

Caring for the caregiver: a systematic review characterising the experience of caregivers of older adults with advanced cancers



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ABSTRACT

The steady advances in oncology bring a host of therapeutic options for older adults (≤ 65 years old) with cancer. As these patients experience this proliferation of anticancer therapies, their caregivers too have witnessed their role rapidly expanding and evolving as they care for these individuals. To better understand the caregiver experience, a review of the current literature on informal caregiving and cancer caregiving was conducted. These informal caregivers are often individuals with a strong personal connection to the person with advanced cancer, such as a close relative, spouse/partner or friend. Caregivers provide a broad range of assistance with most aspects of day-to-day life. However, we have limited knowledge of the impact of this role on the caregivers themselves, particularly in the context of an older adult patient and their unique needs. Here, we explore the data on caregiver experience when caring for a person with advanced cancers—specifically, we characterise the symptom burden and effects on the caregiver well-being with emphasis on the care of older adults with cancer.

INTRODUCTION

Older adults aged 65 years and above carry a heavy burden in cancer incidence—the projected incidence of new cancer diagnoses and mortality in the USA in 2019 underscores the burden of cancer in older adults.¹ Indeed, among persons aged 60–69 years, men have a 1 in 8 probability while women have a 1 in 10 probability of developing invasive cancer. With increasing age, this risk is further increased to where among those 70 years and above, men have a 1 in 3 and women a 1 in 4 probability of developing a new invasive cancer. Such data on cancer incidence further underscore the high likelihood of any person becoming the informal caregiver (IC) for a loved one with cancer. Advances in treatment had brought more therapy options for patients and in turn new challenges for their caregivers. With the expanding and evolving role of cancer caregivers in this environment of rapid advances in oncology, we seek to describe the impact of caregiving on

the IC particularly in the context of an older adult with cancer. To further understand the role of caregiving in oncology, a review of the current literature was performed.

METHODS

A review of the literature via PubMed was conducted where all articles were approved for inclusion by the senior author who is a board-certified palliative care physician.

Moving cancer treatment to the outpatient setting

Over the past decade, cancer treatments have moved to the outpatient setting often either as periodic intravenous administration of anticancer drug(s) occurring in a community-based infusion centre or a regimen that is entirely taken orally. This movement to the outpatient setting is reflected in the three most prevalent cancers in the USA: breast, lung and prostate cancers where over the past 5 years, most newly approved therapies are taken orally or are brief infusions. For melanoma, immunotherapies take a prominent role in not only the relapsed setting but also as front-line treatments to where a patient may safely receive a 30 min infusion of immunotherapy once every 2–3 weeks,² whereas for breast cancer the cyclin-dependent kinase 4/6 inhibitor, palbociclib,³ can be taken by mouth once a day. Such that, patients largely prefer oral agents (89%) to intravenous (9.7%), but not if response rates (70%) nor durations of response (74%) would be potentially compromised.⁴ Other such examples of oral therapies are alectinib⁵ for *ALK*-mutated non-small cell lung cancer (NSCLC), osimertinib⁶ for *EGFR*-mutated NSCLC, cabozantinib for renal cell carcinoma⁷ and enzalutamide⁸ or abiraterone⁹ for prostate cancer. This steady move to the outpatient setting leaves weeks to months between clinic visits when the patient sees their clinical team. Consequently, with

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Table 1 Common tasks of informal cancer caregivers

Medical	Domestic	Personal	Social/emotional
Medication administration	Household tasks including laundry, meal preparation	Maintenance of finances and legal matters	Emotional support for the patient
Management of symptoms (cancer pain, nausea, etc)	Home safety to ensure few barriers for patient mobility	Physical assistance with mobility (wheelchair, walker)	Recreational activities of patient (visits to parks, restaurants, etc)
Monitoring for disease-related and treatment-related side effects	Transportation for appointments, etc	Activities of daily living (bathing, eating, etc)	Maintenance of religious observances and customs
Wound care (eg, postsurgical care)	Shopping for necessities (eg, groceries)	Assistance with medical decision making (eg, pursue additional treatment)	Cultivation of relationships with friends and family
Catheter or line care (eg, PICC, nephrostomy, gastrostomy)	Home maintenance and upkeep (eg, home repairs)	Communication with the medical team (eg, bringing a side effect of concern to the medical team's attention)	

PICC, peripherally inserted central catheter.

few points of contact with the medical team, the majority of vigilance and care falls with the patient themselves or their primary caregiver(s).

