of infiltrating glial tumors affecting young and middle-aged patients, exciting advances that redefine our understanding of the biology of these tumors and the development of novel therapeutic approaches have evolved over the past several years.[22] Nonetheless, these tumors, which remain ultimately fatal, and the sequelae of their treatments, profoundly impact the functional capabilities and well-being of afflicted patients. Such transformative effects that uniquely affect each patient, share common themes, and general outcomes. In busy neuro-oncology clinics, the limited time of patient visits is often devoted to the status of tumor assessment, ongoing treatment strategies, and pragmatic issues such as concurrent medication dosing and follow-up scheduling. The unintended consequence is often less dedicated time to address survivorship needs and concerns.

To address this deficiency, with key input and support from lower-grade glioma patients, we developed the *GROWS* program. This program formally brings together

**Table 3.** Patient and Tumor Characteristics (*N* = 85)

| Characteristic | Value |
|---|---|
| *Age* | |
| Median (range), years | 41 (20–70) |
| Distribution, no. (%) | |
| 18–39 years | 38 (44.7) |
| 40–64 years | 44 (51.7) |
| 65+ years | 3 (2.3) |
| *Sex, no. (%)* | |
| Female | 41 (48.2) |
| Male | 44 (52.4) |
| *Race, no. (%)* | |
| White | 75 (88.2) |
| Black or African American | 2 (2.3) |
| Asian | 2 (2.3) |
| Multiple | 2 (2.3) |
| Other | 2 (2.3) |
| Unknown | 2 (2.3) |
| *Ethnicity, no. (%)* | |
| Hispanic | 5 (5.9) |
| Non-Hispanic | 76 (89.4) |
| Unknown | 4 (4.7) |
| *Marital status, no. (%)* | |
| Married/civil union | 46 (54.1) |
| Divorced | 7 (8.2) |
| Single | 32 (37.6) |
| Has dependent children, no. (%) | 40 (47) |
| *Employment status, no. (%)* | |
| Full-time | 40 (47) |
| Part-time | 1 (1.1) |
| Not employed | 23 (27) |
| On temporary leave | 5 (5.8) |
| Student | 4 (4.7) |
| Unknown | 12 (14.1) |
| *Tumor histologic subtype, no. (%)* | |
| Astrocytoma | 41 (48.2) |
| Oligodendroglioma | 44 (51.8) |
| *Tumor grade, no. (%)* | |
| 2 | 58 (68.2) |
| 3 | 27 (31.8) |
| *IDH mutation, no. (%)* | |
| IDH1 | 67 (78.2) |
| R132H | 61 (71.7) |
| R132C | 2 (2.3) |
| R132G | 2 (2.3) |
| Unknown | 2 (2.3) |
| IDH2 | 7 (8.2) |
| R172K (IDH2) | 7 (8.2) |
| Unknown | 11 (12.9) |
| *Time since initial diagnosis* | |
| Median (range), months | 63 (0.4-365.3) |
| Distribution, no. (%) | |
| <2 years | 23 (27) |
| ≥2 and <5 years | 22 (25.8) |
| ≥5 and <10 years | 21 (24.7) |
| 10+ years | 19 (22.3) |
| Currently receiving treatment, no. (%) | 34 (39.5) |
| Chemoradiation with temozolomide | 3 (3.5) |
| Temozolomide | 11 (12.9) |
| Lomustine | 2 (2.3) |
| IDH-inhibitor | 16 (18.8) |
| Other | 2 (2.3) |
| *Prior therapy received, no. (%)* | |
| Radiation therapy | 49 (57.6) |
| Chemotherapy | 55 (64.7) |
| Other | 38 (44.7) |
| *Prior surgical interventions have undergone, no. (%)* | |
| 1 | 59 (69.4) |
| 2 | 22 (25.8) |
| 3 | 3 (3.5) |
| >3 | 1 (1.1) |
| Currently taking anti-epileptic drugs, no. (%) | 57 (67) |
| Currently taking stimulant medications, no (%) | 9 (10.5) |

a multidisciplinary team with diverse and complimentary perspectives. Our team consensus was to develop a strategy to better define unmet needs of our lower-grade glioma patients and caregivers, both as a population and on an individual basis, and then to embark on a strategy to help these patients and families access established resources to potentially help address these needs.

