



Care Coordination Survey Qualitative Research Results

Our Goals

- Our aim was to understand **patient perspectives** around the coordination of care in regard to their acoustic neuroma **treatment, recovery, and ongoing support.**

Key Points:

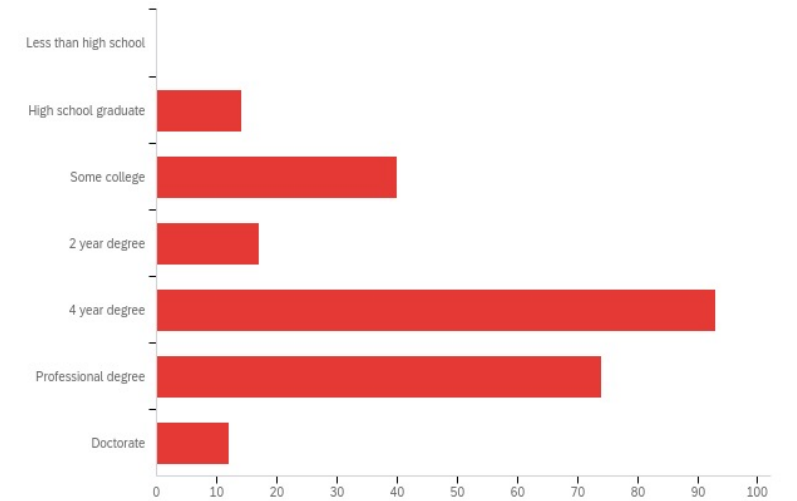
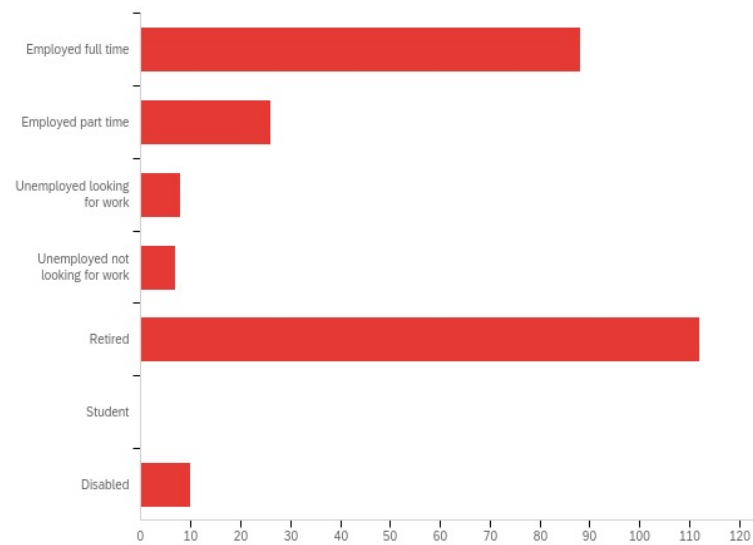
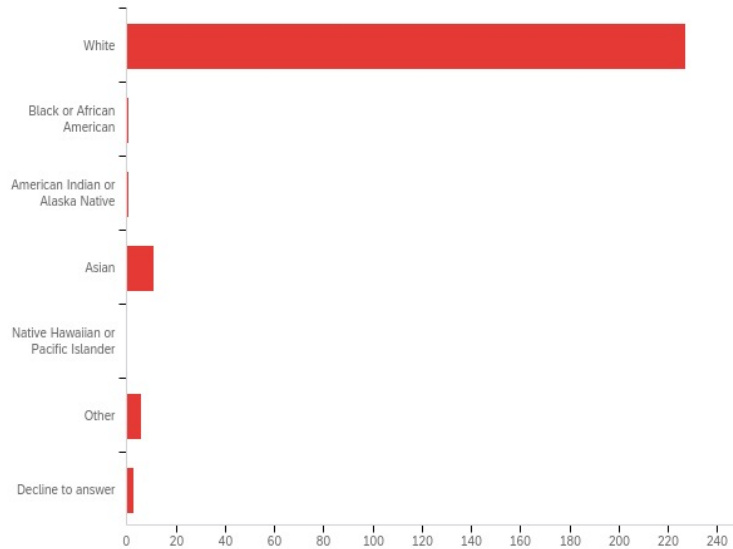
- A qualitative survey was conducted to determine how care coordination impacted **patient experience** and well-being.
- The survey focused on overall patient experience in regard to **coordination** rather than treatment.
- The focus was on **care coordinators** or **patient navigators** who worked with doctor's offices, hospitals, or other patient care facilities.

