

eTable 5. Characteristics of surveys identified in qualitative studies

	Survey Format	Respondent	Administration	Open-ended questions	Validation
Krivosic 2019	Questionnaire	Patient	Unknown	Closed	None
Jansen 2018	Questionnaire	Physician	Self-administered	Closed	None
Varano 2015	Questionnaire	Patients and caretakers	Self-administered	Closed	None
Droege 2014	Questionnaire	Patients	Face-to-face	Closed	Internal validation of 5 patients
Iida 2016	Interviews	Physicians	Face-to-face	Open	None
Spooner 2018	Mixed interview and questionnaire	Patients	Face-to-face	Open	Validated questionnaires
Hanemoto 2018 ⁷	Questionnaire	Patients and caretakers	Self-administered	Closed	Validated questionnaires
McGrath 2013	Interview	Patient	Telephone	Open	None
Sii 2018	Questionnaire	Patient	Face-to-face	Closed	Modified from validated questionnaire
Boulanger-Scemama 2015	Questionnaire	Patient	Telephone	Closed	None
Kruger Falk 2013	Interview	Patient	Unknown	Unknown	None
Boyle 2018	Mixed interview and survey	Patient	Face-to-face	Open + closed	Validated questionnaire
Nunes 2010	Questionnaire	Patient	Telephone	Closed	None
Husler 2013	Interview	Patient	Telephone	Open	Internal validation of 5 volunteers
Polat 2017	Interview	Patient or caretaker	Telephone	Open	None
Wintergast 2018	Interview	Patient	Telephone	Unknown	None
Ehlken 2018	Questionnaire	Patient	Telephone	Unknown	None
Droege 2013	Questionnaire	Patient	Face-to-face	Closed	None
Oishi 2011	Interview	Patient	Telephone	Unknown	None