

Wonders & Worries: evaluation of a child centered psychosocial intervention for families who have a parent/primary caregiver with cancer

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Abstract

Objective: Scant evidence exists to guide interventions for children who have a parent with cancer. This study evaluated the outcomes of a community based psychosocial intervention targeted to children dealing with parental or primary caregiver cancer. This curriculum provided an age-appropriate understanding of the illness, facilitated the expression of feelings, identified individual coping skills to help ease feelings related to parent's cancer, and enhanced the family's ability to communicate about the disease.

Methods: Families whose children participated in the six-week curriculum-based intervention completed a questionnaire that included demographic information, a five-item assessment of changes in parenting abilities, and a nine-item assessment of changes in children's behavioral issues. The prevalence of each reported item was determined through a secondary analyses of cross-sectional data derived from a multi-year sample of these survey results.

Results: A sample of 156 families responded to the survey between 2009 and 2014. A majority of families described improvement in all five areas of parenting abilities assessed including communication skills and confidence in parenting. Amelioration of multiple children's issues was reported including improved communication skills (87%), reduced anxiety (84%), increased feeling of security at home (90%), and improved school performance (73%).

Conclusions: The results reported here suggest that this child centered psychosocial intervention promoted positive adaptation by actively supporting families and children while a parent/primary caregiver coped with a cancer diagnosis. Future research is planned utilizing a randomized controlled study design to formally evaluate the effectiveness and preventative impact of this manualized six-week curriculum.

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Received: 16 June 2015

Revised: 12 January 2016

Accepted: 16 February 2016

Introduction

In 2011 approximately 1.59 million people in the United States were newly diagnosed with cancer [1]. Of these, an estimated 296 000 were parents with a child under the age of 18 years [2]. It is estimated that 2.85 million dependent children in the United States are living with a parent diagnosed with cancer [2].

Researchers acknowledge that cancer affects the whole family, not just the individual patient [3]. A parent's serious illness can have a profound impact on children and may result in the development of psychosocial problems such as 'anxiety, confusion, sadness, anger, and feelings of uncertainty with respect to outcome of the illness' [4,5]. Parental cancer is a stressful experience for young people, constituting a potential threat to physical well-being, mental health, and normative development. Cancer creates many disruptions to normal family routines because of treatment demands, frequent hospitalizations,

increased care of parent when at home, redistribution of household roles, possible decline in income, and a decrease in the physical and emotional availability of both parents [4,6]. There are a paucity of child centered interventions to help offset the stress of a cancer diagnosis on a family [7].

Studies suggest children struggle a great deal in isolation with their reactions to a parent's illness. Many studies found that on the surface it appeared that there was little impact on children after an initial period of upset, but upon closer examination, these children were found to be deeply affected by the diagnosis [8–11]. Months after the initial diagnosis parents described behavioral concerns such as emotional upset, problems with sleeping, energy levels, concentration, and grades [8,10]. Children often were hesitant to communicate feelings with others. They wanted to protect their parents, and they tried to cope by using diversion and denial [9,12,13].

Good parent–child communication is thought to help families adjust more easily during stressful events such as parental cancer. Families dealing with cancer who communicate openly have reported less psychological distress [14,15]. Research suggests that psychological intervention programs can lead to improvement of mood, quality of life, coping skills, and stress management in these families [16–18].

Recognizing the impact of cancer on the lives of patients, their partners, children, and the family as a whole is an essential factor in providing appropriate and adequate psychosocial services to families facing cancer. To date research on children’s adjustment to parental cancer has focused almost exclusively on documenting children’s adjustment problems and on describing associations between the characteristics of children and their families and children’s adjustment. Scant literature exists regarding clinical intervention programs available for children whose parents have cancer [7,19]. Moreover, few of these programs systematically evaluated their effects on children’s psychosocial adjustment or behavioral change [7,19]. The purpose of this study is to evaluate parent and child outcomes following participation in a six-week curriculum-based psychosocial intervention targeted to children who have a parent or primary caregiver with cancer.

Methods

Design

Cross-sectional analyses of secondary data were based upon a multi-year sample of survey results obtained from families who received the psychosocial intervention targeted to children dealing with parental or primary caregiver cancer. The study protocol for secondary data analyses was approved by the University of Texas at Austin Institutional Review Board.