While several recent studies have investigated the unmet needs of patients with primary brain tumors, our study is the first initiative of which we are aware that sought to identify, characterize, and begin to address unmet needs in patients with lower-grade glioma specifically.[15,23–27] We employed a primarily inductive, qualitative content analysis to extract diverse thematic data from the semi-structured interviews. The use of qualitative data collection via interviews enabled us to capture broad yet detailed information about the experiences of patients living with lower-grade glioma tumors. We were able to organize our findings into domain-specific action items. With this framework, we were then able to direct patients to existing interventions defined in our database of local and regional resources. Our unique approach enabled a clear delineation of the gaps in this population's survivorship experience and opened a discussion for how these needs can best be addressed programmatically and prospectively through targeted interventions.

**Table 4.** Ranking of Domains of Unmet Needs Based on the Frequency of Their Occurrence in Different Patient Subgroups

| Domain | Psychosocial | Neurologic/ cognitive | Lifestyle | Financial | Medical | Total unmet needs (No.) |
|---|---|---|---|---|---|---|
| | Rank (frequency, %) | Rank (frequency, %) | Rank (frequency, %) | Rank (frequency, %) | Rank (frequency, %) | |
| All patients | 1 (36.4) | 4 (11.9) | 2 (24.4) | 3 (20.5) | 5 (6.8) | 176 |
| *Tumor grade* | | | | | | |
| **2** | 1 (34.8) | 4 (14.4) | 2 (25) | 3 (16.7) | 5 (9.1) | 132 |
| **3** | 1 (41.2) | 4 (2.9) | 2 (29.4) | 3 (26.5) | n/a (0) | 34 |
| *Age (years)* | | | | | | |
| 18–44 | 1 (42.2) | 4 (7.8) | 2 (23.5) | 3 (20.6) | 5 (5.9) | 102 |
| 45+ | 1 (28.4) | 4 (17.6) | 2 (25.7) | 3 (20.3) | 5 (8.1) | 74 |
| *Diagnosis* | | | | | | |
| Astrocytoma, IDH-mut | 1 (33.7) | 4 (13.5) | 3 (22.1) | 2 (24) | 5 (6.7) | 104 |
| Oligodendroglioma, IDH-mut | 1 (40.3) | 4 (9.7) | 2 (27.8) | 3 (15.3) | 5 (6.9) | 72 |
| *Employment status* | | | | | | |
| [1]Employed | 1 (42.3) | 4 (8.7) | 2 (26.9) | 3 (15.4) | 5 (6.7) | 104 |
| Unemployed | 2 (23.9) | 3 (19.6) | 1 (30.4) | 4 (15.2) | 5 (10.9) | 46 |
| *Sex* | | | | | | |
| Female | 1 (38.3) | 3.5 (16) | 3.5 (16) | 2 (22.3) | 5 (7.4) | 94 |
| Male | 2 (34.1) | 4 (7.3) | 1 (34.1) | 3 (18.3) | 5 (6.1) | 82 |
| *Dependent children status* | | | | | | |
| **Yes** | 2 (30.1) | 4 (12.3) | 1 (31.5) | 3 (19.2) | 5 (6.8) | 73 |
| **No** | 1 (40.8) | 4 (11.7) | 3 (19.4) | 2 (21.4) | 5 (6.8) | 103 |
| *Treatment status* | | | | | | |
| On treatment—IDH inhibitor | 1 (36.4) | 3 (24.2) | 4 (18.2) | 2 (27.3) | 5 (6.1) | 33 |
| [2]On treatment—other | 1 (16.4) | n/a (0) | 1 (16.4) | 3 (3.6) | 4 (1.8) | 55 |
| Off treatment | 1 (38) | 4 (15.7) | 3 (17.4) | 2 (22.3) | 5 (6.6) | 121 |
| *Time since initial diagnosis* | | | | | | |
| <18 months | 1 (48.6) | 4 (5.7) | 2 (22.9) | 3 (20) | 5 (2.9) | 35 |
| ≥18 months, <10 years | 1 (31.6) | 4 (11.8) | 2 (30.3) | 3 (21.1) | 5 (5.3) | 76 |
| 10+ years | 1 (38.3) | 3 (16.7) | 4 (13.3) | 2 (21.7) | 5 (10) | 60 |

