Visual analytics for the integration of health related quality of life data into "point of contact" clinical care in orthopaedic oncology: a pilot study

Justin E. Bird MD, Theresa Nalty PhD, Jing He, Alex Penny, Kristi Posey, Valerae Lewis MD*

Justin Bird, MD
E-mail: jebird@mdanderson.org
Theresa Nalty, PhD
E-mail: tnalty@mdanderson.org
Jing He
E-mail: jinghe@mdanderson.org
Alexander Penny
E-mail: anpenny@mdanderson.org
Kristi Posey
E-mail: kknava@mdanderson.org
Valerae Lewis, MD
E-mail: volewis@mdanderson.org

*Department of Orthopaedic Oncology, University of Texas MD Anderson Cancer Center, Houston, TX

Background: The Institute of Medicine supports the use of quality measures to document the patterns of care associated with good outcomes. Evidenced-based cancer care utilizes comparative effectiveness research to inform medical decisions. To deliver high quality cancer care, clinicians need innovative tools to quickly assess and compare patient outcome and performance progress using real-time technology and to allow efficient patient centered decision making consistent with their needs, values, and preferences.

Purposes: 1) Develop a web-based instrument for real-time collection of disease-specific survivorship measures, patient-reported quality of life and satisfaction measures, and clinician reported functional outcome measures

2) Determine the feasibility of providing patient-centered quality of life and functional outcome data to patients during clinical encounters using interactive visual interfaces to enhance patient's understanding of their disease and ease the decision-making process.

Methods: A prospective case series design to collect patient, physician, and physical therapist reported outcome measures tailored for each anatomic site for surgical patients treated within the orthopaedic oncology department at our institution. Validated outcome instruments that were used for appropriate site included the clinician reported MSTS, ECOG, ASES, ASIA, Karnofsky, SINS, Biagini Neuro Classification, Mayo Wrist, Mayo Elbow, Harris Hip, American Foot and Ankle, and the Knee Society Score. Validated patient reported outcome measures included the Neck Disability Index, MDASI or MDASI tumor, SF 36, ESAS, Oswestry, Oxford Shoulder, Oxford Elbow, Quick DASH, WOMAC, Foot and Ankle Disability Index, Michigan Hand Outcomes Questionnaire, Borg RPE, Borg Dyspnea, VAS pain, Barthel, Rivermead Mobility, SOGOQ, BFI, TESS, ASES, , PROMIS NeuroQOL UE function, PROMIS Phys Function, PROMIS sexual function, PROMIS GH short form, MSKCC Bowel, Neurogenic Bladder, EuroQOL EQ-5D, and the EORTC QLQ C30. Physical therapy reported validated measures included the TUG, timed walk test, Berg Balance, FIM stairs, 9 hole peg test, and the Braden Scale. An automated process was built to collect and transfer data into our surgical database. Study data was collected electronically with validated outcome measures created using a research electronic data capture (REDCap) tool. Patient outcome data was then analyzed using customized visual analytic software. This enabled the clinicians to provide graphic representation of the most up-to-date data available at each clinic visit in order to illustrate the individual's functional progress and health related quality of life status after surgery. Data was also used to calculate functional expectations based on post-operative day and assistive device. Grouped regression formulas were used to project an individual's functional return at any given post-intervention date. Norm-based outcomes from summary scores of standardized outcome measures were used to report meaningful change over time. In addition, graphic representation using bar charts, pie charts,

survival graphs and other visual analytics were used to illustrate in real time to the patient and family current functional status and projected functional improvements.

Figure 1. Web-based electronic platform for patient-centered data collection and real-time data sharing

