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PERSONAL VIEW

Patients organise and train doctors to provide better care

Two patients explain the work they do to reduce their disease burden

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Patients with complex chronic conditions face not only the biological burden of the disease itself but also the burden of treatment, which might be defined as "work that patients do to care for their health, problem focused strategies to facilitate self care, and factors that exacerbate the felt burden."[1]

The burden of treatment is exacerbated because patients must align with institutional work processes that have been designed around institutional operations and clinicians' needs. Sometimes patients have to reorganise and retrain clinicians to receive the high quality healthcare that is in our best interests.[2]

We both have Parkinson's disease and experience a complex array of motor and non-motor symptoms. Here is a glimpse at the invisible work that, in our experience, leads to better care.

Assemble the best team

Many complex medical conditions are best managed in interdisciplinary teams, leading to better outcomes.[3 4] Unfortunately, not all healthcare systems offer team based care of Parkinson's disease—so many patients don't get the best care. Even if some team based care is available, the individuality of the disease makes it unlikely that a hospital will have the precise constellation of knowledge required.

Our first step was to identify the clinical experts we required, including neurologists, movement disorder specialists, physical therapists, speech therapists, exercise physiologists, and primary care providers. By assembling the right interdisciplinary team we have been able to stabilise and improve our functioning, including the speech necessary for public speaking that our work requires; mobility, so that we can play with our children; and stamina for work and family obligations.

Manage information efficiently

Time with clinicians is limited, so we prioritise collecting, organising, and communicating information about our evolving health status. Kenton T Unruh generates a single page, colour coded summary of current drugs, clinical status (including changes since the last visit), and questions. Sometimes we present "data snapshots" and summaries of trending data, both subjective and objective, on our evolving health.

Sara Riggare has created a functional prototype of a smartphone app for collecting data on drug intake and wellbeing to provide data for shared decision making during the visit with the neurologist. Patients would use it for about a week before the visit.

Central to both approaches is the idea of communicating targeted information in a simple format. It has also to be communicated efficiently. For example, encouraging clinicians to preview information before the consultation will lead to more productive discussions; however, previewing data from patients is not usually part of a clinician's institution centred work flow. Clinicians often have to be retrained to do this.

Evidence or opinion?

We ask our clinicians whether the information they give us is from scientific sources or general clinical practice.[5] We value both, but this understanding improves decision making.[6] For example, such information helps patients to choose appropriate drugs and when to start levodopa, given his or her life stage, work responsibilities, and family obligations. With practice, our clinicians have improved this communication.

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Extra material supplied by the author (see http://www.bmj.com/content/351/bmj.h6318?tab=related#datasupp)

Examples of authors' data snapshots

Coordination between visits

Few hospitals or healthcare systems have all of the staff necessary for all patients' specific needs. For example, although one of our institutions has physical therapists available, it does not have physical therapists with certified vestibular expertise, so a physical therapist was incorporated from another institution. When work among different institutions is necessary, we, the patients, take on the role of information carriers between the clinicians involved in our care.

For providers who share access to online records, we strategically email health status updates so that providers viewing that record are up to date. For our providers who don't have access to a shared online system, we establish new work flows with the nurses to fax our records back and forth between our clinicians to ensure that everyone's notes are up to date.

Our approach enables us to manage our health, optimise the outcome of our healthcare interactions, and construct integrated care in a fragmented care system. Quality healthcare doesn't just happen—it takes work, adding to the overall disease burden. Our hope is that patients, clinicians, and healthcare organisations can together innovate to reduce the total burden of disease.

