

Balancing Illness and Parental Demands: Coping With Cancer While Raising Minor Children

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Cancer profoundly affects patients and their family members, posing unique and pressing challenges to parents with minor children (Golby, 2014; Weaver, Rowland, Alfano, & McNeel, 2010). In the United States, about 20% of recently diagnosed survivors have minor children residing in the household (Weaver et al., 2010). In Canada, about 30% of newly diagnosed patients with cancer are aged from 20–59 years (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2013), which are prime childbearing and parenting years.

Existing literature suggests that parents with cancer struggle to balance their own needs with those of their family (Golby, 2014; Helseth & Ulfsaet, 2005), often prioritizing their children's needs over their own self-care (Elmberger, Bolund, Magnusson, Lützén, & Andershed, 2008; Stiffler, Haase, Hosei, & Barada, 2008). Parents strive to be "good" parents (Semple & McCance, 2010) by staying strong for their children (Asbury, Lalayanianis, & Walshe, 2014; Billhult & Segesten, 2003), spending more time with them (Phillips, 2014; Shands, Lewis, & Zahlis, 2000), trying to make the best of the situation (Helseth & Ulfsaet, 2005), and minimizing disruptions to family life (Bell & Ristovski-Slijepcevic, 2011).

Despite the documented importance for healthcare providers to anticipate and appreciate the challenges for parents with cancer, their psychosocial needs (Ernst, Beierlein, et al., 2013) and tangible needs (Gould, Grasso, Manthorne, Gray, & Fitch, 2006) often remain inadequately addressed. Proposed timely interventions include recommending counseling and support services for parents and children (Golby, 2014; Semple & McCaughan, 2013), providing tips for managing family life (Semple & McCance, 2010), educating parents about children's reactions to parental cancer (Hasson-Ohayon & Braun, 2011), discussing when and how to share cancer information in an age-appropriate manner with children (Asbury et al., 2014; Phillips, 2014), and implementing instrumental support, such as child care, meals, and housekeeping (Gould et al., 2006).

Purpose/Objectives: To explore the cancer experience of parents and their perceptions of supportive strategies to assist them with illness- and family-related challenges.

Design: Qualitative, descriptive design.

Setting: A large McGill University-affiliated hospital cancer care center in Montreal, Quebec, Canada.

Participants: Five mothers and seven fathers aged 33–67 years with a first cancer diagnosis who received treatment at the cancer clinic within the previous year. Participants had to have at least one minor child living with them.

Methodologic Approach: Semistructured, audio-recorded interviews.

Findings: Three main categories emerged: (a) parental self-activated strategies, including maintaining child routines, selective disclosure, strength and positivity, adapting to illness-related physical changes, and connecting with others who are similar; (b) tangible social networks that meet transportation, child care, meal care, and psychoemotional support needs; and (c) suggestions to enhance person- and family-centered care, including information to benefit the children, coordination of appointments, optimizing timing for support services, and the need for more tangible support.

Conclusions: Coping with cancer while raising children requires delicate balancing of illness and parenting demands. Tangible support systems must include access to childcare services, home healthcare services, and transportation solutions.

Interpretation: Support for parenting needs is a key component of comprehensive cancer care. Oncology nurses should stay informed of all hospital, clinic, and community resources to facilitate access for parents. Unmet support needs indicate that improvements need to be made in access to medical appointments around family schedules, expanded resources for children, and reduction of wait times.

Key Words: parents with cancer; qualitative research; family-centered care; child care; psychosocial support

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Although providing crucial insights, the existing research focuses disproportionately on young women with breast cancer, which underscores the need to more generally explore parents' experiences (both

Table 1. Sample Characteristics (N = 12)