The Sample

- 908 qualitative survey respondents with 251 completed surveys
- 192 reported having some form of care coordinator
- 99.06% of respondents were patients
- 80.5% of respondents are post-treatment
- 64.54% female | 35.46% male

Age range	%
65 & older	39.3
55-64	32.3
45-54	17.1
35-44	6.4
18-25	2.79

The Sample



Findings

Care Coordination eases the logistical burden on patients & families/caregivers.

A designated support person can feel like a touch point for patients to feel heard.

Care Coordinators facilitate insurance, disability, and follow-up treatment organization for patients.

Good care coordinators made patients feel heard, comforted and emotionally supported.

Care coordinators do not remove the patient responsibility of self-advocacy.

Care coordinators are only effective if consistent, empathetic and responsive.

Care Coordination eases the logistical burden on patients & families/caregivers.

- What they do & how it helps: Care Coordinators routinely coordinate patient appointments, **most frequently pre-treatment**, especially when patients opt for surgery. Care coordinators also helped out-of-town patients **navigate the logistics** of receiving treatment away from home.
- Benefit: In facilitating logistics care coordinators **helped patients feel more prepared** for surgical outcomes, for follow up care, and often helped them navigate everything from insurance to finding lodging near medical centers.
- Satisfaction: Patients, families and care givers expressed that having a care coordinator **made everything easier**.
- Concerns: Some patients felt that their care coordination was **not proactive enough** and that patients still had a large role to play in coordination of their care.

Care Coordination
eases the logistical
burden on patients
&
families/caregivers:
Patient Stories

“[The hospital] and my patient navigator did everything to streamline the logistics of having brain surgery. My patient navigator made the process effortless so I could focus on the things that really mattered like being well, being present and staying strong!”

- *Patient is a female between ages 55-65, married, who traveled from Washington state to a university hospital system in Southern California for surgical treatment.*

Care Coordination
eases the logistical
burden on patients
&
families/caregivers:
Patient Stories

“They guided me through the process, offered emotional and psychological support, and relieved me from the burden of dealing with the insurance component.”

- *Patient is a working female, married, between ages 55-65, who received radiosurgery treatment in Puerto Rico.*

A designated support person can feel like a touch point for patients to feel heard.

- What they do & how it helps: For many their designated support person (at the medical facility) was not called a navigator or coordinator. Often nurses, schedulers, and coordinators become touch points for patients. Patients were able to **contact these professionals consistently, most often through phone and email** (portals) to address a wide variety of needs before and after treatment. Most patients **had access to these same professionals at all stages of their AN journeys**.
- Benefit: Having a designated contact point helped patients know how to plan ahead, **allowed them to feel cared for**, and clarify any concerns with doctors.
- Satisfaction: Patients report that these people **“took care” of them** and their families, long after their treatment had passed. Having a consistent person helped patients **feel more secure**.
- Concerns: Despite many patients having long term care relationships, others felt that **the contact person did not remain in touch** after they returned home from treatment; this report was rare but demonstrates a meaningful subset of experiences.

A designated support person can feel like a touch point for patients to feel heard: Patient Stories

“She was always timely, efficient and most of all caring... She was encouraging and caring... My patient coordinator is always the person I contact.”

- Patient is a married, retired male, between the ages of 55-64 who received both surgery and gamma knife treatment in a university hospital system in Southern California.

A designated support person can feel like a touch point for patients to feel heard: Patient Stories

“She was the one stop shop for anything I needed to know or do - no confusion about who to call or what would happen.”

- Patient is a married, retired female, between the ages of 55-64 who received surgical treatment at a university hospital system in Southern California.

Care Coordinators facilitate insurance, disability, and follow-up treatment organization for patients.

- What they do & how it helps: Care coordinators help facilitate the coordination of follow-up care as well as the **complex processes** many patients must navigate with large **disability and insurance systems**. This works especially well when hospital systems have user friendly patient portals that allow hands on engagement from patients.
- Benefit: Patients and care givers are able to **focus more on healing** and making important treatment decisions.
- Satisfaction: Overall **patients love having this option** and note that it helps them prepare better for life after treatment, particularly surgery.
- Concerns: Despite having some help in this space, this was not universal and even patients with care coordination felt doctors and doctor's offices need **more training in providing follow up care**.

Care Coordinators
facilitate
insurance,
disability, and
follow-up
treatment
organization for
patients: Patient
Stories

“She set up all tests and appointments. This is a huge issue as the coordination was one less thing I had to deal with when I was already extremely stressed. Very pleasant experience dealing with one person or her teammate. She was very reassuring and met my needs as far as timing of appointments, critical since I was not local.”