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1 Eton DT, Ramalho de Oliveira D, Egginton JS, et al. Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Relat Outcome Meas* 2012;3:39-49, doi:10.2147/PROM.S34681.
2 Unruh KT, Pratt W. The invisible work of being a patient and implications for health care: "[the doctor is] my business partner in the most important business in my life, staying alive." *Conf Proc Ethnogr Prax Ind Conf* 2008;2008:40-50, doi:10.1111/j.1559-8918.2008.tb00093.x.
3 van der Eijk M, Faber MJ, Al Shamma S, Munneke M, Bloem BR. Moving towards patient-centered healthcare for patients with Parkinson's disease. *Parkinsonism Relat Disord* 2011;17:360-4, doi:10.1016/j.parkreldis.2011.02.012.
4 Post B, van der Eijk M, Munneke M, Bloem BR. Multidisciplinary care for Parkinson's disease: not if, but how! *Postgrad Med J* 2011;87:575-8, doi:10.1136/pgmj.2011.241604rep.
5 Rosenberg W, Donald A. Evidence based medicine: an approach to clinical problem-solving. *BMJ* 1995;310:1122-6.
6 Alavi M, Leidner DE. Knowledge management and knowledge management systems: conceptual foundations and research issues. *MIS Quarterly* 2001;25:107-36, doi:10.2307/3250961.

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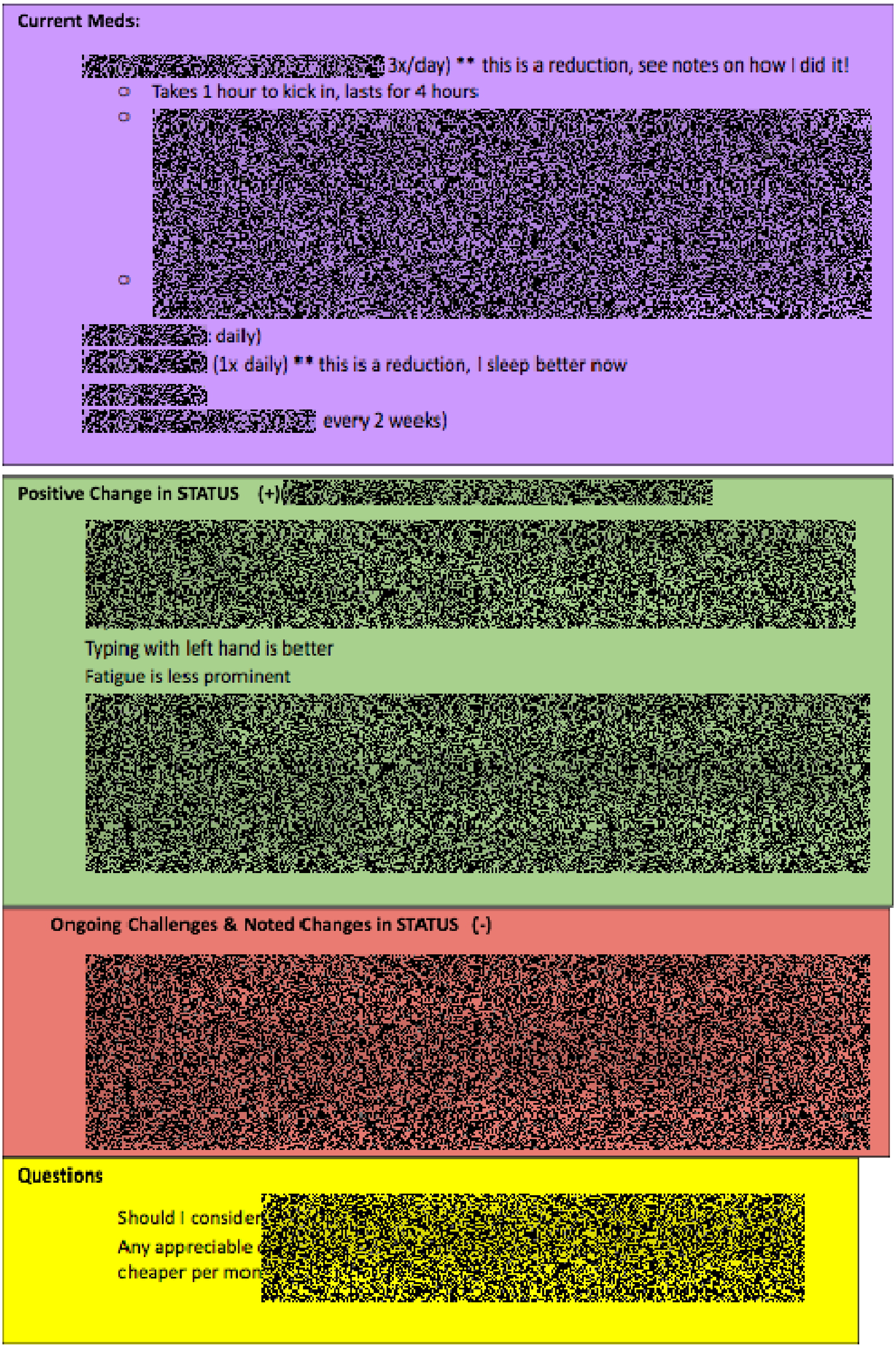
Appendix

