

# Decreasing Avoidable Vision Loss: Identifying Antecedents of Adherence

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**Abstract:** Adherence to medication treatment protocols and active participation by individuals in their medical care are important for all patients, but especially for those with chronic conditions such as vision loss. Adherence is crucial for decreasing avoidable vision loss. Failure to take medications as prescribed and keep scheduled appointments reduces treatment effectiveness, increases complications and results in poorer outcomes. Reasons for nonadherence vary by diagnosis and include not understanding the importance of adherence, low health literacy, lack of adequate self-efficacy, low level of activation and behavioral issues including depression. Patients may lack information about their condition and its prognosis, available treatment alternatives, and other essential information such as how to monitor their eye condition, what to do if vision deteriorates and how to get needed community-based help. Each of these factors impedes patients' ability to engage with their physician and participate in their own care. The ability of individuals with vision loss to actively and effectively manage their health care, ie, activation, has been understudied. When patients are involved with their own care, their care experience, and most importantly, their outcomes, are improved. Identifying antecedents of adherence may help provide disease- and patient-specific pathways to reduce avoidable vision loss.

**Keywords:** avoidable vision loss, adherence, activation, engagement, patient activation, patient engagement, AMD, diabetic eye disease, glaucoma

Adherence to medications and appointments is crucial for decreasing avoidable vision loss. Failure to take medications as prescribed and keep scheduled appointments reduces treatment effectiveness, increases complications and results in poorer outcomes.<sup>1,2</sup> Reasons for nonadherence<sup>3</sup> include low health literacy,<sup>4</sup> poor knowledge about their eye diagnosis<sup>5</sup> and not understanding the importance of adherence.<sup>6</sup> Lack of belief in medication effectiveness<sup>7</sup> and depression and other behavioral issues also have been implicated in nonadherence.<sup>8–10</sup> Current concerns due to COVID-19 also may affect appointment attendance, although this has not been established. Unsurprisingly, medication cost may also be a barrier to adherence.<sup>11,12</sup> However, in one recent study only about a third of patients discussed medication cost with their physicians.<sup>13</sup> Lack of patient-physician communication can impair treatment effectiveness and result in vision loss since as many as 30% of all prescriptions are never filled<sup>14</sup> and within 6 months, an estimated 50% of prescriptions that are filled are no longer being used,<sup>15</sup> whether cost is a factor in such cases is unknown. Moreover, even if prescriptions are filled, patients with vision loss may have difficulty in medication administration and are more than twice as likely to need help with medication management,<sup>16</sup> adding to

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patients' burden of adherence and contributing to avoidable loss of vision.<sup>17,18</sup> Where medications are administered by intravitreal injection, appointments are necessarily adding significantly to patient burden. Adherence to medications and appointments is crucial for decreasing avoidable vision loss.

Glaucoma, age-related macular degeneration (AMD) and diabetic eye diseases are the leading causes of vision loss in Western countries and increase in prevalence with the aging of the population; each has effective treatments that can prevent or slow additional loss of vision. Reasons for nonadherence may vary by diagnosis and indicate the need for different interventions.

For glaucoma, eye drops often require instillation multiple times a day to control intraocular pressure<sup>19</sup> which if unchecked results in progressive loss of peripheral vision. Glaucoma medication adherence has been studied most extensively, particularly since the mid-1990s with the introduction of prostaglandin analogs. Unfortunately, in a study of adherence among classes of drugs used for chronic conditions – prostaglandin analogs, statins (hypercholesteremia), bisphosphonates (osteoporosis), oral anti-diabetics, angiotensin II receptor blockers (hypertension) and overactive bladder (OAB) medications – prostaglandin analogs had the second poorest adherence with only OAB medication adherence worse.<sup>20</sup> Poor glaucoma medication adherence is a significant risk factor for avoidable loss of vision.<sup>21</sup>