[1] ie, with occupation or standing employment; student, full-time employed, part-time employed, or on temporary leave.
[2] temozolomide, parp-inhibitor, or concurrent chemoradiation with temozolomide.

By integrating questions with specific queries during our individual interviews, patients were able to share their perspectives and experiences of their disease trajectory. In our lower-grade glioma patient population, more than 70% of all participants reported at least one unmet need. We identified needs across 5 different major domains. Specifically, 40.7% of our participants identified greater psychosocial support as an unmet need. Our findings are in line with the currently available data on psychosocial needs in glioma patients and illustrate the pressing need for broader access and novel interventions to address these needs.[28–31] A recent report among 28 low-grade glioma patients in the United Kingdom that utilized semi-structured interviews defined 4 major themes related to the impact of this diagnosis on daily life that align with those identified by our effort including: "Emotional response to the diagnosis," "Living with the 'What ifs'," "Changing relationships," and "Faltering independence."[16] Some neuro-oncology programs, including ours, prioritize limited psychosocial supportive care resources to patients who are actively receiving tumor therapy. Although the needs of patients undergoing tumor treatment are substantive, those of patients and caregivers following completion of therapy can be equally or more challenging, but they are often relegated to community-level providers who may have little to no experience with the lower-grade glioma population. Furthermore, patients and their caregivers are often left on their own to try to identify and navigate to appropriate supportive resources, which can be quite frustrating even for the most savvy and energetic.

Unmet needs classified in the Lifestyle Domain were identified by 34.9% of our participants. Many patients and caregivers identified a need for resources that can help patients foster healthy lifestyle choices, including regular