1 The document for data and information developed by KU



Current Meds:

[redacted] 3x/day) ** this is a reduction, see notes on how I did it!
  - Takes 1 hour to kick in, lasts for 4 hours
  - [redacted]
  -

[redacted]: daily)
[redacted] (1x daily) ** this is a reduction, I sleep better now
[redacted]
[redacted] every 2 weeks)

Positive Change in STATUS (+)[redacted]

[redacted]

Typing with left hand is better

Fatigue is less prominent

[redacted]

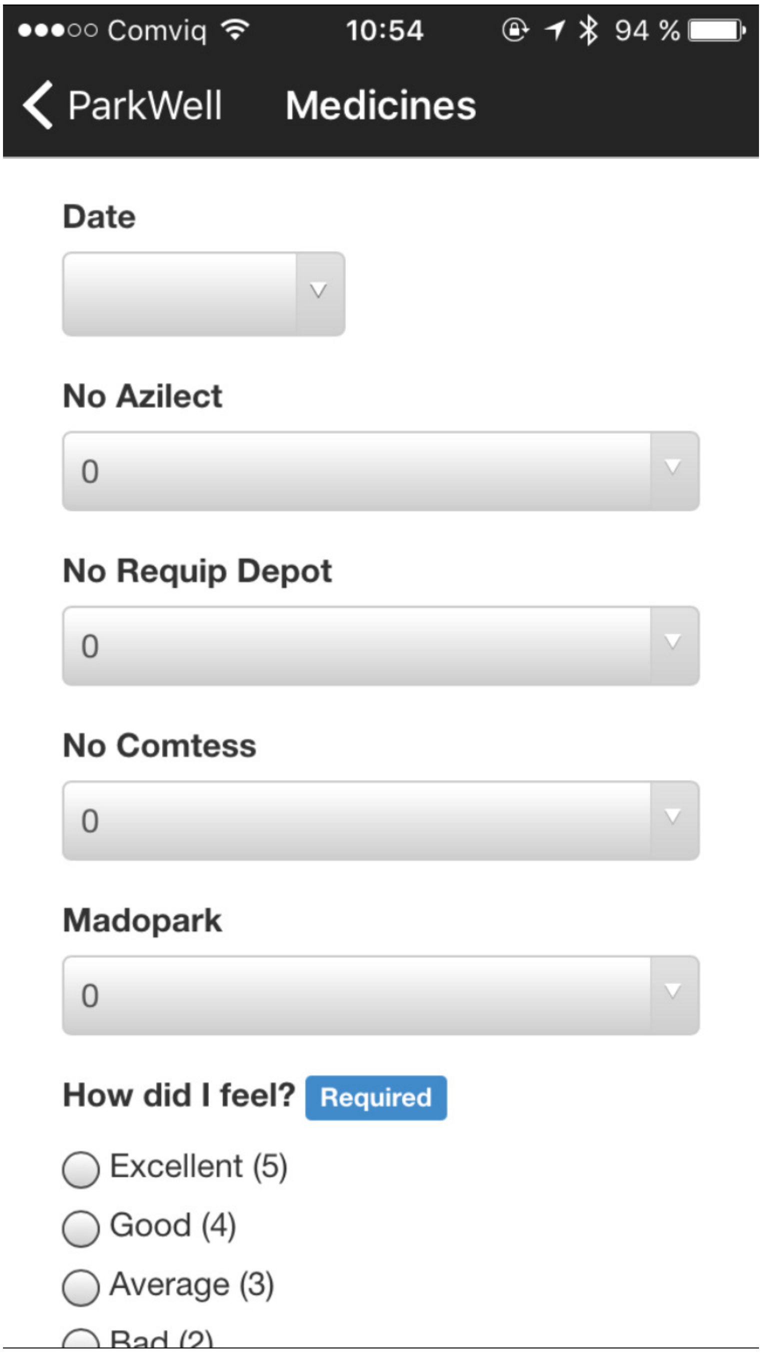
Ongoing Challenges & Noted Changes in STATUS (-)