| Patient | Marital Status | Child Age | Type of Cancer | Annual Household Income (\$) |
|---------|----------------------------------|---------------------|---------------------|------------------------------|
| Father | Married | 5 and 9 years | Nasopharyngeal | 80,001–125,000 |
| Father | Married | 16 years | Lymphoma | 80,001–125,000 |
| Mother | Married | 21 months, 4 years | Breast | Greater than 125,000 |
| Father | Married (common law) | 17 and 22 years | Lymphoma | Greater than 125,000 |
| Father | Married | 2, 19, and 21 years | Leukemia | Greater than 125,000 |
| Mother | Married | 8 and 12 years | Metastatic breast | 40,001–80,000 |
| Father | Married | 4 and 8 years | Multiple myeloma | Greater than 125,000 |
| Mother | Married | 5 years | Metastatic melanoma | 40,001–80,000 |
| Father | Divorced, remarried (common law) | 4 and 9 years | Colon and liver | 80,001–125,000 |
| Father | Single | 11 weeks | Cholangiocarcinoma | Prefer not to answer |
| Mother | Married (common law) | 11 and 16 years | Uterine | Greater than 125,000 |
| Mother | Single | 11 months, 14 years | Colorectal | 40,001–80,000 |

mothers and fathers) across various types of cancer diagnoses.

The objectives of this study were to gain a deeper understanding of the cancer experience of parents of minor children and to explore parents' perceptions of supportive strategies to assist them with illness- and family-related challenges.

Methods

Following approval from the institutional Research Ethics Committee, a qualitative, descriptive study was conducted in the outpatient cancer clinic of a large McGill University–affiliated cancer care center in Montreal, Quebec, Canada. Patients were eligible to participate if they (a) had at least one minor child living with them (younger than 18 years), (b) had been followed at the cancer clinic within the previous year for a first cancer diagnosis, and (c) were able to speak English or French.

Recruitment and Data Collection

Participants were recruited via referrals from clinical nurse specialists (with patient permission) and posters in the oncology, medical oncology, and radiation oncology clinics. Following written informed consent, a single face-to-face, audio-recorded, semistructured interview was conducted, lasting 35–90 minutes. The interviews took place in a private space at the hospital or in the participant's home and were guided by an interview guide developed for the purpose of this study and reviewed by members of the clinical team. The

interview guide contained open-ended questions, such as, "What challenges, if any, did you face being a parent with cancer?" and, "Tell me about the support you received, or would have liked to receive, throughout your cancer journey." At the close of each interview, participants completed a sociodemographic questionnaire and were offered a pamphlet explaining a free community-based, hospital-affiliated support program for young families affected by cancer.

Audio-recorded interviews were downloaded, transcribed verbatim, and reviewed by members of the research team. Transcripts were coded line by line to highlight excerpts related to the study's purpose. Coded data were conceptualized into category schemes and then organized into broader themes representing parents' experience with cancer.

Twelve parents with cancer—five mothers and seven fathers—participated, with a mean age of 45 years (range = 33–67 years). English- and French-speaking participants were almost equally represented. Two participants were single parents, and the others were married legally or by common law. The majority of the participants were receiving treatment (for multiple cancer types), and 4 of 12 had completed treatment within the past year (see Table 1).

Findings

Participants shared their experiences of being diagnosed with cancer while raising minor children. They highlighted ways to cope with their illness while balancing parental demands. The need to protect their

children and preserve the family equilibrium was paramount. Attempts to achieve this balance consisted of self-activating parental strategies and mobilizing their tangible social networks. Finally, participants offered suggestions to enhance person- and family-centered care (see Figure 1).

Parental Self-Activated Strategies

Throughout the illness trajectory, participants experienced disruptions to family life, including changes in routines, roles, and responsibilities, as well as new financial concerns and personal sacrifices. The following subcategories describe parental strategies used to help family members cope with illness and reduce feelings of grief, fear, and anxiety.

Maintaining child routines: Participants prioritized the need to minimize change by maintaining their children's daily routines (e.g., school, activities, play, meals, bed time) and special occasions (e.g., vacation). One mother emphasized, "This shouldn't affect [the children]. It's my problem, not theirs. I like things routine. . . . Kids like routine." Despite their best efforts, several participants had to postpone or cancel previously planned vacations because of financial considerations or immunity concerns. In several cases, preserving children's activities during treatment meant that the spouse had to take on more daily responsibilities despite continuing to work outside the home to prevent financial burden.

Cancer talk and selective disclosure: Several participants chose to communicate only certain types of cancer information to their younger children by simplifying or withholding information about their diagnosis, prognosis, and treatment. For example, one mother referenced one of her son's favorite movies. "They will [remove the mass] with a laser, like *Star Wars*."