Defining informal caregiving

The expanding roles of the IC highlight the truly vast scope of their responsibilities. Informal cancer caregivers are characterised as those persons (often a family member or friend) who provide ongoing care often at home for patients with cancer with a degree of debility.¹⁰ ICs are by definition uncompensated, unlike paid services such as home health aides. The generic and disease-specific tasks of caregiving tend to be time-consuming and energy-consuming and cover far-reaching domains of capability ranging from the medical, domestic and personal task spectrum (table 1; figure 1). Factors impacting the intensity of caregiving include the level of debility, particularly as it evolves over time, and anticipated duration of illness, which, in the context of cancer treatment, can last from weeks to years. Identification and availability of a caregiver itself may pose a challenge in the context of families scattered geographically, decreasing rates of marriage, higher rates of divorce, smaller family sizes with fewer or no children as an increasing challenge as well as concurrent domestic and professional responsibilities. Among the few studies investigating the impact of caregiver education, one reported fewer behavioural and psychological symptoms in patients with dementia whose

caregivers participated in a coaching programme versus control patients (table 2).

Current state of preparation for cancer caregiving

A literature review on the level of preparedness of cancer caregivers reveals the lack of a standardised approach to providing education and ongoing support to these caregivers.¹¹ Given that one major role of caregivers is that of communicators on behalf of the patient to stakeholders (medical teams, insurance, friend, family, etc), one study sought to better characterise the available caregiver education materials in print aimed to develop caregiver health literacy skills.¹² A search across all National Cancer Institute (NCI)-designated cancer centres revealed that only 3 of the 28 print materials were written at the sixth grade reading level (recommended) and only five addressed all six domains of caregiver health literacy skills.

One particular study centred on optimising preparation of patients and their family caregivers prior to lung cancer surgery by incorporating a component of multimedia interventions.¹³ Building on the foundation of data on caregiver burden, symptoms and quality of life after thoracic surgery, the three-prong intervention encompasses what to expect after surgery (pre-op counselling), what to expect when healing at home (before discharge) and telephone support (after discharge).

As the prevalence of people, especially older adults, living with cancer continues to increase, the number of cancer caregivers can also be expected to increase in parallel with a concurrent rise in the expectations and responsibilities placed on the caregiver particularly as many cancer therapies are administered in longer intervals between infusions or are wholly taken by mouth. In a study of 201 surveys, ICs spent an average of 6.6 hours per day performing instrumental and basic activities of daily living (ADLs).¹⁴ Importantly, 55.9% of IC were interested in services that they had not yet accessed, which significantly correlated to higher IC burden.¹⁴ Further, 63.8%

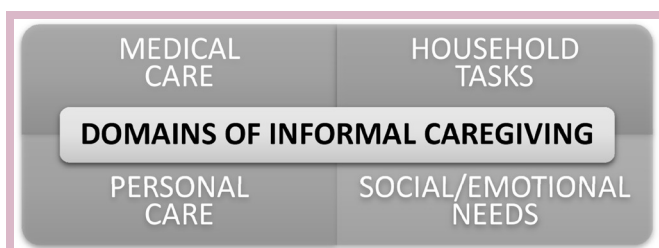
**Figure 1** Domains of Informal Caregiving.

Table 2 Components of a caregiver education programme

Medical	Familial/social	Caregiver self-care
Managing symptoms	Handling role and relationship changes in the family	Caregivers support for their feelings about the challenges of the caregiving role
Improving technical competence	Talking to children	Strategies for coping with these reactions
Administering medication in the home	Managing other jobs and responsibilities	Family role changes
Talking to a loved one's physician	Handling insurance and financial issues	Strategies for negotiating a complex medical system
Managing other aspects of the healthcare system	Dealing with emotional reactions	Recognition of common emotional reactions to caregiving, such as anger and depression
Caring for medical equipment	Finding and asking for help	Identification of changes in caregiver health (eg, developing hypertension)
Managing uncomfortable symptoms	Maintaining self-care	

Adapted from the Family Caregiver Cancer Education Programme.

had previously access support services, including but not limited to home care (37.2%) and pharmacy (29.1%).¹⁴ Given that the physical and psychosocial well-being of the patient is entwined with that of their caregivers, interventions designed to improve the experience of former will need to take the latter into account.