[redacted]

Questions

Should I consider[redacted]
Any appreciable [redacted]
cheaper per mon[redacted]

2 Screenshots of the app developed by SR



Medicines

Date

No Azilect
0

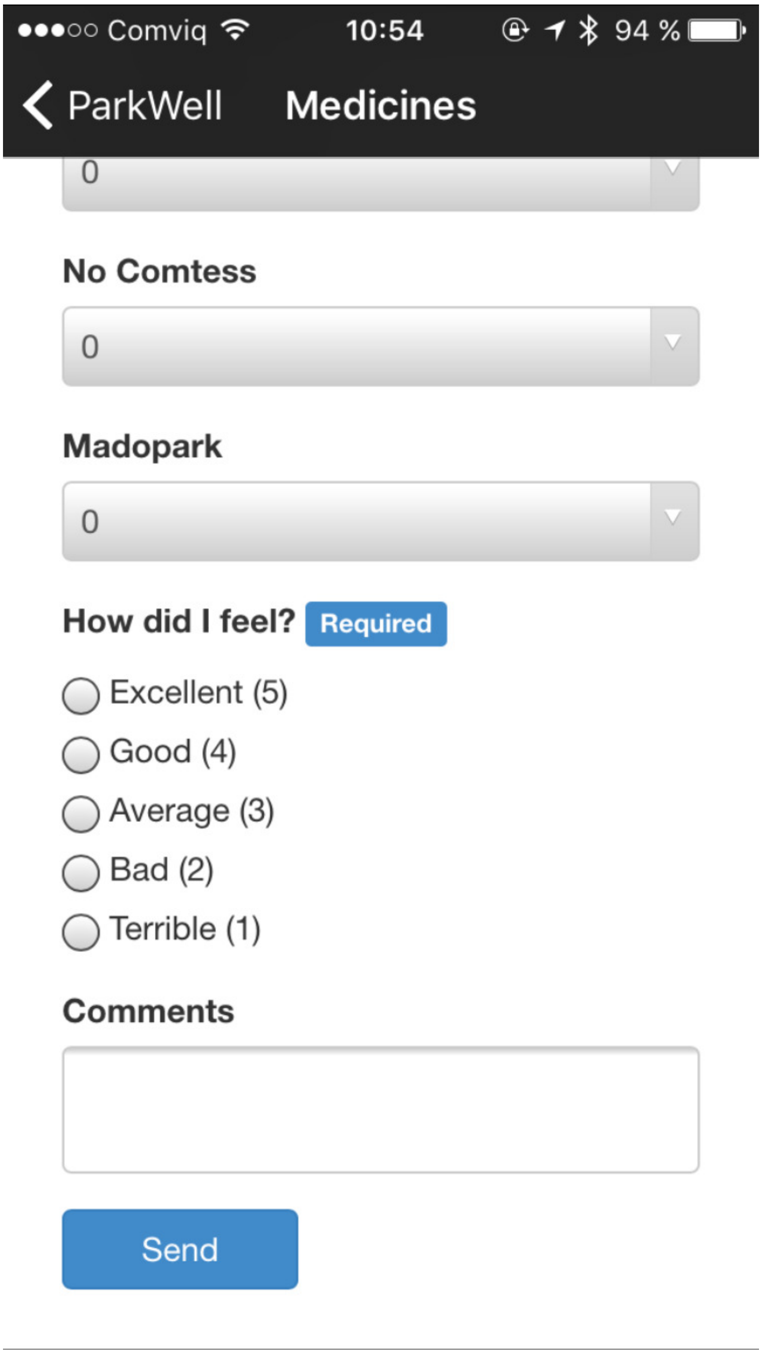
No Requip Depot
0

No Comtess
0

Madopark
0

How did I feel? Required

○ Excellent (5)
○ Good (4)
○ Average (3)
○ Bad (2)