For AMD and diabetic eye disease, intravitreal injections can reduce or delay further vision loss and often can restore some lost vision<sup>22</sup> but require frequent appointments to monitor progress and administer injections if needed, to be effective. Unlike glaucoma where medications are generally self-administered and visits for monitoring are commonly only 2–3 times a year, the patient burden, including travel time, missed time at work and the need for an escort is more substantial for AMD and diabetic eye disease. Extending the interval between appointments and injections using *pro re nata* (PRN) or treat-and-extend (T&E) protocols, reduces patient burden but longer intervals between injections may contribute to poorer visual outcomes since more frequent injections consistently result in better visual outcomes.<sup>23,24</sup> For patients with AMD or diabetic eye disease, failure keeps scheduled appointments for intravitreal injections or monitoring undermines treatment efficacy, impairs successful patient outcomes and results in loss of vision that might have been avoided.

Learning of a diagnosis that is chronic, progressive and will result in vision loss can be devastating. Fear of vision loss is related to perceived or anticipated inability to engage in specific and desired activities and the potential impact on everyday life, rather than performance on a clinical measure of vision such as visual acuity.<sup>25</sup> Clinical vision measures are different from patients' assessments of their own functional vision; the former are necessary to diagnose and evaluate pathology and its clinical progression, whereas the latter addresses the impact of patients' vision on their everyday lives. Patient perceptions are the operative reality. Thus, from the outset, while the goals of physicians and patients agree, ie, to minimize vision loss, their definitions and priorities differ. Moreover, real-world patient treatment outcomes often do not replicate clinical trial results, no doubt in part due to the multitude of intervening factors resulting in missed appointments and medication doses. Increasingly, studies are focusing on real-world outcomes to make them more relevant and reflective of patient experiences.<sup>23,26–29</sup>

Vision loss is a harbinger of significant change; it affects independence and one's sense of wellbeing, self-efficacy and activation. Self-efficacy, ie, perceived competence to perform desired tasks, is a significant factor in self-management of health behaviors. Beliefs about one's ability to affect and control one's own health, internal locus of control, may mediate patient activation and help to address adherence and reduce avoidable vision loss.<sup>30</sup> Activation, having the knowledge, skill and confidence to self-manage health symptoms and problems, engage in activities that maintain or enhance functioning and be an active participant in one's own health care includes self-efficacy, locus of control and other behavioral constructs.<sup>31</sup> Focusing on patients' perceptions and prioritizing patient-relevant outcomes is essential for effective patient engagement with their own care.<sup>32</sup>

Understanding patients' lived experiences is the cornerstone of patient-centered care. A recent survey<sup>33</sup> identified a number of common themes in physician interactions with their patients that reflect a lack of this understanding. Patients expressed anxiety about their diagnosis; lacked adequate information about their condition, treatment alternatives and prognosis; had insufficient opportunity to ask questions; and patient supports were absent or ineffective. Basic information such as how to monitor their eye condition, what to do if vision deteriorates and how to get needed community-based help often was not provided. Importantly, 14% of patients with

significant eye disease did not understand that they are at risk for vision loss, and among these patient nonadherence is particularly high.<sup>34</sup> Physician communication affects patient knowledge about their disease and mediates patient self-care beliefs and behaviors,<sup>35</sup> essential elements of patient adherence.

Patient engagement requires effective and ongoing communication between patients and their physicians. Without sufficient and shared knowledge with their physician, patients are unable to be active participants in their own care, even when they are motivated to do so. Patients want and need information to help minimize the deleterious consequences and impact of vision loss. Physicians have a duty to ensure that patients are knowledgeable about their diagnoses so that they are able to participate in informed choices about their treatment, but informed choice for patients means that they have and understand all relevant information.<sup>36</sup> Patients cannot use the information they do not have or understand.