Measuring the economic impact of informal caregiving

The number of cancer therapies and the economic impact of ICs has steadily risen over the past decade. A recent report estimated that, in the year 2013, approximately 40 million people in the USA served as ICs and delivered roughly 37 billion hours of care, placing the value of their uncompensated services to be nearly US\$470 billion.¹⁵ This is compounded by the growing shortage of nursing/healthcare staff and continual increase in the cost of long-term care and hospital stays.¹⁶ Another sobering realisation is that approximately 15% of ICs live greater than an hour away and are forced to provide care at a distance.¹⁷ In these circumstances, an estimated 3.4 hours per week are spent coordinating home care/services and an additional 4 hours per week are spend on care surveillance and checking-in on the patient. Further, a third of these long-distance ICs visit at least weekly and spend an average of 34 hours per month assisting with ADLs.¹⁷

In 1997, the estimated economic impact of IC was US\$196 billion, where an estimated 24–28 million people served as ICs.¹⁸ This estimate comes from a time when the minimum wage rate was US\$5.15 per hour and average home health aide wage rate was US\$11.20 per hour.¹⁹ Almost 20 years later, the amount of individuals requiring ICs as well as the minimum wage and home health aide wage rates have dramatically increased. The estimated value of IC in 2000 was US\$257 billion and estimated that there were 44 million ICs.²⁰

In a more recent study of dementia ICs, an estimated 4.1 billion hours of care over the course of a year was provided at an estimated US\$41.5 billion value, averaging to US\$13 069 per caregiver.²¹ This helps to represent the financial toxicity of providing IC, where cancer care IC

averages US\$2877–US\$4809 per month. More so, out of pocket costs per month were estimated at US\$447 and inability to attend work cost US\$207 per month for ICs.²² This has significant implications as 46.8% of ICs reported an annual income of US\$15 000 to US\$30 000, where 22.1% also provided care for at least one child under the age of 13 years.²³

Quantifying the effort of cancer caregiving

Cancer incidence and prevalence are expected to increase particularly with improved survival and a significant increase in the number of older adults overall in the population. One study quantified the time commitment for cancer caregiving using questionnaires initially and at 4-month follow-up. This study found that 57% and 35% of cancer ICs spent up to 20 and 40 hours per week, respectively, on caregiving at baseline. Further, 28% of ICs provided care for greater than 6 months, which included doctor appointments, medication administration and sleeping an average of 6.5 hours per night since 35% of ICs reported getting up at night to deliver care. Importantly, 30% of the ICs in this study had physical disabilities as well as 33% who were too sick themselves to provide adequate care; however, the health of ICs remained grossly stable during this time and did not worsen.²⁴

The effort attributed to cancer caregiving extends to its impact on the caregiver's employment. Of the employed caregivers in one study of patients with advanced breast cancer, over two-thirds (69%) reported adverse impact on their work in one form or another; as the functional status of the patient declined, a vast majority (77%) of caregivers reported that their caregiving responsibilities led them to miss work.²⁵ Prescription drugs were the most important component of financial burden.

Caregiving issues unique to older adults

When caring for an older adult with cancer, the caregiver themselves may often be an older adult. There is limited data providing understanding of the needs unique to the older adult caregiver. The needs of older ICs are poorly



characterised as ICs older than 60 years old often provide higher levels of care and for longer hours, with fewer social, financial and palliative care resources. In addition, older ICs often themselves have more serious health conditions and generally poor bereavement outcomes in the long-term. It is unclear however if these findings are due to older age and/or spouse–spouse versus adult child relationships.²⁶

Characterisation of symptom burden/burnout/distress in caregivers

Efforts to characterise the symptom burden of caregivers underscore the complexities and intensity of the caregiver experience. In one study of caregivers of women with advanced breast cancer, the mental well-being of caregivers was equal to or worse than the patients themselves.²⁵ Specifically, at the start of the palliative period (defined as a Karnofsky Performance Status (KPS) >50), the caregivers when compared with the patients had a similar mean mental functioning scores and rates of depression (11% and 12%) as the patients themselves. With the progressive decline of the patient's functional status in the terminal phase (defined as KPS of ≤50), caregivers had significantly higher rates of anxiety (35% vs 19%, $p=0.009$) and depression (30% vs 9%, $p=0.02$) than patients.²⁷ Furthermore, caregivers themselves have higher level of responsibilities measured as perceived burden through the Zarit Burden Inventory at the onset of the terminal period when compared with the same time point in the palliative period (26.2 vs 19.4, $p=0.02$).²⁸ Multivariate analysis revealed this perceived burden to be the most important predictor of anxiety and depression.

