

In sickness and in health: classmates are highly motivated to provide in-hospital support during childhood cancer therapy

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Abstract

Objectives: Extended hospitalization for school-aged cancer patients increases their risk of social marginalization. School-aged children mature through peer-interaction, but healthcare providers fail to incorporate this in rehabilitation efforts. The RESPECT study offers classmates to cancer patients to become ambassadors during hospital stays. This study explores classmate decision-making patterns about ambassadorship.

Methods: An open-ended question was prospectively and consecutively provided to classmates (N = 221) (and parents) of 10 children diagnosed with cancer in 2014 and enrolled in the RESPECT study. Statements were analysed using thematic content analysis.

Results: Of 221 classmates, 140 responded (63%). Of these, 81 applied for ambassadorship (median 8/patient), 58 declined, one was undecided. Nine forms were incomplete; leaving 131 in total that revealed 303 statements for analysis. Five major themes emerged: existing friendship (132/303 statements), personal resources (academic, emotional and social) (107/303), attitudes towards the ambassadorship (34/303), hospital environment (18/303) and logistics (12/303). Of the classmates with pre-existing friendships, 77% applied for ambassadorship and 80% with a surplus of personal resources applied. These were predominant predictors for ambassadorship application. Classmate motives were condensed into four archetypes: pre-existing friendship with a surplus of resources (100% applied), non-friend classmates with a surplus of resources (63% applied), pre-existing friendship with limited resources (22% applied) and non-friend classmates with limited resources (0% applied).

Conclusion: Classmates are highly motivated to support patients during serious illness, irrespective of pre-existing friendships. Ambassadors offer a novel in-hospital approach to promote rehabilitation in children with severe/chronic diseases. Results need validation in other settings.

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Introduction

Healthcare developments have dramatically reduced childhood mortality rates and diseases that previously were life threatening or chronic have become curable [1]. Children mature emotionally and socially through interaction with their peers and intensified therapy, and extensive hospitalization to cure serious diseases may increase their risk of social marginalization, leaving them with burdensome consequences such as loneliness, anxiety and depression [2–4]. Despite impressive medical advances [5], the social cost for children with cancer is greater than for other patient groups because of their extensive disconnect with normal activities [6–8]. Furthermore, changes in their physical appearance and capabilities caused by their disease and treatment may also cause peers to disassociate themselves from these patients [9]. Thus, both during and following treatment, many childhood cancer patients struggle to be part of

their peer group [10]; they often experience low self-esteem [11] and social isolation (12–14), and some even report being bullied in school (15–17). Although maintaining social relationships during treatment provides emotional support and a sense of normality, more ensured inclusion in peer groups and facilitated rehabilitation from diagnosis (18–21), healthcare providers fail to recognize its relevance in improving quality of life and facilitating back-to-school rehabilitation [22].

In the ongoing Danish, nationwide, controlled rehabilitation including social and physical activity and education in children and teenagers with cancer (RESPECT) study (clinicaltrials.gov: NCT01772849 and NCT01772862) [23], two healthy classmates serve as ambassadors to each hospitalized peer with cancer. They alternate in being co-admitted once monthly to the paediatric oncology unit, from morning through afternoon, participating in educational, physical and social activities with the inpatient and as such provide educational and psychosocial support.

Bringing healthy classmates into a paediatric oncology unit raises challenges, including: the current hospital culture, adherence to hospital isolation guidelines, absence from school and leisure activities, personal and societal fears about hospitals and cancer, and extensive distances from their respective homes to the hospital imposed by centralization of paediatric oncology treatment.

The aim of this study is to explore classmate decision-making patterns regarding ambassadorship as a means to facilitate future identification of classmates as candidates for ambassadorship for seriously ill hospitalized children.

Method

Setting

This study is embedded in the intervention programme, RESPECT, that provides educational, physical and social components for children with cancer.

Eligibility criteria to enter the RESPECT programme include: (a) aged 6–18 years, (b) diagnosed with cancer, Langerhans cell histiocytosis or myelodysplastic syndrome treated with chemotherapy and/or irradiation in a paediatric oncology unit in Denmark, (c) enrolled in school at the time of diagnosis, and (d) being able to communicate in Danish. Exclusion criteria include mental disability (e.g. Down's syndrome) or severe compromising co-morbidities.

All children in Denmark have 10 years of mandatory school education (Kindergarten - 9th grade), with an additional optional 10th grade. The average number of students per class is 20–25, in a mixed-gender setting. Eighty-two per cent of the children attend State-run schools where education is free; 15% attend private schools where out-of-pocket expenses cover approximately 25% of school costs, and 3% attend special needs schools, which are free-of-charge [24].

