Invisible no more: unpaid care giving in the shadow of covid-19

Miles Sibley and colleagues argue that families must be recognised and valued as partners in patient care

Covid-19 brought radical shifts in healthcare policies and practice, including the abandonment of families as partners in care. This happened in multiple countries, including Australia, Canada, and the UK, which are all high income countries with mixed public and private healthcare as well as being our home countries.

In response to covid-19, England, introduced blanket bans on visiting hospitals and care homes—a practice that was subsequently condemned in parliament.[1] In maternity services, the presence of birth partners was restricted, leading to a deterioration in women's experiences of care.[2] Strict visitor restrictions in Canada did not differentiate between visitors and essential care partners, and caregivers were prevented from providing supportive care to their family members in health and care facilities.[3] Australia saw immediate visitor bans and, later, exception based visitor permissions in hospitals and residential care. Consumer partners who engage in health organisational design and governance were also excluded from decision making in response to covid-19. This resulted in pandemic decisions being made without consumer stakeholders to advocate for patients and families.[4]

Patients define their own "family" and determine how they will participate in care and decision making.[5] As such, the term can include one or more people and can include family members, friends, carers, informal carers, caregivers, and other partners in care who provide unpaid care and support. The swift exclusion of families during the pandemic exposed systems that do not recognise families as fundamental contributors to patient care and outcomes and to safe and effective health systems.

Unintended consequences of excluding families

Although the exclusion of families from health and care facilities was a well intended infection control measure, the resulting absence of family support had unintended consequences for patients and staff. Visitation policies that excluded families resulted in poor patient experiences. In situations where families would attend to the physical and emotional needs of patients, these duties were now left to overstretched staff. Consumer representatives in Australia described how the lack of family presence meant that patient information was less comprehensive, discharge home was less informed and coordinated, and patients experienced poorer mental and emotional health.[4]

The absence of family members had more negative than positive implications for service providers. Participants in a qualitative study of 10 nurses in Portugal[6] and an online nationwide survey of 7846 health workers in Australia[7] reported that more time was needed to calm and comfort patients, yet they felt less effective than a family member. The enforced separation also created greater family anxiety and hypervigilance, with more time spent fielding family members' frequent calls to facilities and requests for updates. A 2021 review of the consequences of visitation restrictions similarly found an increased demand for communication with families and the need for service providers to learn and use digital technology to enable social interactions between families and patients.[8]

The same health workers in Portugal and Australia felt less able to deliver individualised patient centred care and were more aware of the increased safety risks posed to the patient without family presence.[6][7] Acute care staff were also unable to properly prepare patients for discharge without family members to support the process.[6][7] Service providers experienced the moral anguish of turning families away and maintaining forced separation between people who were in clear distress.[6-8] Providers in Canada experienced secondary trauma and psychological and emotional distress from adhering to restricted visitation policies, and their job satisfaction decreased.[3]

Families bolster patient health and healthcare systems

Australia has 2.8 million informal carers—that's one in nine Australians. Each year, they contribute 2.2 billion hours amounting to A$77.9bn (£41.9bn; €48.9bn, $52.7bn) of primary and secondary care, if they were paid.[9] In the UK, 6.5 million people are carers, providing support valued at £530m per day during the pandemic or £193bn for a full year.[10] In Canada, family caregivers contribute 5.7 billion hours of care work per year, with an estimated annual economic value of C$97.1bn.[11] The benefits of family inclusion in healthcare systems have been noted by policy makers, such as the UK's *Carers Action Plan,* which states, "The enormous contribution of our country's carers . . . is an integral part of our health and social care system."[12]

Patients recognise that the path to independence includes the support of their family.[13] Many patients with chronic health conditions consider daily family support to be vital.[14] Patients with supportive families are more likely to adhere to treatment plans,[15] have better communication with their clinicians,[15] are more confident in their daily care, and are better problem solvers as symptoms arise. They also have better clinical outcomes and quality of life.[14][16-18] Conversely, patients who are socially isolated and do not have family support are at a heightened risk of poor self-care and clinical and quality-of-life outcomes.[19]

KEY MESSAGES

- Families are vital to patient care and safety, but their contribution is predominantly unrecognised by healthcare systems and service providers
- Families were shut out from hospitals and care facilities during the covid-19 pandemic, creating negative consequences for both patients and staff
- As families resume their caring roles, we have the opportunity to recognise them as partners in care and support them with practical measures across all care settings

Families construct environments that are conducive to good patient outcomes.[18] They coordinate healthcare appointments, help manage drug routines, are vigilant to new and changing symptoms, and facilitate healthy behaviours, like improved diet and exercise. Families can provide emotional, social, and life affirming support to increase motivation and reduce patients' feelings of isolation, anxiety, and depression.[17] In hospital settings, patients rely on family members for hygiene and feeding support as well as emotional support, safety, and comfort.[20] Families are integral to giving and receiving information when patients are too ill or anxious to do so. Their involvement can encourage treatment acceptance and adherence in reluctant patients, by approaching the treatment and decision process together.[13 15] Families help to manage and synthesise the information provided to reach and support a decision, and they identify and tackle logistical and emotional barriers to care. Sharing the processes of information management, decision making, and logistics with family members gives patients the physical and emotional space to focus their depleted energy on rest and recovery.