Study measures and sample

The survey was developed collaboratively between Wonders & Worries (W&W) certified child life specialists and Academic Research Associates, an independent external evaluation firm, to secure information about perceived changes in parenting abilities and changes in children’s behaviors following the intervention [6,20–23]. The survey was pilot tested online in 2007 followed by field testing using approximately 100 families in 2008. Refinements were made resulting in the 14 question survey used for this study. Families were invited to participate in the survey through the postal service and email (when available). At least two attempts were made to contact each family. Surveys were administered by Nybeck Analytics to an adult family member (once per family) online (93.5%) or provided by trained personnel via

telephone (6.5%) for families lacking internet service no later than 6 months following completion of the intervention. Of 349 families whose children participated in the intervention between January 1, 2009 and December 31, 2014, 156 (45%) responded to the survey and provided demographic information. The five-item assessment of parenting abilities was measured rated on a Likert item ranging from 1 (strongly disagree) to 5 (strongly agree). The nine-item assessment of changes in children’s behavioral issues was rated using a nominal categorical scale from 1 (had no issues and has none after intervention), to 2 (had no issues but developed some after intervention), to 3 (had issues that improved after intervention), to 4 (had issues that worsened after intervention), to 5 (had issues that are still the same after intervention).

Statistical methods

Demographic information was tabulated. Likert items were tabulated for each of the five parenting abilities items. The proportions of children who had parent reported issues in nine areas prior to participation in the intervention were determined. The proportions of children who had parent reported issues that improved, worsened, or were unchanged following the intervention were calculated. Stata Statistical Software, Release 12 [24] was used for all analyses.

Intervention and setting

Wonders & Worries (W&W) is a non-profit agency based in Austin, Texas that provides counseling and support for children ages 2 to 18 who have a parent with a serious illness. All services are provided free of charge in English and Spanish. W&W serves approximately 300 families per year and about 85% of those families have a parent/primary caregiver with cancer.

The W&W intervention, a manualized six-week curriculum, was designed to be individualized to each family’s variable needs (Table 1). The activities provided for each session revolved around similar themes but were individualized to the child’s developmental level and preferences such as a game vs. an art activity focused on expressing feelings about cancer. The W&W intervention was typically provided through individual (63%) or group sessions (35%) held at the W&W offices and local schools. All sessions were approximately 90 min in length with the exception Session 3 (Cancer Treatment Center Tour) which was a 2-h field trip. The goal of the program was to provide children an age-appropriate understanding of the illness, its treatment, and side effects, and to help children and adolescents cope with the stress and fear related to illness in the family. All parents received information during the initial intake session to assist with understanding children’s reaction to illness, support positive parenting techniques, and communicate more openly with their children

Wonders and Worries evaluation

Table 1. Description of W & W intervention sessions and rationale

<p>Session 1: Getting to Know Each Other: The goal of this session is to build rapport between the child and the child life specialist (CCLS). The goal is to create a sense of safety within the group so that the children feel comfortable discussing difficult topics. The activities promote self expression and self discovery and provide the CCLS with an initial assessment of anxiety level, temperament, and the children's perception of their family functioning.</p> <p>Session 2: Cancer Education: This session provides developmentally appropriate education about the illness, treatment, and side effects. The activities focus on general teaching about cancer but each educational session is carefully planned to meet the needs of the particular children that are participating. The CCLS will frequently allow for questions, reflections, and concerns the children may voice.</p> <p>Session 3: Cancer Treatment Center Tour: This session consists of a treatment center tour and education about treatment plan involved in family's care in a safe environment. This includes tour of chemo infusion rooms, radiation machine, CT scanner, MRI machine, and laboratory to view blood cells under a microscope. This type of hands on experience with a trained CCLS helps to clear up misconceptions and alleviate fears around parent's treatment plan.</p> <p>Session 4: Feelings: This session's focus is to assist children label and identify various feelings that may occur while a family is dealing with the changes related to a serious illness. The focus of this session is expression and validation of all feelings the children may experience.</p> <p>Session 5: Stress and Coping: This session begins with a discussion of the definition of stress and various ways people choose to cope. CCLS invites the children to identify the things they already do in their lives to cope and help them feel better when stressed. Ideas may include sports, playing with pets, talking to loved ones, journaling, and art. Goal is to emphasize the different ways individuals cope and differentiate positive vs. negative coping strategies.</p> <p>Session 6: Hopes for the Future/Closure: This session's focus is the children's hopes for the future. An emphasis is made on the idea that positive things may evolve from the most difficult circumstances. Children are invited to discuss some positives that have occurred in their lives since the diagnosis of their parent's illness. Closure activity is provided for children as a way to remember their time with the group and each other.</p>
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about the cancer. A series of special events were organized to bring families and children who share this situation together at a variety of community settings. Families at any stage of illness, from recent diagnosis, to recurrence, end of life, and beyond were served. Families were encouraged to participate in services at any point during their illness experience including survivorship and re-accessing services as children reached different developmental stages or after bereavement. All services were provided by child life specialists and counselors specially trained to help children and their families understand and manage stressful experiences related to life-threatening illness.