When a school-aged patient is diagnosed with cancer, his or her classmates are offered a 90-minute presentation at the school, introducing them to: (a) childhood cancer, (b) communicational and emotional strains on cancer patients during therapy, (c) the goals of the RESPECT study, and (d) the need for and role of ambassadors. All classmates and their parents are then provided with written information about the RESPECT programme. Based on nominations by the schoolteacher, the child with cancer and the ambassador applications, the RESPECT research team matches two ambassadors with each patient. Before considering election for ambassadorship, the schoolteacher alerts the RESPECT team of any volunteering classmate who may have problems with anxiety and mood instability.

Participants and data collection

After the educational session on childhood cancer and introduction to ambassadorship, we prospectively addressed

all 221 classmates (and parents) of 10 consecutively recruited children (five boys and five girls, aged 6–15 years (median: 10 years) in kindergarten (6 years old) through 9th grade (median: 3rd–4th grade) and diagnosed with (N=5) or without (N=5) haematological cancer in 2014 and enrolled in RESPECT at the University hospital (Rigshospitalet), Copenhagen. Eight patients attended State-run schools, and a further two patients attended private schools. The following open-ended question: 'please explain why you did/did not apply for the ambassador function' exploring decision-making patterns was presented on forms and distributed to all classmates. The respondent could reply anonymously but had to specify his or her gender and whether he or she was a parent or classmate. All parents were informed about the open-end question; however, it was optional whether the classmate or his or her parent(s) or both replied.

Data analysis

All completed forms were imported into the QSR NVivo 10 [25] computer program for processing. Data were analysed using thematic content analysis [26], and each statement given by the classmate and/or parents was coded independently by two researchers (L.H.L. and H.B.L.) and then compared. Parent and classmate responses were not analysed separately. As described by Strauss and Corbin [27], we applied open and axial coding where data were examined, compared, conceptualized, categorized and regrouped based on relationships and patterns within and between the identified categories. Interpretation and code labelling were agreed through consensus. We condensed the contents of the five themes to generalize descriptions and concepts, which were displayed as 'The Classmate Support Model', representing four archetypes of classmates. Following the development of the model, we listed the number of applicants/non-applicants who matched one of the four archetypes. The Classmate Support Model illustrates the characteristics of classmates who are able and willing to apply for ambassadorship (Figure 2).

The influences of gender, age and distance to the hospital on motivation for applying were analysed using a chi-square test. Age was categorized into younger (6–10 years) and older children (11–15 years). Distance to the hospital was categorized by being less or more than one hour of travel time. The median distance to the hospital was 84 km (range: 8–297 km).

Results

The median number of classmates as potential ambassadors per patient was 24 (range: 14–30). Of the 221 classmates, 140 (59 boys, 76 girls and 5 unidentified) classmates returned the forms (response rate 63.3%). The percentage of applicants for ambassadorship in each class (median:

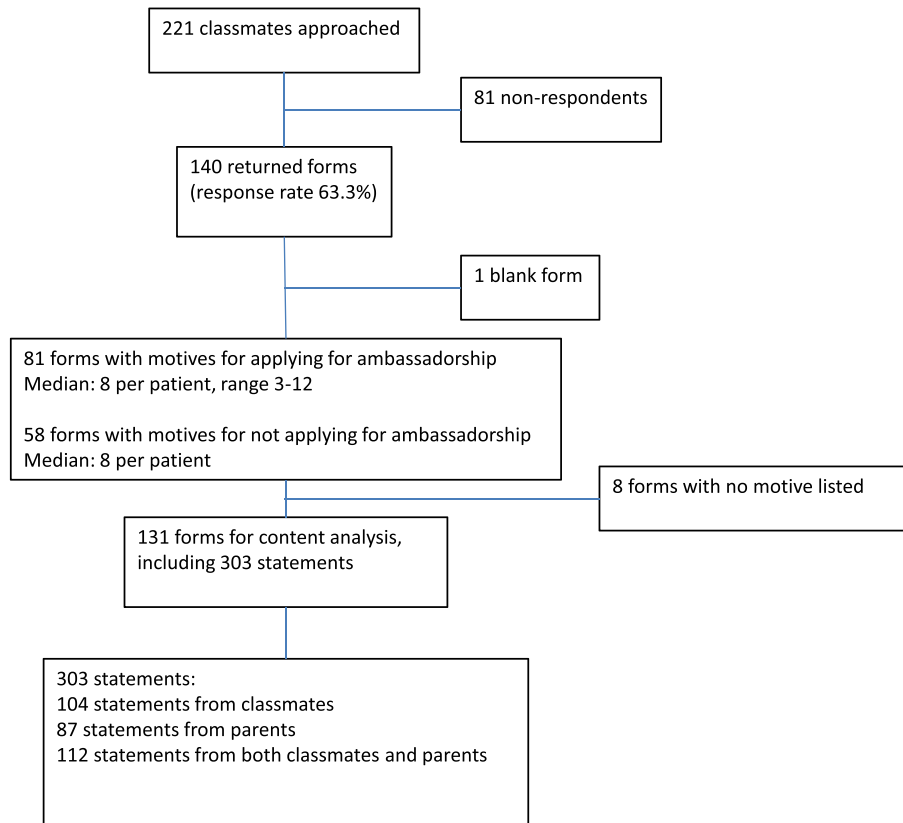


Figure 1. Consort diagram with an overview of the returned forms.

44%) was not significantly associated with the percentage of returned forms. Eight classmates returned forms with no motives indicated, and one returned a blank form, leaving 131 forms for content analysis. The median number of returned forms per school class was 10 for younger patients and 14 for older patients. The 131 forms included a total of 303 statements. The youngest children (6–7 years) did not complete the forms on their own, however, with increasing age more children completed the forms independently. Figure 1 shows an overview of the returned forms.

The 303 statements were categorized into five motivational themes: acceptability of the ambassador function, friendship, resources, hospital environment and logistics. Based on these themes, we developed the ‘Classmate Support Model’ that represents four archetypes of classmate motivational patterns. The ‘Classmate Support Model’ is shown in Figure 2. Each of the five themes reflected determining motives for applicants and for those who declined the ambassadorship.

Overall, the five male children with cancer had 25 applicants of the same gender and 23 applicants of the opposite gender, while the five female cancer patients had 25 applicants of the same gender but only 8 applicants of the opposite gender. Thus, male classmates were more likely to apply for ambassadorship when the patient was of the same gender ($p=0.004$), which was not the case for the

girls ($p=0.36$). There was no significant association between age or distance to the hospital and the likelihood of applying for ambassadorship.

Theme 1. Acceptability of the ambassadorship (34 statements)

Classmates applying for ambassadorship (29 statements) stated generally positive views about the RESPECT study, including the benefit of removing the taboo of talking about cancer in school. Parents appreciated the opportunity to offer support to children with cancer and recognized their own needs had their child been affected by cancer. Even respondents declining ambassadorship (5 statements) declared that RESPECT was a positive initiative, and no classmates or parents expressed any concerns about involving classmates to support peers with cancer.

Theme 2. Friendship (132 statements)

Friendship was the most frequently addressed theme. The dominating motive for applying for ambassadorship was pre-existing friendship with the child with cancer (101 statements). The classmates expressed their desire to be supportive and to boost the patient’s mood, being a link for the patient between the hospital and the school and preventing the child with cancer from experiencing social exclusion and loneliness when not in school. This was

Best Friends forever	Yes/no: 42/0	The Good Samaritan	Yes/no: 33/19
<ul style="list-style-type: none"> + Friendship + Academic, emotional, and/or social resources + Hospital environment appeal <p style="text-align: center;">⇓</p> <ul style="list-style-type: none"> • Optimal match • Eligible for ambassadorship 		<ul style="list-style-type: none"> ÷ Friendship + Academic, emotional, and/or social resources + Hospital environment appeal <p style="text-align: center;">⇓</p> <ul style="list-style-type: none"> • Discrepancy – possibility of friendship • Eligible for ambassadorship 	
Friends With Challenges	Yes/no: 4/14	Classmate Acquaintances	Yes/no: 0/19
<ul style="list-style-type: none"> + Friendship ÷ Academic, emotional, and/or social resources ± Hospital environment appeal <p style="text-align: center;">⇓</p> <ul style="list-style-type: none"> • Discrepancy – risk of distress • Eligibility for ambassadorship depends on the type of resource deficit 		<ul style="list-style-type: none"> ÷ Friendship ÷ Academic, emotional, and/or social resources ± Hospital environment appeal <p style="text-align: center;">⇓</p> <ul style="list-style-type: none"> • Discrepancy • Not eligible for ambassadorship 	

Figure 2. Of the 131 forms analysed, 79 were from classmates applying for ambassadorship, 52 from classmates who declined. Yes: applicants, No: non-applicants. +: positive influence of the factors important for ambassadorship. ÷: lack of factors important for ambassadorship. Discrepancy: mismatch between the positive influence and lack of factors important for ambassadorship.

expressed differently depending on age. The younger children's (6–8 years) motives were described in concrete terms, e.g. being supportive by bringing homework, whereas the older children's motives were expressed in more abstract terms, e.g. to 'prevent loneliness'. Furthermore, classmates (and their parents) expressed a desire to be involved in and to understand what the child with cancer is experiencing, specifically highlighting the necessity for reciprocity in friendship.