0

No Comtess

0

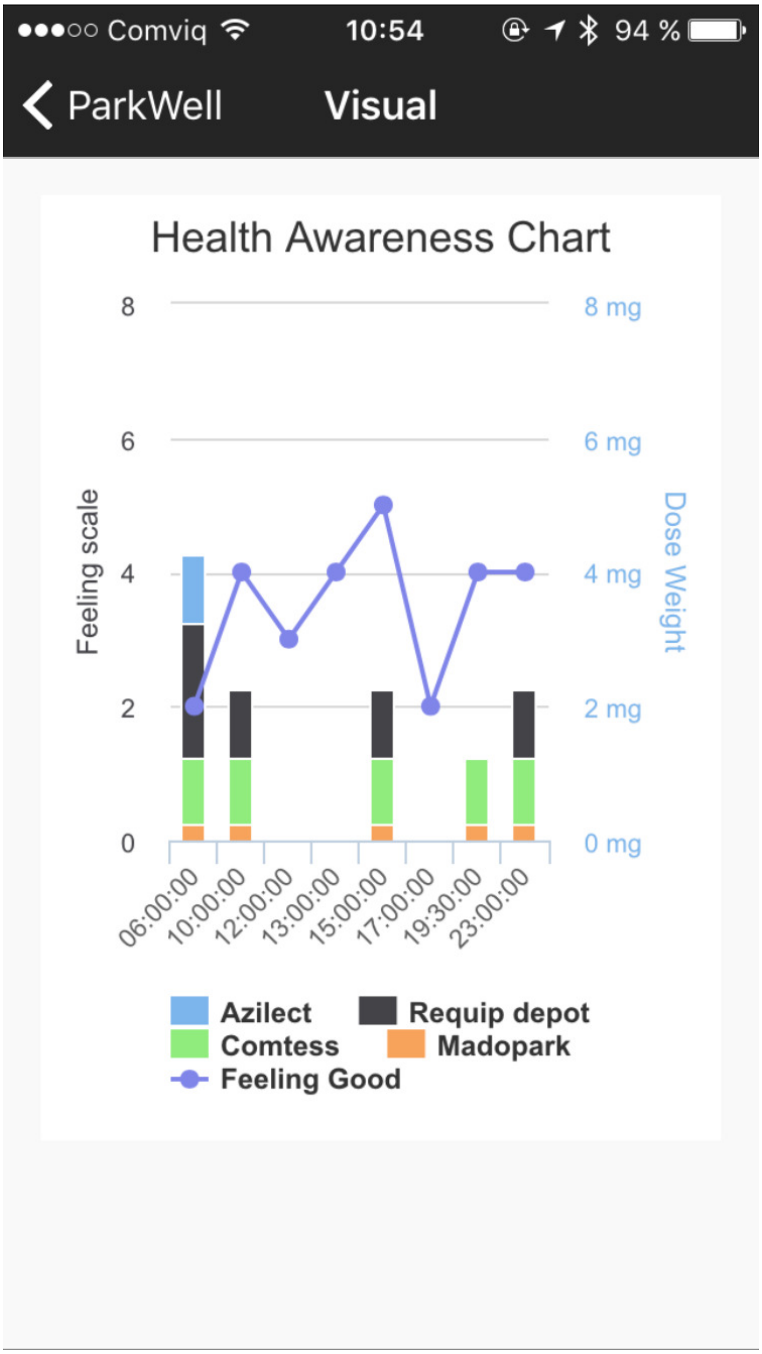
Madopark

0

How did I feel? Required

○ Excellent (5)
○ Good (4)
○ Average (3)
○ Bad (2)
○ Terrible (1)

Comments


●●●○○ Comviq
10:54
94 %
ParkWell
Visual
Health Awareness Chart
Feeling scale
8
6
4
2
0
8 mg
6 mg
4 mg
2 mg
0 mg
Dose Weight
06:00:00
10:00:00
12:00:00
13:00:00
15:00:00
17:00:00
19:30:00
23:00:00
Azilect
Requip depot
Comtess
Madopark
Feeling Good