Impact of cancer caregivers on healthcare utilisation

Recognising that ICs may have little or no formal training, the role of ICs on healthcare utilisation impacts their utility. A study analysing 13 randomised controlled trials including 4361 patients found that having an IC involved in discharge planning led to 25% fewer readmissions in 3 months (relative risk (RR) 0.75; 95% CI, 0.62 to 0.91) and 24% fewer readmissions in 6 months (RR 0.76; 95% CI, 0.64 to 0.90).²⁹ This has large implications on costs of care and healthcare costs overall. One of the studies analysed found that 24-week aggregate cost of readmission for the control group totalled US\$1 024 218 compared with US\$427 217 in the group with ICs ($p<0.001$).³⁰ An additional study further dissected this into a 52-week adjusted total per patient to equate US\$12 481 for the control group compared with US\$7636 for the group with ICs ($p=0.002$).³¹ This is a prime example of the value ICs have on both patient outcomes and lower healthcare utilisation in terms of readmission rates and overall costs.

A prospective study analysing including 479 patients in Canada compared the difference in emergency room visits and 180-day admission rate in patients with and without ICs. In this study, 44.9% of patients had an IC and 53% of patients had an emergency room visit within 6 months after being admitted. This was in contrast to 47.7% of

patients without an IC who had an emergency room visit within 6 months after being admitted. The patients with IC were no more likely to have an emergency room visit than those without (OR 1.16; 95% CI, 0.80 to 1.69).³² This may suggest that although there are many positive roles ICs play, there may be some limitations.

Caregiver well-being outcomes

Being an IC is a significant role in the lives of the patients as well as on themselves for those who are delivering care. A study including 100 ICs assessed the quality of life using the Caregiver Quality of Life Index tool along with mental health social activity and social support.³³ This study found that 40% of ICs had major comorbidities and 22% of ICs health worsened due to caregiving. Additionally, the lower the quality of life of the IC correlated to worse IC mental health, social support, as well as patient KPS ($p<0.05$).³³

Another study used a comprehensive needs assessment tool to analyse the association between quality of life of ICs and unmet needs. This study reported that elder and female ICs had lower qualities of life as well as higher unmet needs. They also found a significant association between family/social support and suffering a health/psychological problem during the first 12 months after a cancer diagnosis as well as 60 months after diagnosis for ICs.³⁴ This study highlights the importance of social support as well as physical well-being on IC-reported quality of life.

A study of 414 ICs compared the impact of geriatric assessments for patients and IC quality of life.³⁵ Roughly, 25% of ICs reported having anxiety, ~20% reported depression and ~45% had distress symptoms. Further, higher patient scores for impairments on geriatric assessments were significantly related to IC depression ($p<0.001$), physical health ($p<0.001$) and overall quality of life ($p<0.001$).³⁵ Patient health status significantly impacts the quality of life and mental health of ICs as demonstrated in this study.

In a nationwide cluster-randomised clinical trial including 541 older adults with metastatic cancer from 31 community oncology practices, using a geriatric assessment tool to improve age-related concerns improved patient satisfaction ($p=0.04$).³⁶ Further, the satisfaction rates were sustained over a 6-month period and remained higher in the group who received geriatric assessments compared with those who were only assessed if the patients met criteria for depression or cognitive impairment ($p=0.04$).³⁶ Additionally, caregivers in the intervention group were more satisfied ($p=0.03$). This study showed that including an assessment at patient visits improves both patient and caregiver satisfaction with communication.

Strategies to reduce stress and burden on ICs have included therapeutic conversations. Using 60–90 min family strength-oriented conversations, ICs reported significantly less stress symptoms ($p=0.029$) and less perceived burden ($p=0.012$).³⁷ This is an important and

effective way to make significant improvements in IC quality of life by reducing stress levels and perceptions of burden. More studies looking at similar interventions are warranted to better assess as well as impact caregiver quality of life outcomes.