The W&W curriculum was based upon the previous research and clinical work of child life specialists with

hospitalized children and upon a strong foundation of child development and family systems [25–27]. Child life specialists promoted effective coping through play, preparation, education, and self-expression activities [28].

Theoretical model

The ultimate goal of theory and research in a practice discipline such as psycho-oncology is development of effective interventions. To achieve this, psychosocial interventions should be derived from theory, research, and clinical observations. A theoretical model is a useful way to illustrate how important concepts interrelate. In the 1980s and 1990s a series of family focused studies

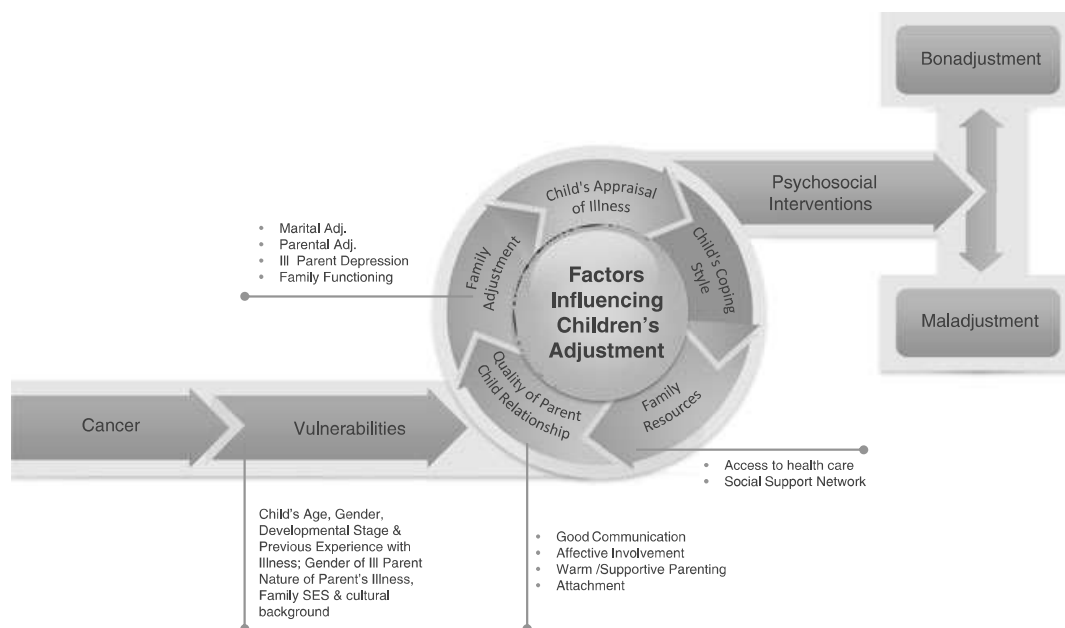


Figure 1. Model of factors influencing children's adjustment to parental cancer (adapted from the Resiliency model of family stress, adjustment and adaptation (McCubbin & McCubbin, 1996))