In contrast, other participants divulged more information to lessen the impact of cancer-related changes on their children. With older children and adolescents having access to independent sources of information, parents of adolescents were more open, addressed key issues, and dis-

pelled myths (e.g., cancer equates death). Many participants felt equipped to handle the "cancer talk" and did not seek professional advice. They underscored the importance of tailoring information to meet their children's developmental and emotional needs. At times, the strategy to selectively disclose cancer information was also directed to spouses or other family members.

Projecting an image of strength and positivity:

Most participants explicitly described the need to keep morale high, exemplify strength and positivity, and encourage their children to remain hopeful about the outcome. They reassured their family that everything would be "OK" and that the cancer was only temporary. Several underscored positive aspects amidst struggles—for example, that they have a "good cancer" with good outcomes and that the time off work gave them a chance to spend extra time with their children. On the other hand, participants recounted stories of trying to hide (and occasionally failing to hide) some of their sad emotions. Their time to "feel" and "break down" occurred after the children were sleeping. When they felt emotional for a brief time, "You cry . . . get it out of your system. . . . Then you have no choice but to get up because [the baby]'s crying." Several participants did not want their spouse, children, or parents to see visible signs of illness (e.g., pain, weakness, hair loss, wounds). Interestingly, participants showed the most emotion when discussing those moments, at times fighting back tears. Several fathers with cancer felt that their illness affected their spouse more than themselves and made a link between their gender and showing strength for their family. One father may have coined a new term, the "man manner," when he shared his view

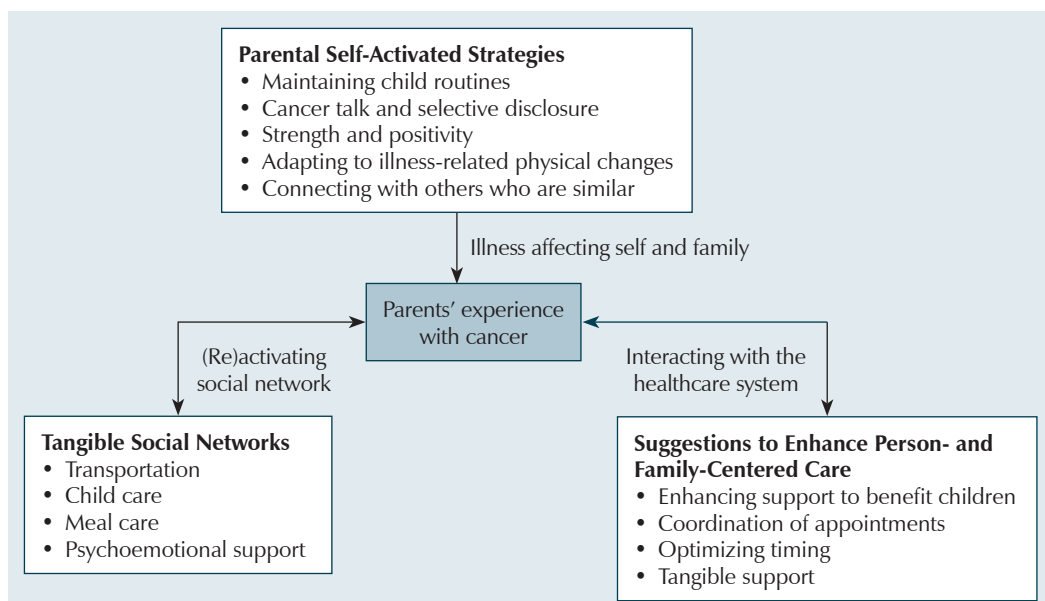


Figure 1. Abbreviated Findings of Coping With Cancer While Raising Minor Children

on moving forward with cancer. "Let's go out there like a man. Let's go face this . . . like a grown up. . . . We are going to take care of this in a man manner."

Adapting to illness-related physical changes: Participants described multiple physical barriers (e.g., fatigue, increased infection risk) that affected regular activities with their children. However, they also described their children being their "natural medicine," pushing through their own discomforts to put their children first. For example, a father described picking up his child from day care, only days after a major surgery. He recounted, "I don't let my pain get to me. . . . It doesn't exist. . . . Your priority is [the children]. . . . My head does not communicate with my body when I'm with both kids." Participants also encountered a new reality whereby everyday activities seemed to have "taken on a different dynamic." One mother described her inability to lift her young children following a double mastectomy, sharing a story of the family's new approach to affection.