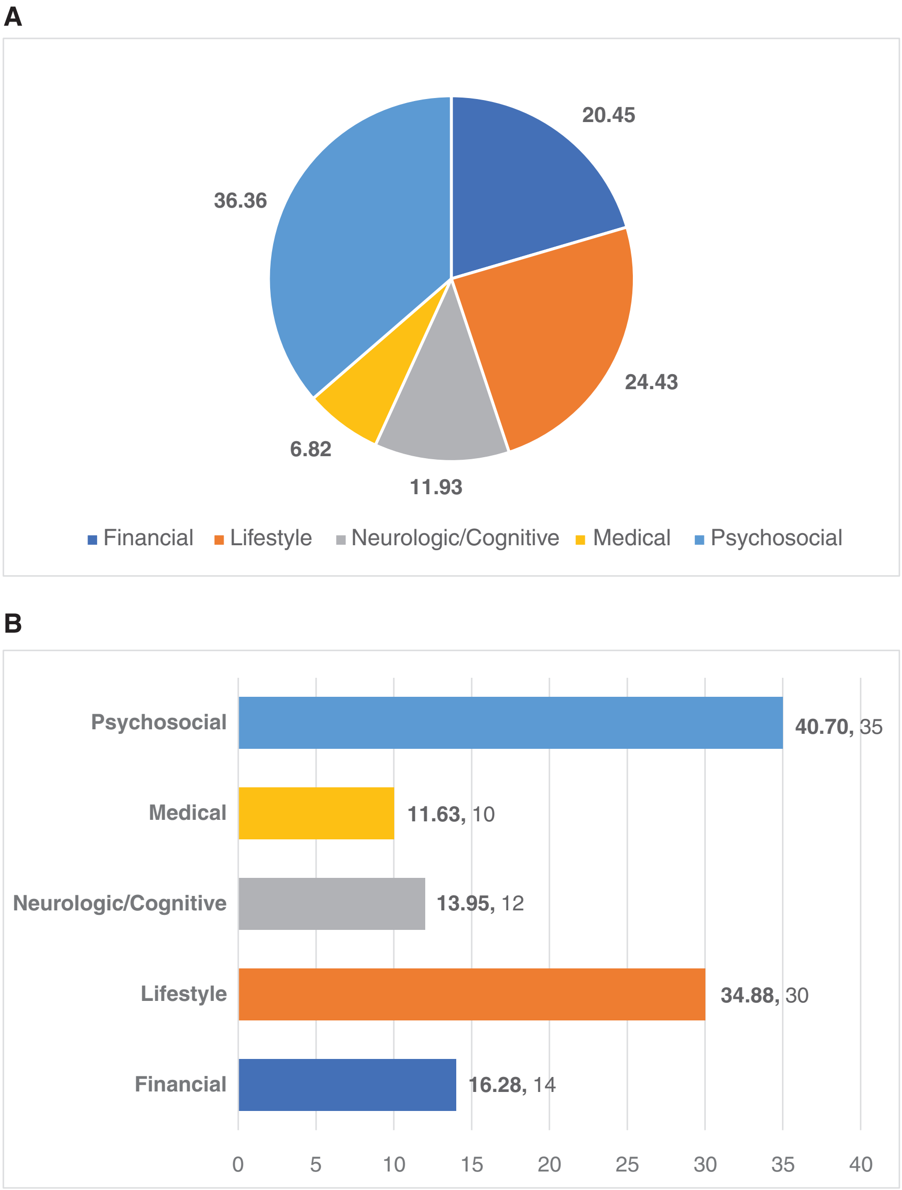

**Figure 2.** (A) Distribution of total instances of unmet need, by domain of need (%), N = 176. (B) Distribution of patients with at least 1 instance unmet need, by domain of need (%, No.), N = 85.

exercise and better nutrition to promote overall health. Exercise has been shown to influence a number of domains within HRQoL in cancer survivors.[32] Recent studies have demonstrated a significant relationship between cancer-related fatigue, a symptom commonly experienced by primary brain tumor patients, and physical activity.[33–35] At the DFCI, the Zakim Center for Integrative Therapies and Healthy Living provides patients and caregivers with free exercise classes and one-on-one virtual meetings with an exercise physiologist. During this project we identified that many patients were unaware of these services, further underscoring the importance of connecting patients with available supportive services, even within the same institution. It remains unclear whether such resources will be sufficient to address the needs of the lower-grade glioma patient population, or whether more tailored resources supporting healthy living are needed for this population.

Fourteen percent of participants reported unmet needs in the Neurologic/Cognitive domain. This result appears low in consideration of recently published data on quality of life in lower-grade glioma patients, which showed that a majority of patients report difficulty in cognitive domains.[36] We speculate that the relatively low proportion of patients reporting unmet needs in the Neurologic/Cognitive domain of need can be explained by our operational definition of unmet need, which excludes symptoms being evaluated or treated by a participants' care team at the time of their interview from being included or coded in our analysis. Our results nonetheless underscore the importance of engagement with resources, supportive care, or referrals addressing neurological and cognitive needs, relative to other domains of need for lower-grade glioma patients.

