Proposed Strategy - Reintegration of Family Caregivers
Prepared for West Toronto Ontario Health Team
Steering Committee
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Background

The year 2020 will be known as the year of the pandemic taking it's place in history like the Plague. In this day of vaccinations, leaders were taken by surprise as they watched the disease make its way around the world. By the time it got to Toronto, plans to corral and reduce the virus had been hastily made. It wasn't a perfect plan, but it was a plan. We knew how contagious it was so having people stay home as much as possible was a good strategy and still is.

The pandemic response resulted in some decisions which, at the time, were to protect as many people as possible but, upon reflection, caused other, unforeseen issues. For instance, imposing a 'no visitor' policy was implemented by most, if not all, healthcare facilities. Unfortunately, for those at end of life, they were unable to be with family and their families had that burden of extra grief and frustration at not being able to comfort their loved one. Non-communicative and/or complex patients who relied on parents or other family to understand and interpret their needs were also on their own during this time. Those patients with dementia could not comprehend why they could not see their family and friends.

These restrictive policies can cause trauma not only for the patient and family caregiver, but for the healthcare professionals as well, who now have added duties. Activities that were normally carried out by the family caregivers were now the responsibility of the staff. The staff, already had low numbers because of budget cuts, but were now also victims of this virus, reducing the numbers even more. I'm sure you are getting the picture.

Family caregivers (and I speak from experience) provide, not only emotional and spiritual support for their loved one but also physical support. We are the patient's advocate, we understand their needs and preferences, we keep track of medications, we have the patient's history, we do wound care and in my case, manage a PICC line.

Other family caregivers do much more and the staff rely on this support. It is a huge hole when the family caregiver is not there.

None of this is to place blame or chastise. The best decisions were made with the best information and the best of intentions at that time. Now that we know more, we can revisit those decisions with a view to eliminating, or at least, reducing the unforeseen issues that arose because of those decisions. As we prepare for the next wave, it is imperative that we include a review of the 'no visitors' policy.

Recommendation

Now that the virus seems to be under control, or at least manageable, we have the opportunity to welcome family caregivers back to the healthcare facilities. I have not used the term 'visitors' because I believe we need to identify the different levels of 'visitor'.

Tier 1 is the 'essential care partner'. This is the designated one or two family members who are most familiar with the patient's diagnosis and have been performing medical and personal tasks for the patient, who has complex needs.

Tier 2 is the 'family caregiver'. This is a person who is close with the patient and may be taking care of the patient when they are transitioned 'home'. The patient is not complex and could manage somewhat on their own. It would be helpful for both the patient and healthcare staff if a family caregiver could attend to the patient.

Tier 3 is the visitor. This person brings emotional and spiritual support to the patient.

Staged reintegration of the caregivers appears to be the most helpful and least disruptive to the healthcare professionals.

Tier 1 care partners should be the first ones to access their loved ones. Most are familiar with hygiene issues, but some training in light of the virus may be needed. PPE must be supplied for them. If the patient's health status is such that in-person caring is not possible, access to virtual visits should be provided. At the very least a daily phone call updating the caregiver on the health and well-being of the patient is required.

Tier 2 caregivers would be the next group to access their loved ones. PPE protection should be provided along with hygiene training. If the patient is not available for health reasons, access to virtual visits or daily phone calls should be offered.

Tier 3 visitors could be allowed access when ‘the coast is clear’.

There is a cost to denied access in terms of mental health. Worry, anxiety, feelings of helplessness, etc. have been expressed by both patients and their caregivers causing distress and trauma. This can be reduced in the future if we plan now for the ‘next time’.

We have a shared purpose of keeping everyone as healthy as possible. Healthcare professionals and family caregivers can join together working out how to respect and value the role of the caregiver while providing the best care possible and protecting our most vulnerable population.

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