If she wants me to hold her, I sit down on the floor. She crawls onto my lap. . . . I was sitting on the couch. She wanted to come onto my lap, so my 4-year-old very clumsily lifted her.

Another mother with colorectal cancer described being unable to provide basic care to her infant during several cancer-related pain crises, relying on her teen-aged son to prepare formula and feed his baby brother during night awakenings.

Connecting with others who are similar: Participants found learning about and connecting with other parents with cancer encouraging. Helpful strategies included reaching out to an acquaintance with cancer for advice, sharing tips about their children, seeking online discussion forums, asking for recommendations about a specific treatment or doctor, researching celebrities who have recovered from the same cancer, and sharing tips with other parents because of the desire to "pay it forward." One mother of young children described feeling hopeful after hearing about the experience of other young mothers. "All these women went through this, and they're fine. Then I was like, 'OK, I'm going to be fine.'" Language was a barrier for one French-speaking participant who was unable to communicate with a mostly English-speaking online community.

Tangible Social Networks

Participants mobilized an already existing social network of family, friends, and neighbors to fulfill a range of practical and emotional needs and assist with family routines. Members of their social network travelled from out of town—even from overseas—to lend a helping hand. Most participants expressed gratitude

for their network, contributing to the sense that they were "lucky in an unlucky situation." Single parents described not having a partner to share the load, highlighting their pronounced need for the support of a network. Practical and tangible support (e.g., taking the children to the park) were more highly valued than strictly moral, emotional, or "phone" support. In particular, the extended social network addressed the following four needs.

Transportation: Driving was not recommended following particular therapies. Parents also found public transportation impractical for varying reasons (e.g., travel time, discomfort, increased risk of infection, geographic inaccessibility). Participants relied on alternate modes of transportation. Network and volunteer driving support was considered an indispensable resource, often freeing spouses to tend to other family needs.

Child care: Because of the unpredictability of their treatment and anticipated appointment delays, most participants turned to their social network for the provision of child care, particularly outside regular school and daycare hours. In several instances, financial obligations prevented their spouses from taking time off from work to look after the children. Participants were thankful and relieved when children were happy with extended family members, but leaving children with someone with whom they were not comfortable was anxiety-provoking.

Meal care: When participants lacked time and strength to cook for their children, particularly when returning from the hospital at dinner time, they felt grateful for others preparing food. "Every so often [the neighbors] come with a plate of food. . . . That, to me, is so much. 'Cause, really, I can't taste it, but at least my son will have a healthy meal." Because of the side effects associated with treatment (e.g., fatigue), other participants hired help when social network support was unavailable.

Psychoemotional support: Many participants identified friends and family as their primary source of emotional and psychosocial support, expressing that they did not seek assistance outside of this social network. They described being equipped to handle the illness as a family. One father said, "I didn't feel I needed anyone from the outside to come in . . . just complicate things more. . . . [My wife, my son, and I are] the three musketeers."

Suggestions to Enhance Person- and Family-Centered Care

Participants spoke highly of the medical and nursing cancer care that was provided, but most felt a disconnect between their specific parenting needs and the targeted psychosocial services offered. One participant stressed that "[healthcare providers] got to listen to the

patient” because “it’s individual” what each parent needs and that the generalized cancer support program was “not the right fit for me, or for my family.” Therefore, participants suggested the following institutional measures to bolster their cancer care experience.

Enhancing information and support to benefit the children: Participants expressed the need for more resources for children (e.g., information workshops, counseling, support groups) and the assurance that in the event of their own death, the family would receive psychological and medical support. One mother explained that in light of her melanoma, she feared elevated risk for her daughter and hoped for her to have early and continued access to dermatology screening. Despite their need for more resources, many participants were unaware of existing services offered at the study site for parents with cancer (e.g., the provision of frozen meals, secondhand children’s clothing, youth workshops). Participants also wanted their information needs (e.g., details about treatment, side effects, and prognosis) to be tailored to the effects on their family. Several participants received guidance from healthcare professionals related to talking with children about cancer but stated that the books and pamphlets offered were not always a good description of their own experience. One participant said,

They gave me a book . . . but what stayed in my [child’s] mind [from the book] was the hair loss . . . but there are a lot of people who do not lose their hair. . . . We have to focus on other things, not just the hair.

