

# Patient-Centred, Technology-Based Interventions for High Treatment Burden: An Overview of the State of the Art

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**Abstract.** This study provides an overview of recent efforts to develop technology-based interventions for patients with high treatment burden. Adoption of a technological intervention for high treatment burden will depend on a range of factors, including: the reliability and accessibility of the technology, patient factors – including age, socio-economic factors, technology literacy, overall health status and personal priorities – as well as the perceived benefits provided by the technology intervention, from the perspectives of both patients and clinicians.

**Keywords:** High treatment burden, patient-centred digital health interventions.

## 1. Introduction

Treatment burden has previously been defined as *'the work placed upon a patient as a result of their healthcare and the impact upon their wellbeing'* [1]. 'Work' in this instance refers to both 'the treatment' as well as the process of 'self-care' for a condition, including attending clinical appointments, monitoring one's health, doing exercise as part of a treatment or recovery programme; or taking medications [2,3]. There has in recent years been an increased interest in the concept of *"minimally disruptive medicine"*, i.e. the provision of care and services that are designed to minimise the treatment burden of patients while furthering their healthcare goals [4]. There is also an increased interest in objectively measuring treatment burden by means of disease-specific measures [5].

We here present an overview of the state of the art in technologies specifically developed for patients with high treatment burden, based on a recent scoping review that we have conducted in this domain [6]. Scoping reviews can be particularly useful to identify emerging patterns in the literature or mapping multi-dimensional and potentially loosely defined concepts such as 'eHealth', 'ePrescribing', 'optimisation' or potentially extremely large research domains such as 'digital technology' and 'postoperative monitoring' for example [7-9]. This mode of investigation is particularly useful for researching emerging technology innovations, where identifying broad trends is key but absolute recall is not essential, as opposed to systematic reviews aiming to underpin the development of policies or clinical guidelines for example [10].

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## 2. Methods

The review protocol is described in detail in [6] and was conducted using Arksey and O'Malley scoping review methodology [11]. The literature searches were carried out between June 2020 and December 2021. We included scientific papers that were published between 1995 and 2020, describing the implementation of technology driven, patient-centred interventions for high treatment burden. Thematic analysis was performed using a framework approach using prior work conducted as part of a meta-synthesis of patients' experiences of technology in care by Korhonen et al. [12]. Korhonen identified 5 key dimensions that significantly affected patients' experiences. We iteratively developed a thematic framework using the 5 overarching themes of: *patient-centredness, support, uniqueness, technology and competence*.

## 3. Results

A total of 39 studies were included for analysis which included application to the following clinical domains: oncology, chemotherapy, radiotherapy, chronic kidney diseases and cystic fibrosis [6]. The range of technology deployed to support patients included: web-based interventions, teleconferencing technology or purposely developed devices, such touch-screen computers, handsets, personal digital assistants (PDA) or phone-based & mobile applications. The nature of the interventions included: the self-reporting of disease, treatment-related symptoms and Patient Reported outcomes Measures (PROMs) or telemedicine interventions. Other interventions included the delivery of personalised / tailored information or recommendations for patients or clinical reading reporting [6]. We provide in the following sections some of the key findings from our thematic analysis.

- **Technology Accessibility:** Studies suggested that important barriers to technology use included: age, deprivation, lower internet and computer use which could impact intervention completion and adherence [13]. Concerns were also expressed that those who are less 'digitally able' due to resources, literacy, physical or social limitation could be further disenfranchised or have additional burden placed on their care if such issues are not considered in the design and implementation processes of health technology research [14].
- **Patients' Attitudes and Experiences of Technology:** Another important factor that could also create significant barriers to technology adoption was patients' 'aversion' of technology [13,15,16]. It was noted compliance of submitting QoL assessments was better in younger and economically advantaged patients, with concerns those who would benefit the most from the regular assessments were the most likely to refuse [16,17]. It was suggested older patients' difficulties with using technologies could be explained by a "fear of innovations", with computer-inexperienced patients described as "older, frailer and symptomatic" compared to their more computer-literate peers [18].
- **Impact of Health Status:** The health of the patient may be a barrier to intervention use with some patients e.g. being too ill, sick, or distressed to submit symptom reports [19-23]. Other studies have also associated health deterioration with a decrease in intervention adherence [15,16,23].

Interestingly, patients whose health improved or did not change also demonstrated discontinued use of interventions. In a population of breast cancer patients, patients who did not experience significant physical effects because of their illness or treatment found the intervention and its tailored information for their illness less helpful [24], while patients completing PRO forms reported they perceived no benefit reporting if they are well [19,20] or their symptoms have not changed since their previous report [21].

- **Perceived Benefit:** The theme of perceived benefit was very common amongst the identified studies investigating patient reporting interventions, with varying factors described influencing patients' perceptions. Health care technology interventions should not increase burden of care or reduce patient capacity. Understanding the effectiveness of healthcare technology interventions in either reducing treatment burden or increasing patient capacity is key to effective implementation of proposed technologies. The perception that reported information was not essential to treatment or was under-utilised by healthcare staff was demonstrated in one study where it was noted clinicians reviewed data but did not overly refer to it [25].

#### 4. Discussion

A key benefit of collecting data directly from patients is the removal of a third-party bias, ensuring data is captured consistently and limiting risk for interpretation and inconsistency between individuals [18] e.g., patients reporting to nurses who then record data in system. However, these findings indicate a potential problematic relationship between patient perceptions and clinician utilisation of patient reported data. As discussed earlier, patients often fail to report frequently due to no perceived benefit of doing so, which reduces the availability and perceived value of reported data to clinicians, resulting in it being underused or not referred to at all. This in turn confirms the patients' perceptions that there is limited benefit or gain from using such interventions. However, patients are not solely responsible for incomplete or missing data. For example, staff often failed to complete a standardised grading assessment of symptoms reported via a telephone triage system by cancer patients [26]. When the form completed was graded as poor, it was later established that the staff had used the form for notetaking rather than a decision-support tool as intended. This was attributed to time-constraints during phone calls, lack of training for new staff and the forms not covering confusion or medication queries when reported. While the issue of infrequent reporting was exclusive to interventions facilitating PROM reporting, several telemedicine interventions, notably those providing video consultation for dialysis patients, met and surpassed clinician and nurse expectations. This included the ability to view and evaluate physical treatment methods via high quality video, such as catheter exit sites [17] and fistula appearance [27]. In one study, a senior nephrologist commented the intervention "met its greatest challenge, to show its legitimate clinical role" [28] and nurses felt regular videoconferencing calls were a direct replacement to telephone calls and extra time spent on these calls averted the patient needing to travel for unnecessary treatment [27]. Patients were reported to have received intensive and personalised clinical monitoring, while health providers were able to access higher quality of support than available via a telephone conversation [29]. These studies were all conducted in regions where travel

for potentially unnecessary treatment can be lengthy and costly, and these practical benefits can in turn reduce patients' treatment burden significantly.

The impact of COVID-19 was very significant on high treatment burden populations and their support. These updates are discussed further in the full scoping review [6].

## 5. Conclusions

Patients have a range of competing goals and priorities, in addition to the 'work' necessary to manage their health. Previous studies suggest some patients may choose to disengage from an intervention if they fail to clearly identify the perceived benefits vs. the tradeoff of adherence. While well-designed technologies can indeed provide useful and practical support for high treatment burden patients, special consideration should be given to ensure patients who cannot access or use technology-based interventions are not inadvertently excluded [14]. The relationship between patient and healthcare provider should also be taken into consideration during the design and implementation phases [30-35] to ensure that patient-centered care remains the focus of the intervention for both patients and clinicians.

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