Caregiving and its impact on patient health outcomes

Caregivers play important roles in home care in symptom management and rehabilitation of patients. Both these serve to improve patient outcomes and have been shown in survey studies as well as a randomised controlled trial. A study of 152 ICs analysed the associations between IC self-efficacy and measures of patient/IC adjustment.³⁸ In efforts to minimise confounding of patient outcomes on self-efficacy, analyses used regression plots for demographic, medical variables and patient self-efficacy. This study found significant associations with patient physical well-being ($p=0.03$), functional well-being ($p=0.009$) and patient depressive symptoms ($p=0.008$).³⁸ This study defines the important role that ICs can have on various measures of adjustment.

The role that ICs have on rehabilitation has also been tested in patients who underwent lung cancer resection surgery.³⁹ In this randomised study, 22 ICs participated in a pulmonary rehabilitation education programme compared with 19 ICs who received standard of care for 4 weeks. The endpoints of this study were pulmonary function (forced vital capacity (FVC) and forced expiratory volume in 1s (FEV_1)) as well as patient-reported pain scores. In patients where their IC received education, there was a significant improvement in lung function over time for both measures: FVC ($p<0.01$) and FEV_1 ($p<0.01$).³⁹ Although not significant, there was a larger change pain scores, with an absolute lower value in patients with ICs who received education. This randomised study showed the significant value that ICs can have on rehabilitation and pulmonary function in patients after lung cancer resection surgery.

Tools for caregiver assessments

Patient appointments typically do not include IC symptom assessments. This is due to many constraints including but not limited to length of appointments, overall patient assessments and feasibility. A prospective study using a 12-item Edmonton Symptom Assessment for ICs and patients was conducted to see if implementing these assessments was feasible (defined as $\geq 9/12$ items completed) and how it compared with the Zarit Burden Interview.⁴⁰ This study found that 100% (90/90 completed $\geq 9/12$ items) caregiver assessments were feasible and 73% (66/90) of ICs found these assessments to be a useful way to report their symptom burden.⁴⁰ The validity of the Zarit Burden Interview to Edmonton Assessment was not reported in this study ($r=0.53$; $p=0.74$); however, there was a significant correlation between these two assessment tools and time ICs spent on patient feeding, housekeeping and cumulative caregiver activities. Incorporating caregiver assessment tools, particularly the Edmonton Assessment, are feasible and seen as

useful by most ICs. This should inform future studies and assessment integration programmes in oncology practice.

Strategies for preparing the cancer caregiver

The existing data highlight the limited guidance provided to cancer caregivers for this role that they have already or are about to undertake. Efforts to improve the caregiver experience must be as multidimensional as the caregiver experience itself.

Formalising caregiver education

One approach to better preparing the caregiver places emphasis on engaging the multidisciplinary team in delivering caregiver education. One single-arm longitudinal study examined the impact of a 6-hour caregiver education programme taught by nurses and social workers over three 2-hour group sessions. The programme provides guidance on psychosocial support, symptom management and resource identification for cancer caregivers.²⁴ The number of caregivers who said they were well informed and confident about caregiving after programme attendance increased over time. After analysing a dataset including 187 cancer ICs, only 20% of ICs at baseline felt that they were 'well informed' regarding providing cancer care and 16% felt confident in their ability to provide home care and arrange home services.⁴¹ At 4-month follow-up, up to 54% of ICs considered themselves informed and approximately half felt confidence in home care abilities and service arranging.⁴¹ Of the ICs who received formalised caregiving education, 98% found that it helped them fulfil their role as an IC. This study also found that as caregiving tasks increased, IC burden perception remained unchanged and that over time IC personal health perceptions improved. Studies that randomise ICs to education and control groups are needed to further validate the importance of caregiver education in improving caregiver skill and perceptions of burden. Another dimension of caregiver training underscores the role of ICs as a valued (and sometimes primary) conduit for communicating regarding the patient both with medical teams and also with friends and family. Engaging technological advancements and the pervasiveness of smartphones in culture and healthcare opens the opportunity to develop smartphone apps that serve as resources for caregivers when communicating with all stakeholders including medical team, friend and family, both near and far.⁴¹