Families can also enhance patient safety. When families are effectively incorporated into hospital safety system surveillance, they can identify errors and adverse events that are not picked up by hospital reporting systems, providing more opportunities to avoid potential harm.[21] Isolating patients from their families in their most vulnerable moments can put them at risk of medical error and inconsistent, unnecessary, and expensive healthcare interventions.[6] Socially isolated patients can be more passive and less likely to speak up when receiving treatment, feel stressors more intensely, and have higher blood pressure, slower wound healing, and poorer sleep.[22]

Family support also contributes to discharge from hospital, which is known to be a vulnerable time for patients.[23] Discharge is a time of transition for patient care, and a period of high risk for patient readmissions. Discharge plans individualised to patients' personal needs and environment are known to reduce length of stay in hospital and reduce the risk of post-discharge errors and readmission.[6 17] Improving information sharing and management with patients and families reduces medication errors and improves symptom management. Understanding the environment that patients enter after discharge, and the level of care available to them, helps plan for the support patients need to recover.

Failing to support families

In the crisis period of the pandemic, family care became visible in its absence. The workload of healthcare staff grew, as did emotional burdens, and patient care worsened. The ending of visiting bans resulted in the extra weight being lifted off staff and placed back on families.

Given the evidence on the value of family care, and the negative consequences of excluding families, we might expect that healthcare systems are working harder to bolster their partners in care. UK research, however, indicates an 11% drop between 2015-16 and 2020-21 in local government spending on services for carers and a 42% decline in access to breaks for carers—for example, day sitting, night sitting, or respite care.[24]

Care giving comes at a cost. Carers Canada (formerly called the Canadian Caregiver Coalition)[25] reports that many family caregivers use their personal savings to weather financial hardships, and reduce their work hours because of care giving responsibilities. In Australia, financial packages available to support people with complex healthcare who are cared for at home have fallen substantially in the past decade.[26]

Bringing family carers out of the shadows

The exclusion of families from health and care settings during the covid-19 pandemic highlighted that families were not valued or recognised as essential partners in care. Systematic withdrawal of state support for families has further increased their marginalisation. Families bolster healthcare systems, support staff, and provide better patient care and outcomes. Actions can be taken to recognise, value, and support families in their roles as essential partners in care.

NHS England, as well as the Australian National Health Service Accreditation Standards, identify partnering with patients and families to design policies, cultures, and structures to apply at the point of care as the cornerstone of patient centred care and consequently fundamental to health system performance and improvement.[27 28] But the exclusion of families during the pandemic had avoidable consequences. Including families in these decisions could have helped services tackle infection control while accommodating patient needs without separating patients and families at times of severe illness, pain, uncertainty, fear, and vulnerability.

An important first step would be to create system visibility for families as partners in care. Debates within health systems about "living with covid-19" focus on matters such as staff workforce, delivery models, and funding, but not on the role of families. Despite growing evidence on patient care, safety, outcomes, and quality of life, the role and contribution of families is still not systemically built into healthcare cultures and processes, including orientation, information sharing, discharge planning, safety surveillance, and treatment decisions. Their immense contribution is not recognised as an important resource, without which the health system would struggle to cope and perform; nor is the role of families considered in reporting or in system evaluation. In a 2022 Australian study of the impact of covid-19 on nursing and midwifery workload and wellbeing, the staff respondents made no connection between their increasing workload and the absence of patients' family members who ordinarily support and attend to their patients. The link between family support and staff workload is not top of mind and rarely made.[29] Yet, in other studies where family exclusion was specifically probed, the consequential and additional burdens on staff became apparent, most notably in a 2022 Swiss study of nurses, who outlined how much harder their role became when family members were not there to support them to calm agitated patients and to encourage treatment in fearful patients unwilling to accept treatment.[6 15 17-19]

Health systems and services need to recognise the role of families, involve them as partners, and report on their contribution to individual patient care, safety, and outcomes, as well as to health system performance and sustainability. The development of systematic reporting within services on these matters would be a good start to creating visibility for families as partners in care.

Specific practical, system-wide measures can be put in place for services to partner with families. When patients are admitted to hospital, for example, implementing family orientation can help to inform patients and their families about the services and healthcare being provided. Other measures to support family members as partners in care include accommodation for family sleeping, shower and kitchen facilities, providing private spaces for families to gather and have sensitive conversations, offering families access

to 24 hour food services at no or low cost, and removing expensive parking costs.[30][31] These measures require dedicated resources and have been used, for example, in children's hospitals, where families are offered physical accommodations such as cots, linens, and access to shower facilities.[32] The costs incurred in making provisions of this kind might be offset by the value of having family members present—especially in children's hospitals, where family presence is an expectation and is seen as a means of distributing staff workload.[32] Standardising times for ward rounds so that families can be present when information is shared and decisions need to be made also helps to support patient care.[33]

Finally, government policies should formally recognise families as caregivers, including paying for their labour, offering universal respite funding and services, and providing caregiver benefits. Universal and accessible peer and emotional support for families can help alleviate high rates of isolation and anxiety. Policy examples are offered by organisations like the Canadian Centre for Caregiving.[34] As shown above, measures such as financial support, respite care, and carers' breaks are being substantially reduced and should be restored.

Conclusions

The covid-19 pandemic showed that healthcare cannot function sustainably without the active involvement of families. We now have the opportunity to correct a major, long term, systemic gap in how health services interact with and value family partners. Key actions can be taken to make family care giving visible and valued. It is time to acknowledge, support, and count the contributions that families make in healthcare settings. Valuing family care giving will finally make unpaid care giving visible, enable families to improve patient care and outcomes, support health systems, and better prepare systems for future healthcare crises.

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