- *Patient is a retired female between ages 65-74, widowed and was treated at a university hospital system in Northern California.*

Care Coordinators
facilitate
insurance,
disability, and
follow-up
treatment
organization for
patients: Patient
Stories

“The coordination between UCSD and my insurance provider far surpassed my expectations. After giving my patient navigator my insurance information everything was taking care of. All the medical bills were paid and there were no surprises. I couldn't have asked for a better financial outcome after a major surgery.”

- *Patient is a female between ages 55-65, married, who traveled from Washington state to a university hospital system in Southern California for surgical treatment.*

Good care coordinators made patients feel heard, comforted and emotionally supported.

- What they do & how it helps: Effective care coordination requires more than just technical and organizational knowledge. Patients and caregivers report benefiting from **a friendly presence** to help them **manage difficult feelings** about their diagnosis and the long-term effects it may have on quality of life.
- Benefit: Supportive care coordination leads to **higher satisfaction** reporting from patients when they consider their care and their willingness to recommend their providers to others with acoustic neuromas.
- Satisfaction: Patients report that the warmth they received from care coordinators made them **feel less alone** in their treatment process.
- Concerns: Care coordination **often felt limited** to the time immediately surrounding treatment.

Good care
coordinators
made patients
feel heard,
comforted and
emotionally
supported:
Patient Stories

“My care coordinator is an extremely warm individual. She always presented herself as available to listen to any issues, thoughts, or problems I may have. She let me know that she was a resource for me. She helped me through a time when I was most vulnerable and emotionally distraught. I’m so thankful for her and thankful to have a care coordinator to give me the extra support I so needed.”

- *Patient is a female between ages 55-65, married and retired, who received surgical treatment in North Carolina.*

Good care
coordinators
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comforted and
emotionally
supported:
Patient Stories

“My patient navigator made me feel like I was in very capable and compassionate hands...and that they all truly cared :)”

- *Patient is a female between ages 55-65, married, who traveled from Washington state to a university hospital system in Southern California for surgical treatment.*

Care coordinators do not remove the patient responsibility of self-advocacy.

- What they do & how it helps: Patient care coordinators can help **alleviate burdens** of follow-up care and ease logistical challenges, but a majority of patients with care coordinators **still expressed the need to advocate for themselves** and see room for improvement when it comes to navigating long-term follow-up care in particular.
- Benefit: Care coordination does help patients, but **patients are ultimately still responsible for their medical advocacy**, and they recognize that.
- Satisfaction: Needing to advocate for themselves is something many **patients are willing to do**.
- Concerns: For some patients, managing their acoustic neuroma symptoms and the weight of a big diagnosis, alongside **self-advocacy can feel burdensome**.

Care
coordinators
do not remove
the patient
responsibility
of self-
advocacy:
Patient Stories

When asked if this patient continued to interact with their care provider they responded, “Too infrequently and only on my own initiative.”

- Patient is a retired, married male between the ages of 65-74, he is a “watch and wait” patient in British Columbia.

Care
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Patient Stories

When asked if their experience with coordination of care would be a reason to recommend their treatment center to others this patient responded: “I guess I’m confused about this concept of coordination of care. I did not have one point person. I had 4 different doctors and none of them communicated with each other. I was in fact my own care coordinator.”

- Patient is a working female , married between the ages of 35-44, she received cyber-knife treatment in California. She reported having multiple points of contact for care coordination.

Care coordinators are only effective if consistent, empathetic and responsive.

- What they do & how it helps: Patient care coordinators **alleviate burdens on patients overwhelmed with coordinating care** while dealing with symptoms of acoustic neuromas. For these patients, care coordination needs to be ongoing, even after treatment and always be paired with **care and compassion**.
- Benefit: An empathetic ear during a difficult diagnosis **helps with patient satisfaction** and self-reported quality of life outcomes.
- Satisfaction: Many with care coordinators found their coordinators to be **responsive and caring** and reported that was a key reason for recommending their providing facility.
- Concerns: Some patients noted feeling that care coordination was slow, inconsistent, or **required a great deal of effort** on their part.

Care coordinators are only effective if consistent, empathetic and responsive:

Patient Stories

“She was personable and took time needed to answer questions or to get answers on items she could not address...Patient coordination for after surgery would have been very useful. Unfortunately throwing me into PT and expecting them to coordinate care was trying. The ANA helped me find resources and pointed me in a good direction...It is an exhausting journey and for someone dealing with AN issues it is very taxing and you have to muster up energy to find the answers you need.”

- Patient is a female between the ages of 55-64 who received surgical treatment in California.

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Patient Stories

“...she is the one that caused all of my bad experiences. I was even to a point of going out of state, but I loved my doctor and knew I wanted him to do my surgery.”

- Patient is a married working professional, female between the ages of 55-64 who received surgical treatment in North Carolina.

Findings

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