Vision loss represents a time of transition for patients; physician communication that balances realism with hope<sup>37</sup> can facilitate adherence and help patients engage in rehabilitation and community-based support activities. Despite the obvious impact of vision loss on patients' wellbeing, less than 10% of patients with vision loss are referred for services and supports that can improve their quality of life and help them to live more safely and independently, conversation topics of great importance, but time-consuming.<sup>38</sup> Adherence rates are 19% higher when physicians communicate well and when physicians receive training in effective communication their patients' adherence increases by 12%.<sup>39</sup> However, ophthalmology office time is at a premium. Talking about the importance of adherence, possible disease progression, treatment alternatives, potential for vision rehabilitation and availability of community-based services, answer patient questions and address other issues of importance to patients often occurs, if at all, at the end of a visit. For example, typically less than a minute is spent explaining proper use of medications with timing and frequency of dosage addressed only 58% of the time.<sup>40</sup> Newman-Casey et al<sup>41</sup> recognize that physician time constraints create a conundrum. Patients need supports, including emotional support to improve healthcare self-management, ie, effective engagement, but physicians are unable to spend the time for their patients to be engaged and actively involved in their own care. One solution may be to establish practice models that use other health professionals including psychologists,

social workers, counselors, nurses and others to help patients improve their interactions with their physicians.

Okada et al<sup>42</sup> suggest that identifying and addressing needs of patients likely to be non-adherent is a necessary first step to improving overall patient adherence and triaging physician time. Sanchez et al<sup>43</sup> studied patients reporting poor adherence to glaucoma medications. Using the Glaucoma Treatment Compliance Assessment Tool (©Legacy Health Systems, Portland, Oregon, USA), they identified a number of key factors associated with non-adherence, including lack of knowledge (46% of respondents), forgetfulness (88%) and pain or discomfort with medication use (50%). These could make physicians aware of which patients are most likely to be non-adherent and provide a focal point for future visits or appropriate intervention.

For patients to be involved effectively in their own healthcare requires activation. The development of the Patient Activation Measure (PAM) to assess and classify activation levels<sup>31</sup> has been a watershed in understanding the contribution of activation and engagement leading to patients' involvement with their own healthcare. Patients with higher levels of activation are more likely to understand their condition, be more prepared for medical appointments and willing to ask questions,<sup>44</sup> less likely to delay necessary medical care, be more adherent and achieve better outcomes.<sup>45,46</sup> Raw PAM scores are converted to a Likert-scaled PAM score ranging from levels 1–4, with 4 representing the highest level of activation. However, PAM levels do not provide diagnostic information that might aid in improving activation. Activation is multifaceted and complex. Two individuals at the same activation level can be quite different in terms of the behavioral or psychological elements underpinning their activation thus requiring different interventions to improve their activation and engagement. This is much like an exam where 2 people get the same score but miss different questions and require remediation in different content areas. Thus, PAM by itself does not illuminate a path to improve adherence.

Vision loss adds complexity to achieving activation. For example, patients' vision loss makes access to healthcare information more difficult. Thus, even more activated patients can lack sufficient health knowledge to participate fully in their own care. In the first study of PAM with patients identified as having vision loss,<sup>47</sup> individuals with lower PAM scores were found to miss more appointments. While all appointments are

important, appointments for treatments such as intravitreal injections or for monitoring glaucoma progression to determine whether the treatment that is more aggressive is warranted and may be critical to preserve vision. Activation scores also were significantly lower for participants with caregivers, seemingly counterintuitive since caregivers facilitate important activities such as medication administration, transportation to appointments, assuring that written healthcare information is understood and accomplishing other healthcare tasks. However, caregiver involvement can result in patients' becoming overly reliant and, therefore, less engaged with their own care. The balance is delicate because patient self-reliance is necessary for effective self-management of their healthcare but assistance may be necessary for patients to achieve their goals. More nuanced behavioral assessment may be useful to develop appropriate patient intervention strategies to improve activation and engagement.

Active participation by individuals in their medical care is important for all patients, but especially for those with chronic conditions such as vision loss. Adherence to medication and treatment protocols can be facilitated by addressing patient perceptions, enhancing physician communication, improving patient knowledge and addressing behavioral issues. Current practice models place the burden for this on physicians, which is neither appropriate nor effective, portending the need to develop effective multidisciplinary models to address patients' myriad needs.

Multiple factors contributing to nonadherence have been identified in the literature over decades of study but there is sparse evidence of significant and enduring improvement in adherence. Identifying and addressing behavioral and psychosocial antecedents to adherence is one of the keys to reducing avoidable vision loss.

## Disclosure

The authors report no conflicts of interest for this work.

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