Coordination of appointments: All-day wait times at the hospital affected child care because participants were required to rush home to greet children or make alternate care arrangements. They voiced the need for the hospital to respect designated appointment times to “save my time, save my money on a taxi, ‘cause sometimes you take a bus, sometimes you take a taxi, depending on when the kids have to be picked up from day care” and minimize appointments that were perceived to be unnecessary or “overkill.” Participants expressed gratitude for efforts by staff members to cluster appointments and provide treatment in a timely manner, alleviating efforts to coordinate additional child care.

Optimizing timing for support services offered: According to participants, most informational and psychosocial support was offered shortly after diagnosis, when they felt “overwhelmed with all the information.” During the treatment period, informational and psychosocial support “tapers off.” Several participants suggested an opportunity to introduce new information and support at other times besides the diagnosis phase (e.g., What are the next steps following treatment?). A

mother described her disappointment when access to the nurse pivot (navigator), a resource nurse who provides targeted care to patients throughout the cancer trajectory (Horner et al., 2013), was limited during her transition from clinic-based care to home-based oral chemotherapy treatment, during which time she had considerable side effects and felt that follow-up nursing care remained critical.

Need for tangible support: Participants suggested the need for additional tangible support from the healthcare system, which included a hospital-based transportation service and the provision of child care services. Limited parking spots and associated costs were high on the list of concerns, with one father suggesting “reduced taxi fare” as a potential solution. Participants desired more supportive care services to be provided in the home for themselves or their families (e.g., social work, nursing, child care), with services being offered after school hours.

Interpretation

Findings from this descriptive study suggest that participants’ cancer experiences relate to key domains of coping with an illness affecting the self and the family system, mobilizing an already cohesive personal social network and interacting with a complex healthcare system. Throughout their cancer journey, participants represented themselves primarily as a parent and secondarily as a person with cancer, struggling to balance the two competing roles. As acknowledged in the literature, parental cancer is a stressful event for the person and their family, with the parent and children at greater risk for psychological distress (Ernst, Götze, et al., 2013; Huizinga et al., 2011).

Support for parents with cancer requires interventions that are comprehensive in addressing cancer-related and family needs, but these findings identify several mismatches between resources offered and parental preferences at the study setting. Participants relied on self-activated strategies and tapped into their own vast social network of family, friends, and neighbors to address these gaps and maintain family equilibrium, showcasing the significant role the support network plays following a cancer diagnosis in the family (Snyder & Pearse, 2010; Tsimicalis, Stevens, Ungar, Greenberg, et al., 2013). In addition, participants were largely unaware of services tailored to meet their needs of raising minor children while being diagnosed with cancer, the reasons for which suggest additional exploration.

The findings of the current study highlight specific, tangible issues in accessing cancer treatment, such as coordination of medical appointments around family schedules, reduction of wait times for consultation and treatment, and the need for transportation services.

Participants described often having to spend their entire day at the hospital or having to return multiple times in a week for different purposes, which significantly disrupted parent and child routines at home, child care, and overall family life. Healthcare teams opt for patient-centered care, but decisions in the treatment or delivery of health services may not account for patient/family preferences. Their need for transportation services was a dominant concern, similar to the general cancer community (Rossy Cancer Network, 2013). Public transit may not be feasible for the general cancer population for a variety of pragmatic and health reasons, including the perceived risks associated with being immunocompromised (Tsimicalis, Stevens, Ungar, McKeever, et al., 2013). This is even more pronounced for parents with cancer because logistic management of transportation, alongside the coordination of child care, exacerbates the strain on family routines.

A common theme among participants was the importance of showing strength and positivity for the benefit of family members. Although fathers in the current study generally had similar experiences to mothers, fathers tended to draw parallels between strength and being a man, as in previous research exploring fathers' attempts to control emotions and maintain perception of strength (Elmberger, Bolund, & Lützen, 2002).

