Caring for the Caregiver: Lessons Learned from Child Health

Caring for Caregivers: Bridging the Gap
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Acknowledgments


- an invited commentary in response to...

Objectives

• Understand more about the experience and outcomes of paediatric family caregivers
• Consider lessons learned from child health
• Explore assumptions about paediatric caregiving
• Discuss opportunities for integrated caregiver policy
Family Caregivers of Children with Medical Complexity

• Number of children with medical complexity is on the rise
  – 1 or more chronic conditions
  – functional limitations
  – substantial health care use
  – often, technology assistance

• Their family caregivers
  – contribute to significant public savings
  – highly skilled and vigilant
  – express uplifts

Cohen, Kuo et al 2010
Wagner, Power & Fox 1987
Fast, Niehaus et al 2002
Premier’s Council on Health, Wellbeing and Social Justice 1994
Keilty, Nicholas, & Selkirk 2008
Carnevale, Alexandre et al 2005
Challenges among Paediatric Caregivers

• Health
  – Physical: stress, obesity, sleep disturbance
  – Psychological: depression, anxiety

• Safety & Performance
  – Excessive sleepiness
  – Absenteeism, presenteeism

• Caregiver Burden
  – Financial costs
  – Family management

Brehaut, Kohen et al, 2009
Keilty, Cohen et al 2015
Cohen, Berry et al 2012
Kuo, Cohen 2011
Raina, O’Donnell et al 2005
Lesson Learned: Family-Centred Care

- Ubiquitous in pediatrics
- Many accepted practices in pediatrics
  - in-patient and rehabilitation services
- Fewer community based practices & standards
- Misunderstandings persist, lack of consensus & few validated measures

SickKids Model of Child & Family-Centred Care

Kuo, Houtrow et al 2011
Rosenbaum, King et al 1998
Keilty, Nicholas & Karmali 2013
Lesson Learned: Life Course Approach

- An individual within their environment across time
- Many phases & stages in pediatrics
- Problem solving skills are requisite
- Focus on disparities (health, income)
- Slow progression of adverse effects, reverse damage...

Iwin, 2001
Wiliams, Peckham et al 2015
Lesson Learned: The Medical Home

• Model of holistic care
  – accessible, continuous, comprehensive, coordinated, family-centred, compassionate and culturally effective
  – partnership of mutual responsibility & trust, sharing to positively influence quality of life

• Positive outcomes: child, family function & system

AMA, 2002
AAP, 2004
Sia et al, 2004
Homer, Klatka et al 2008
Integrated Complex Care

Enablers:
Alignment with Policy Integration at Point of Care

Opportunities:
Communication strategies
Policy barriers
Interfacing with families

Cohen, Bruce-Barrett et al 2011
Lesson Learned: Human Resources in Homecare

• Homecare supports universally appreciated and desired, yet often criticized

• Innovation necessary
  – Disparate and inadequate resources/jurisdictional
  – Inadequate health human resources
  – Family preferences, trust, ‘fit’

• Promising new models being tested
  – Unregulated providers
  – Self-directed funding
  – Alternatives to home-like settings for youth
Unregulated Caregivers & Paediatric Homecare

Benefits appreciated
• willingness to mirror their care,
• alignment with their values;
• meaningful connections;
• flexibility of the services
• strong parent/provider partnerships

Challenges encountered
• time required for training
• lack of advanced medical skills
• high turnover rates and inequities in access to
• Issues with Registered Nurses
  – trust, competence, mutual respect and affordability/availability

Keilty, Nicholas 2016 in progress
Assumption: ‘Parenting is supposed to be stressful’

• Societal values- financial & fiduciary responsibility to be borne by parents

• In family caregivers of children with medical complexity
  – Extraordinary caregiving, 24 hours/day
  – ADLs not supported vs older adult caregivers
  – Stress r/t family function

Keilty, Nicholas 2012
Canadian Healthcare Association 2009
Schippke, Providenza et al 2015
Caregiver Stress: Keeping vigil

**HCP Perspective**
“Sometimes they have camera and each time they move their own position they can open their eyes and they can be sure if their child is okay. If the nurse is alert and that makes them comfortable and fall asleep again...”
(HCP_03, Site 1)

**FC Perspective**
“For example when I sleep with [child’s name] on the nights that I don’t have a nurse I actually set off my (phone) alarms to wake up every 2 hours also to double check the equipment. Because again if I happen to be so tired and I miss something...”
(FC_02)

Keilty, Cohen et al 2016 in progress
Assumption: ‘Neither seen nor heard’

- Voices muted - children not heard, lack ‘power in numbers’
- Small in numbers (.4-.7%) but healthcare consumption is large (~1/3 total child health budget)
- Overall use of services likely underestimated
- Longitudinal data are needed to illuminate the paediatric caregiver experience and its consequences

Ray 2002
Cohen, Berry et al 2012
Neff, Sharp et al 2004
Making Visible the Invisible

Tasks Perceived as Most Overall Demanding

- Management and Co-ordination: 9.57
- Application of NPPV: 8.91
- Oral Suctioning: 8.77
- Caregiving for Other: 8.56
- Trach Tube Suctioning: 8.20
- Oxygen Therapy: 7.83
- Trach Tube Changes: 7.62
- Application of Mechanical Vent Via Trach: 7.60
- Tube Feeding: 7.59
- Oral Feeding: 7.58
- Speech and Language Therapy: 7.50
- Housekeeping: 7.44
- Occupational Therapy: 7.22
- Play/Developmental Activities: 7.09
- Bathing: 7.00
- Nebulized Medication: 6.95
- Saturation Monitoring: 6.76

Keilty, Nicholas, Selkirk 2007
Assumption: ‘Young, healthy and can bear it’

• Average age typically decades younger than ‘older’ comparators

• Evidence for
  – Poor health
  – Chronic health conditions
  – Activity limitations
  – Inadequate sleep
  – Depression

• Beyond age, caregiving demands & family function strong predictors of caregiver stress

Sleep Disturbance

6.5h ± 1.37h

7.2h ± 0.55

Note: Total sleep time in hours from 9pm-9am, in FC CMT, measured by actigraphy; p=.007

Keilty, Cohen et al 2016 under review
Integrated Practice, Policy Research in Child Health

• Child within family; coordinated delivery models, innovative homecare

• Needed now: rethink societal expectations
  – Caregiver assessments
  – Service quality indicators
  – Sectors aligned & integrated
  – Evidence based care
  – End-user informed interventions
Conclusions

• Care for the caregiver is imperative
• Caregivers in child health share many challenges with their ‘adult’ counterparts
• Pediatric caregivers also have unique needs, learning has occurred, much in progress
• Action & reforms needed now

Thanks ~to the children and family caregivers who have shared of their time and told their stories.