Our study has several limitations. First, one limitation is the homogeneity of our patient population, which was predominantly Caucasian, English-speaking, and insured. While we did have a balanced population in terms of gender and histopathologic diagnosis, our findings may not be generalizable to populations with more diverse ethnic, racial, and socioeconomic compositions. Second, our project did not capture all eligible patients seen at our center. Twenty-four individuals did not complete an interview after initially agreeing to participate in the project, and it is unclear whether specific barriers played a role in their ultimate nonparticipation. Third, we employed a single interviewer for all semi-structured interviews, and the interviewer simultaneously took notes and wrote memos while interviewing. Although these notes were subsequently analyzed in collaboration with other members of the research team to generate and refine the code list of unmet needs, separating the interviewer/note-taker roles and/or employing multiple interviewers may have strengthened the collected data and its subsequent analysis. Fourth, the frequency of unmet needs was based on simply counting the number of times it was identified during the individual interviews. A simple count of the number of verbally indicated needs corresponding to a particular domain does not necessarily equate with the magnitude of its impact on the quality of life of an individual. Moreover, a low absolute count of identified needs for a particular subgroup of patients may reflect a low number of participants in that subgroup rather than an absence of need. However, the relative frequency with which a particular domain is identified can be used to approximate its relative importance to participants. The finding, for instance, that psychological issues are a major source of concern in this population compared to other categories of concern was broadly consistent with results from the existing literature. Fifth, we did not utilize established guidance for qualitative data collection and analysis such as the COREQ-32[37] primarily because this was an initial, exploratory effort for this program. Future efforts by our group will likely correct this deficiency. Sixth, a source of heterogeneity in our data is driven by the fact that our study included patients receiving and not receiving tumor therapy as well as patients with a wide range of time from the original diagnosis. The number of patients defined by treatment status as well as time from diagnosis is not sufficient to perform a subanalysis of the impact of these factors on our findings, however, future studies may likely incorporate such analyses. Of note, we did observe a relatively low ranking of lifestyle concerns among patients on treatment with an IDH inhibitor which is consistent with the lack of impact of such agents on QOL as reported in the INDIGO study.[6] Finally, although our focused groups included both patients and caregivers, data analyzed from our interview tool was derived solely from patient responses. Future efforts will build on our current dataset and strive to include caregiver input as well.

More investigations that characterize the unmet needs of lower-grade glioma patients are warranted. A deeper understanding of these needs will allow us to identify and develop proactive interventions that can improve patient care in neuro-oncology. By integrating neuro-oncology survivorship resource specialists and navigators into neuro-oncologic care of our lower-grade glioma patient population, our *GROWS* program continues to strive to address the unmet needs we identified during this project. Future efforts include assessing the effectiveness of tailored interventions (ie, care navigation, peer support groups, and educational programs) to address the gaps in care reported by lower-grade glioma patients in this project.

## Supplementary material

Supplementary material is available online at *Neuro-Oncology Practice* (https://academic.oup.com/nop).

## Keywords

glioma | IDH-mutant glioma | survivorship | supportive care | unmet needs

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## Conflict of interest statement

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## Authorship statement

R.G.F.: GROWS resource specialist, data curation and formal analysis, manuscript preparation; U.C.: Program leadership and development, data analysis and manuscript preparation; T.S.: Program leadership, data organization, manuscript preparation; D.M.: Program leadership and development, data analysis and manuscript preparation; D.C.: Data curation and formal analysis, manuscript preparation; C.B.: Manuscript preparation; E.G.H.: resource specialist and manuscript preparation; BP: Manuscript preparation; R.B.: Program support and manuscript preparation; G.Y.: Program support and manuscript preparation; J.R.M.F.: Program support and manuscript preparation; E.A.: Program support and manuscript preparation; E.Q.L.: Program support and manuscript preparation; L.N.: Program support and manuscript preparation; P.Y.W.: Program support and manuscript preparation; L.N.G.C.: Data organization and analysis, initial manuscript draft and manuscript revision; D.A.R.: Program initiation and leadership, data organization and analysis, manuscript revision and finalization.

## Data availability

De-identified data generated in the course of this study will be made available upon reasonable request to the corresponding author.

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