Although the current study did not directly explore communication patterns among parents and their children, participants brought to light several intriguing issues. In contrast to existing literature outlining difficulties that parents report in knowing what cancer-related information to disclose to their children (Barnes et al., 2000; Campbell-Enns & Woodgate, 2013; Stiffler et al., 2008), participants in the current study portrayed confidence in addressing cancer-related issues with their children, developing their own personal strategies (e.g., being open, withholding information). In addition, participants in the current study reported engaging in a more open dialogue with adolescents than with school-aged children. This is an important finding because of previous work highlighting the benefits of fostering open and developmentally appropriate communication with children, particularly adolescents (Kristjanson, Chalmers, & Woodgate, 2004; Rauch, Muriel, & Cassem, 2002; Semple & McCaughan, 2013). A number of the current study's participants were offered guidance regarding cancer talk with children, including books and written materials, but several felt that the tools available at the study site were of little benefit because they inadequately described their own experience. Interestingly, despite confidence in direct communication with their children, several participants stated the importance of accessible individual or group counseling sessions for children, suggesting that parents may feel that information is better absorbed when offered

by a trained professional, or that counseling may offer a more effective outlet to the children than can be provided by the immediate family.

Limitations

The current study sought to capture some of the experiences of parents with cancer. The majority of participants reported a higher than average annual household income (i.e., more than \$80,000), and all received treatment at a single hospital, which may contribute to reporting a different experience than those being treated in different healthcare settings or with a lower socioeconomic status. In addition, interview data were collected on a single occasion, limiting the time for extensive elaboration of parents' experiences.

Nursing Implications

The current study was the first Canadian nursing study, to the researchers' knowledge, that addressed the gap in the literature related to fathers' experiences with cancer as well as the experience of parents across multiple cancer types, which may guide person- and family-centered care for a wider range of parents. Parents with cancer perceive themselves as parents first and patients with cancer second and have reported that medical practitioners rarely take into account their parental context when planning care (Fisher & O'Connor, 2012). Comprehensive cancer nursing support should prioritize parenting needs. Families, particularly children, are resilient (Bultmann et al., 2014; Semple & McCaughan, 2013) and may not require psychosocial interventions, particularly given the current study's findings that parents with cancer rely heavily on their social network for emotional support. Avoiding a one-size-fits-all approach may warrant routine nursing assessment of family context and service needs at different times during the cancer trajectory. Few participants were aware of the parental support program already in place; therefore, healthcare settings may wish to consider the use of champions to promote awareness of such programs (Castiglione & Ritchie, 2012). A critical role for oncology nurses is to stay informed of all existing resources (hospital-, clinic-, and community-based) so that they can proactively communicate and facilitate access for parents, as well as inform the multidisciplinary team of their existence.

The unmet needs of parents highlighted in the current study point to the need for changes in the provision of cancer-related care that is affordable and geographically accessible to patients. Childcare arrangements could be made more accessible for parents who do not wish to bring their child to the hospital during cancer treatment, perhaps by linking parents with pivot nurses throughout the cancer continuum to

Knowledge Translation

Comprehensive person- and family-centered nursing care should optimize cancer-related and parental needs.

Improved access to care is warranted, including coordination of medical appointments around family schedules, transportation assistance, expanded resources for children whose parents have cancer, and reduction of wait times for consult and treatment.

Oncology nurses should stay informed of all existing resources (hospital-, clinic-, and community-based) to facilitate access for parents and inform the multidisciplinary team.

learn about local services. To alleviate the added stress of multiple clinic visits, oncology consult appointments could be coordinated in such a way to minimize disruption to family routines, when possible. In addition, community health clinics or hospital-based cancer care clinics may be able to arrange cancer-specialized social workers or nurses visiting the home in the evenings or on weekends to facilitate contact with the children. The lack of transportation solutions may suggest the value of reduced taxi fare, monetary allowance for travel, and more widely available publicly funded cancer transportation services.

Given the importance of timing in providing support, stratifying a large sample of affected parents according to early-, middle-, late-, or post-cancer treatment phases may be revealing to document how support needs vary

across the cancer trajectory. Additional research into the perceived needs of single parents also is merited because single-parent families in the current study and other studies (Semple & McCance, 2010) point to more acute needs and lower quality of life for the children (Bultmann et al., 2014).

Conclusions

Cancer is particularly challenging for patients who also are juggling the demands of raising minor children. Their unique context requires a delicate balancing act between the demands of the illness and protecting the children. Specific suggestions focus on access to care and tangible support, including child care, transportation, coordinating appointments, and additional home-based services for parents and their children.

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