began to move away from primarily stress adaptation-coping models to family systems models within which the family moved from mere context to foreground [29]. It was no longer assumed that patients' responses and levels of adjustment reflected other members' functioning or type of responses, and family members' responses became a primary concern [30]. Lewis and her colleagues (1989; 1993) presented an explanatory model to explain family functioning when a mother has cancer or a chronic illness. This model focuses on the whole family functioning rather than simply children's adjustment. The relationships between the variables are complex. The following theoretical model (Figure 1) proposes a framework that illustrates the interrelationships among child and family characteristics, family functioning and relationships, and child and adolescent well-being. A systematic review of existing literature provided the foundation for this framework incorporating theoretical, clinical, and empirical work on families coping with parental cancer, particularly research grounded in family systems and developmental perspectives [19]. The model is an adaptation of the Resiliency model of family stress, adjustment, and adaptation [31].

Based on Hoke's [32] classification (four types of children's reactions to a parent's cancer), adjustment is defined as the degree to which a child or adolescent is functioning in terms of emotional/mood, somatic, as well as social and interpersonal dimensions. Accordingly, in this model maladjustment suggests the child demonstrates more bio-psychosocial problems than the average population. Bonadjustment suggests that children who have a parent with cancer have fewer than or the same level of bio-psychosocial problems as the average population. The theoretical model proposed strives to conceptualize cancer as a family's experience and emphasizes the need to address the potential impact it may have on children and adolescent's adjustment.

The W&W intervention was informed by this theoretical model (Figure 1). It focused on assessing the vulnerabilities of each individual child and family, followed by offering activities focused on influencing the factors that have been shown to impact children's adjustment to parental cancer. This included positively influencing the child's appraisal of the illness by providing honest accurate information about cancer, increasing the quality of parent child relationship by facilitating open communication, and promoting positive coping strategies to influence the child's coping style.

Results

Demographic characteristics of families and children are presented in Table 2. Families who participated in the W&W intervention were largely white with an annual income greater than \$50 000. The primary caregiver diagnosed with cancer was most often the mother (59%) or

Table 2. Characteristics of families and children who received services from Wonders & Worries

Families	N (%) 156(100)
Families	
Race	
Caucasian	100(64.1)
Hispanic/Latino(a)	30(19.2)
African American	5(3.2)
Other	4(2.6)
Missing	17(10.9)
Annual income	
<\$14 999	9(5.8)
\$15 000–\$24 999	12(7.7)
\$25 000–\$49 999	27(17.3)
\$50 000–\$74 999	20(12.8)
\$75 000–\$99 999	20(12.8)
≥\$100 000	41(26.3)
Don't know	9(5.8)
Missing	18(11.5)
Family member diagnosed with cancer	
Mother	92(59)
Father	49(31.4)
Other primary caregiver (stepparent, grandparent)	15(9.6)
Time after cancer diagnosis when children received services	
Within 3 months of diagnosis	82(52.6)
3–6 months after diagnosis	40(25.6)
More than 6 months after diagnosis	9(5.8)
After recurrence	15(9.6)
End of life	10(6.4)
Children aware of illness before receiving services	
No	17(10.9)
Yes	116(74.4)
Don't know/other	19(12.2)4(2.5)
Family experiencing financial difficulty	
No	79(50.6)
Yes	60(38.5)
Missing	17(10.9)
Children	287(100)
Gender	
Male	130(45.3)
Female	157(54.7)
Age (years)	
2–4	25(8.7)
5–11	149(51.9)
12–18	112(39)
≥19	1(.4)
Type of services received by children (not mutually exclusive)	
Individual support	107(37.3)
Group support	93(32.4)
Attended special event	94(32.8)

father (31.4%). The majority of families (52.6%) sought the intervention within 3 months of the cancer diagnosis. The majority of the children (74.4%) were aware of the cancer diagnosis before receiving services. The prevalence of families who experienced financial difficulty following the diagnosis was 38.5%. Of the 287 children who participated in W&W intervention, the majority were female (54.7%). The largest age group of participants was 5–11 years (51.9%) followed by 12–18 years (39%).

Mothers were the most common overall survey respondent (75%), responding for themselves as the cancer patient (78%) or for fathers with cancer (90%) of the time.

