O-11

Empirically informed conceptual framework for shared decision-making for neuroendocrine tumors care: a multicentre international qualitative study.

Julie Hallet[1], David Chan[2], Thorvardur Halfdanarson[3], Léamarie Meloche-Dumas[4], Simron Singh[1], Sten Myrehaug[5], Frances Wright[4], Allia Karim[6], Jessica Armah[7], Anna Ding[7], Lesley Gotlib Conn[8]

[1]Susan Leslie Clinic for Neuroendocrine Tumors, Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada; [2]Medical Oncology Department, ENETS Centre of Excellence, Royal North Shore Hospital; [3]Department of Oncology, Mayo Clinic, Rochester, MN United States; [4]Department of Surgery, University of Toronto, Toronto, Ontario, Canada; [5]Department of Radiation Oncology, University of Toronto, Toronto, Ontario, Canada; [6]Reserca, Toronto, Ontario, Canada; [7]Evaluative clinical sciences, Sunnybrook Research Institute, Toronto, Ontario, Canada; [8]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

BACKGROUND

Shared decision-making (SDM) has been associated with better outcomes, improved satisfaction, and reduced decisional regret in cancer care, but can be challenging to implement. In neuroendocrine tumors (NETs) care, decision-making (DM) is particularly complex due to lack of clear algorithms and multiple decision points over time. We examined decisional ownership, which is the felt sense of involvement in decision-making, among patients with NETs across three health systems.

METHODS

We conducted semi-structured interviews with patients treated for locoregional and advanced NETs in the USA, Canada, and Australia. Participants were purposively sampled until thematic saturation. Narrative inquiry was used to explore DM and decisional ownership experiences. Data were analyzed inductively using thematic analysis with iterative coding and team member triangulation.

RESULTS

: Twenty-four patients were interviewed (U.S. n=10; Australia n=7; Canada n=7). Distinct patterns of decisional ownership were identified. In the USA, high DO with patient-driven DM was described, especially when supported by personal research and time with physicians. In Australia, a mix of high and low decisional ownership with both patient and doctor-driven DM was reported, emphasizing self-efficacy, collaborative discussion, and team expertise. In Canada, low decisional ownership and doctor-driven DM was described, perceived as the expected pathway and constrained by system barriers. For both high and low decisional ownership, the major underpinning of the DM experience

was trust. Across all settings, trust, rather than decisional control or the presence of choice, emerged as the primary mechanism shaping patients' DM experiences. Trust was built through SDM-enabling practices, including access to specialized NET expertise, clear and honest communication, continuity and coordination of care, and alignment with patients' preferred decisional roles. We developed a conceptual framework positioning decisional ownership as the outcome of SDM experience, mediated by trust which is influenced by actionable care practices.

CONCLUSIONS

Decisional ownership in NETs care differed across health systems but are consistently determined by trust rather than by the degree of decisional control patients hold. Both patient- and clinician-led decision-making can be experienced positively when supported by trusted relationships and coherent care processes. Eliciting patients' preferred role in DM and strengthening access to specialized NETs teams, care navigation supports, and communication tools are actionable strategies to support positive SDM experiences in NETs care.

ABSTRACT ID #36339