Improving the model of healthcare delivery

The movement towards outpatient oncology treatment centred on the occasional infusion or orally administered medication is intuitively associated with fewer prescheduled opportunities for contact between the patient/caregiver and the medical team, barring a complicating event significant enough to warrant communication. Models of care that demonstrate an improved patient and caregiver experience centre around turning the tide on this movement and increasing the number of prespecified occasions for communication between these. One randomised control



trial in patients with Alzheimer disease investigates a collaborative care model, which incorporated a heavy caregiver focus.⁴² Specifically, for the caregiver, the model incorporated frequent points of contact with providers (first twice a month, then monthly for 1 year), regular assessment of caregiver's physical health at these visits, telephone interviews at 6-month intervals, a web-based interface to facilitate communication among a multidisciplinary team and voluntary sessions with the psychologist. After 12 months, caregivers in this intervention arm reported significant improvement in their stress when compared with those in the usual care arm. A similar approach incorporating proactive comprehensive care for chronic health conditions in the primary care setting reported lower health service, specifically as fewer days in the hospital or skilled nursing facility as well as fewer emergency department visits and home health events.⁴³

Empowering the caregiver to deliver holistic care

Delivering cancer care is unique, in that there is intersection between physical and psychological well-being. The gravity of these patients' situation exposes the need for holistic care that often includes psychological support. A study of 97 ICs compared the effect of massage for patients versus attention by reading to patients.⁴⁴ The programme included a curriculum that covered patient attitudes and communication regarding touch in cancer care, how to effectively give/receive touch, as well as massage techniques and acupressure for specific symptoms. In this study, patients were randomised to receive massage from their IC or were read to from their IC three times per week. This study found that there were significant reductions in all symptoms after both activities; 12%–28% for reading versus 29%–44% for massage.⁴⁴ Additionally, the ICs who gave massages had significant improvements (symptom severity, quality of life, perceived stress and caregiver attitudes) in their confidence and self-efficacy for using touch and massage as caregiving activities. This is an example of incorporating multimodality care in mitigating the symptoms of patients with cancer at home.

Supporting caregiver self-care

One of the key ways to support ICs self-care has been by providing information. A randomised trial including 199 ICs compared the effect on satisfaction of ICs when receiving immediate intervention compared with after follow-up intervention when starting chemotherapy.⁴⁵ This study used questionnaires to evaluate IC satisfaction and found that over time the intervention group had significantly higher satisfaction levels in 'lack of information' ($p=0.0039$) and 'lack of attention on ICs well-being' ($p<0.001$) from the healthcare professional compared with the delayed group.⁴⁵ Early intervention for ICs led to higher satisfaction levels compared with a delayed approach.

Another randomised trial analysed the effect of telephone call distress scores on 216 ICs to telephone calls without this scoring system incorporated.⁴⁶ This study found that in addition to phone calls including the Distress

Thermometer⁴⁷ system significantly reduced the number of unmet needs of ICs ($p=0.023$).⁴⁶ In addition, in those ICs at risk for depression, the Distress Thermometer system significantly improved the ICs' confidence in managing their own health ($p=0.040$). This is another example of incorporating a universal intervention that can improve IC self-care and impact perception of burden.

Future directions for improving the experience of IC in older adults

Studies that support ICs in improving patient outcomes and optimising the utilisation of healthcare are desperately needed as well as IC interventions specifically targeting the medically underserved. Additionally, studies that have novel designs to incorporate evidence-based recommendations from the in-home setting as well as involve the complex decision-making triad (patient, physician, IC) are a continual need.⁴⁸ Furthermore, there is a profound dearth of data and more is needed to better understand the caregiving experiences in different ethnicities and customs and their unique cultural norms for approaching, discussing and coping with illness; having this in-depth understanding will shape the development of a personalised caregiving strategy to educate and empower the IC.^{48 49}

CONCLUSION

Cancer care is continually evolving with an increase in oral drugs, more convenient dosing schedules as well as targeted therapeutics with more tolerable toxicity profiles. With all these improvements in cancer care shifts the burden of care from inpatient setting to outpatient setting where there is more reliance on ICs to manage patient symptoms as well as provide a variety of ADLs to patients. The economic impact of ICs is astronomical in terms of the financial equivalent of care that these individuals provide but also on its impact on healthcare costs as a whole; this is not without the financial toxicity that being an IC entails. Being an IC has significant impacts on quality of life as well as physical outcomes for these individuals so identifying and employing various assessment tools and interventions to modify the trajectory of these outcomes are persistently needed.

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