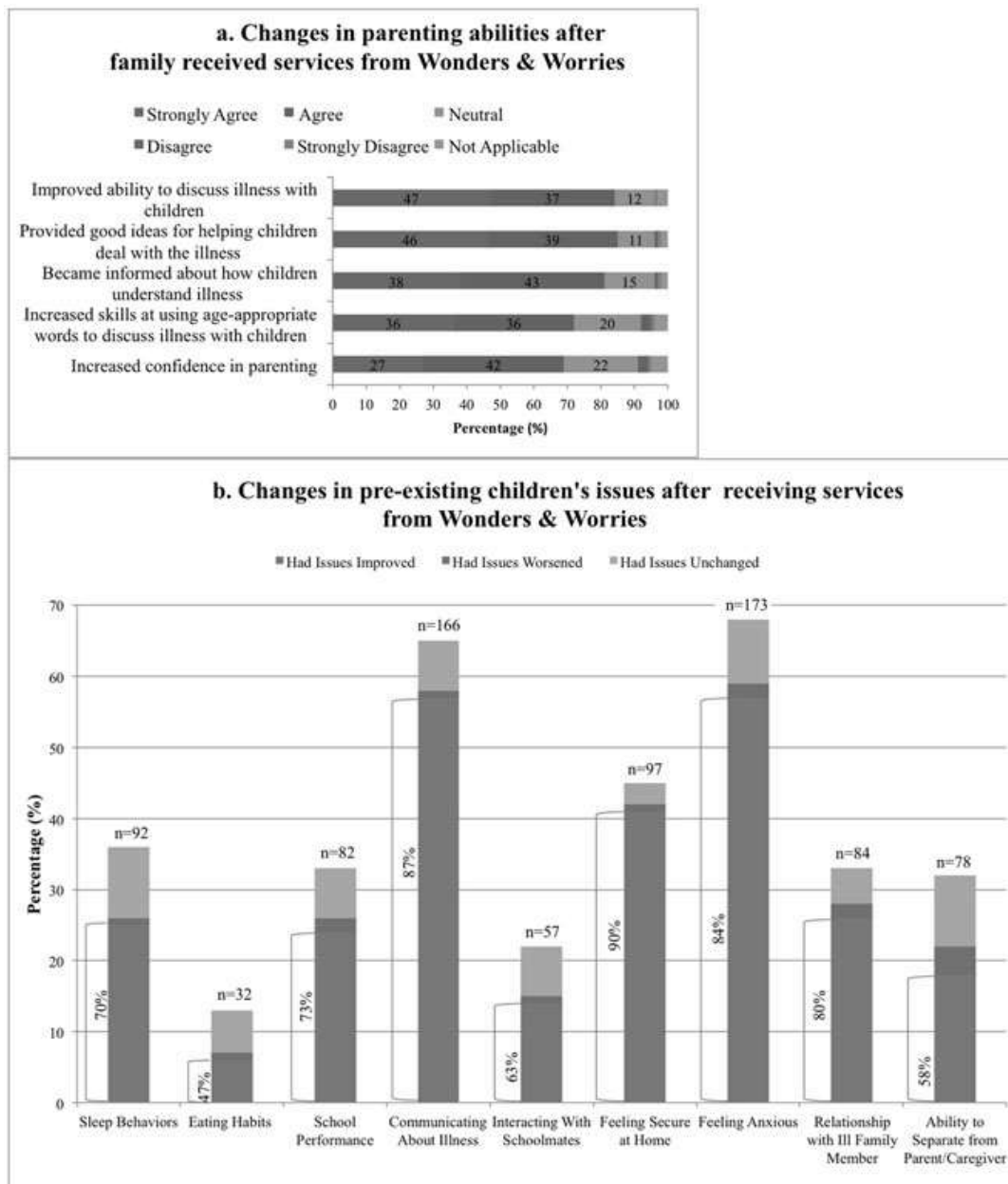


Figure 2. a Parenting abilities. b Changes in pre-existing children’s issues after receiving services from Wonders & Worries

Perceived changes in parenting abilities following the intervention are shown in Figure 2a. At least 69% of parents either strongly agreed or agreed that the intervention was helpful for all five items regarding parenting abilities. Post-intervention changes reported for nine specific children’s issues that existed prior to participation in the intervention are shown in Figure 2b. Difficulty communicating about the illness was reported in 70% of child participants ($n=166$), and of those, 87% had parent reported improvement. Feeling anxious or nervous was reported in 84% of child participants ($n=173$), with 84% of parents reporting perceived improvement in their child’s symptoms. The majority of children with issues related to school performance (73%), sleep behaviors (70%), feeling secure at home

(90%), difficulties relating to the ill family member (80%), ability to separate from the primary caregiver (58%), and difficulty with interacting with schoolmates (63%) had parent reported perceived improvement post-intervention.