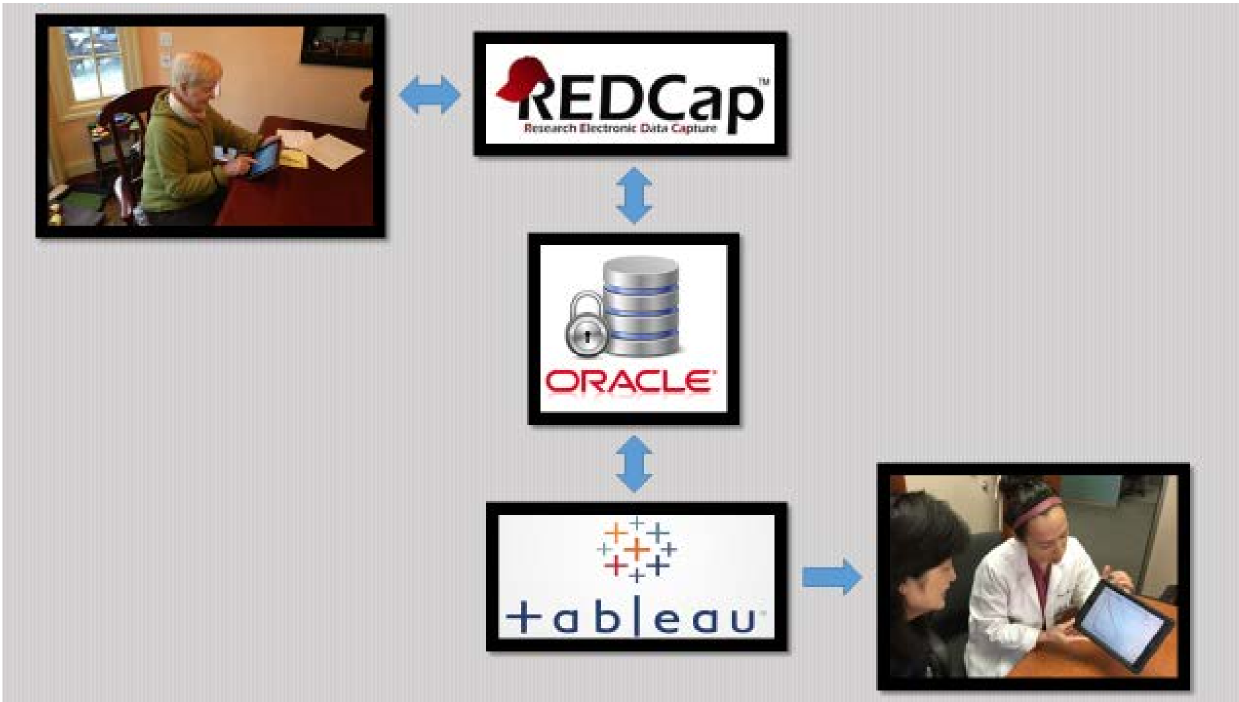
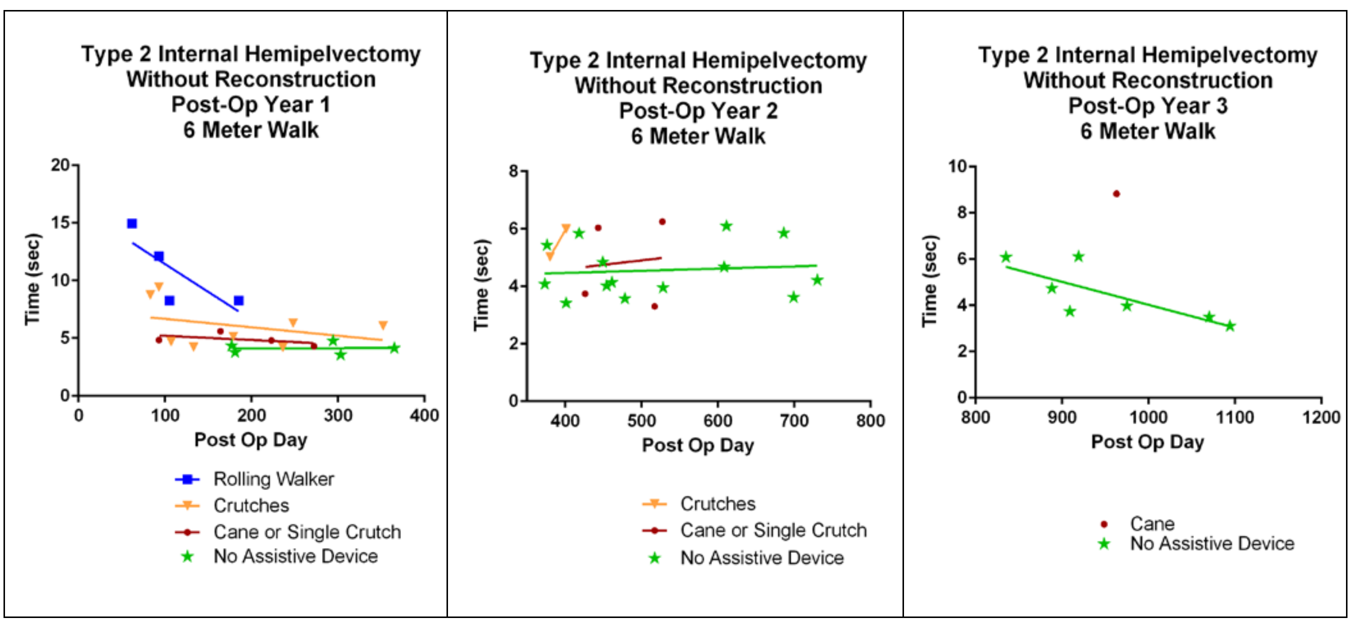


Figure 2.



Results: A web-based data collection and sharing platform was created using customized tools for data collection, storage, and analysis (Figure 1). Data was analyzed using interactive graphic interfaces in real-time. Visual analytic profiles were created, (Figure 2. 10 meter walk test with timed 6 meter section) to illustrate the walking speed based on the surgical method, type of cancer, assistive device needed for ambulation, and the post-operative day.

Using the data set we calculated the linear regression and used the slope, intercept, and 95% confidence intervals to generate a real-time calculator for the patient to see the estimated walking speed if using a walker versus a cane or no assistive device over time. The visual analytics were also used to set realistic goals for patients during physical therapy sessions and to motivate patients with comparative data from similarly matched cancer patients.

Conclusions: This pilot study demonstrates both the feasibility of real-time data capture and the early utility of visual analytics for communicating complex outcome data during routine clinical care workflows. Communicating real-time data using an interactive visual interface enabled clinicians to more confidently communicate prognosis and demonstrate patient progress. The visual interface provides clinicians a means of communicating complex information to patients and caregivers and allows the ability to predict outcomes based on the existing database of patients with similar surgery, age, gender, and/or co-morbidities. Our experience further elucidated an added benefit of improved incentives for patients and providers to collect important outcome data due to this novel direct feedback mechanism. Future directions include performing qualitative analyses to determine the impact of visual analytics for the purpose of communicating treatment options and as a decision aid in cancer care.

Level of Evidence: V