Conclusions

The results of the W&W psychosocial intervention reported here contribute to the limited body of evidence regarding community based child centered interventions and highlight the importance of using evidence based interventions designed specifically for children who have a parent with cancer. To our knowledge, this study is the first to evaluate a manualized child centered intervention and

provide a 5-year snapshot of 156 parental and 287 child outcomes that suggested a positive impact upon families and children. It has been established in previous studies that family's open communication about the illness can improve children's coping and adjustment with their parent's cancer [33–38]. The favorable improvements described by parents for children's sleep behaviors, school performance, security at home, and anxiety may stem in part from improved communication skills reported for both parents and children regarding the illness. The majority of families sought W&W services early in the course of the illness which had the potential to mitigate many of the disruptions that a cancer diagnosis has on family dynamics.

Studies published thus far that evaluated parent and family interventions for parental cancer have shown positive impacts upon parental outcomes in areas of parenting skills, mood, and general distress [37,39,40]. However, these studies have failed to demonstrate a substantial impact upon children's outcomes including children's anxiety levels [37,39,40]. Qualitative results indicated that children felt the interventions provided were too focused on the parent. The majority of the counseling sessions were with the parent or family with minimal time spent with just the child. A more child centered approach would have the likelihood of a greater impact on child outcomes [39]. The study results reported here suggest promising potential outcomes for children's behavioral issues when a child centered intervention is used that directly engages children with hands on age-appropriate activities.

The study design was exploratory, and conclusions regarding causality between intervention participation and observed outcomes cannot be drawn from these results. Interpretation of these findings was limited because families who responded to the survey may have been demographically dissimilar and/or have had a different overall experience with the intervention than families who did not respond. The survey itself was collaboratively developed in the field by the W&W staff and the independent research firm to elucidate specific information not previously described in standardized measures. Outcomes were reported by only one parent, not both, and only on one occasion at varying time points within 6 months post-intervention. As such, outcomes may be misclassified because of recall bias.

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In addition, it was not possible to consider potentially informative variables such as stage of cancer, precise timing of survey response following the intervention, or the exact number of intervention sessions attended because of limitations of the data set provided. Future research should include child reported measures to account for inconsistencies with parent reported child outcomes.

Despite the high number of cancer diagnoses in patients that have dependent children at home, there are few evidence based programs or services to help children manage the emotional toll of their parent's cancer experience. Intervention research is needed to promote appropriate psychosocial care for children and adolescents dealing with a parent's cancer [4,19]. While acknowledging the limitations of the results reported here, these secondary analyses were essential to generate hypotheses for future studies of the W&W psychosocial intervention. Further analyses are necessary to elucidate the relationships between various family and child characteristics such as age, gender, race, and family income upon post-intervention parental and child outcomes. As the W&W intervention has multiple components and is conducted in either group or individual settings, it will be important to determine which aspects of the intervention contribute the most to improvement in parental and child outcomes. A randomized controlled trial is currently underway to rigorously evaluate the effectiveness of the W&W intervention using standardized measures of parent and child reported psychological, behavioral, and family adjustment outcomes. Ultimately, children and families affected by a parent's cancer diagnosis should have access to professionals who are knowledgeable and available to address the psychosocial concerns of the entire family.

Conflict of interest

The authors declare that they have no conflict of interest.

Acknowledgements

The authors wish to acknowledge the support of Meredith Cooper, Executive Director of Wonders & Worries, Nybeck Analytics. This research was supported in part by a Dean's Post-doctoral Fellowship from the University of Texas at Austin's School of Social Work awarded to the first author.

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