The main reason for not applying for ambassadorship was the absence of a pre-existing friendship with the child with cancer (31 statements), because these classmates felt that they had less to offer and that a close friend to the patient would be a more suitable match.

Theme 3. Resources (107 statements)

Classmates' personal resources included their respective family's perceptions of their emotional, social and academic characteristics and competences. Among the classmates applying for ambassadorship, there were 33 statements emphasizing the emotional resources that could be offered

to the child with cancer and the applicants characterized themselves as: 'empathic, caring, positive, dedicated, curious, responsible, outgoing, trustworthy and having good coping skills'. Social competence was reflected in statements such as: 'being a good person to play with, good at facilitating interactions between children, good at engaging in different social relationships and being able to adapt to new situations and new people'. The classmates regarded these social competences to be important skills when functioning in an unfamiliar setting such as the hospital. Furthermore, academic achievement and being familiar with assisting others with homework were considered as positive resources for supporting the child with cancer.

A few of the classmates highlighted that their own personal experience with a severe illness or one within their core family had provided them with insight into and experience with complex treatment, and this could be beneficial for the ambassadorship.

Similarly, some classmates not applying for ambassadorship described their limited emotional, social, and/or academic resources as being insufficient for supporting

the child with cancer (31 statements). Emotional sensitivity descriptions included statements such as: 'being too thoughtful, too shy, too vulnerable, not being good with unfamiliar situations, lacking surplus and coping skills'. Classmates struggling with academic challenges did not apply in order to avoid having to miss classes. Because information regarding academic challenges was not gathered systematically, it is not possible to exclude the possibility that some classmates with academic challenges did apply; however, if a classmate was facing such challenges, it did not appear to concern either the applicant or his or her parents. In contrast to those who applied, some classmates with experience of illness or death among close relatives could not picture themselves as ambassadors. Finally, some parents declined, despite the child's expressed wish for ambassadorship because they were unsure about how to emotionally support their own child during the ambassadorship.

The ethical value of supporting people in need, the so-called Samaritan principle, was explicitly expressed by 21 classmates who did not experience a pre-existing friendship with the patient, and both classmates and parents stated that they understood the importance of support beyond friendship. Twenty-two parents emphasized that supporting other people in need was a virtue that they wished to encourage in their child and further expressed that an ambassadorship provided a positive challenge within a safe environment that could contribute to their child's development of such social competences [28].

Theme 4. Hospital environment (18 statements)

Respondents applying for the ambassador function (14 statements) expressed curiosity about daily life in a paediatric oncology unit and the medical equipment used and stated that they were considering careers as healthcare providers. Three out of the four statements from those who did not apply expressed anxiety about being at the hospital without their parents, and one stated fear of needles and blood.

Theme 5. Logistics (12 statements)

Respondents applying for ambassadorship included statements (N=6) emphasizing that they lived close to the patient's home or their parents' willingness to drive them to the hospital. On the other hand, some parents from among the youngest children (9–10 years) and who lived up to 2 hours driving distance from the hospital were concerned about transportation time, yet they still applied. Motives for declining the ambassadorship (6 statements) included: having busy daily leisure activity schedules or concerns about long distances to the hospital. Some older classmates felt insecure about transport to the hospital if unaccompanied by their parents.

We condensed the five themes into the 'Classmate Support Model' that covered four classmate archetypes and into which the 131 response forms were categorized (Figure. 2).

The first archetype, 'Best Friends Forever', comprises children with pre-existing friendships and a surplus of emotional, social or academic resources. The 42 classmates matching this archetype all applied for ambassadorship. The second archetype, 'The Good Samaritan', comprises classmates with a surplus of resources but without pre-existing friendships. Sixty-three percent (N=33) of these classmates applied for ambassadorship. The third archetype, 'Friends with Challenges', comprises classmates with a pre-existing friendship with the child with cancer but who have limited resources. The majority of these children and their parents (77%) stated the need for resources as being the main reason for declining the ambassadorship. The fourth archetype, 'Classmate Acquaintances', comprises classmates with a combination of no pre-existing friendship and limited resources, and none of these applied for ambassadorship. Because logistics did not significantly influence the decision-making patterns of applying for ambassadorship, this theme was not included in the model. The theme 'Hospital Environment' was included in the model. Because fear of the hospital environment overruled a pre-existing friendship and a surplus of academic, emotional or social resources, it is questionable whether these children actually possess a surplus of resources. These classmates are excluded therefore from the category 'Best Friends Forever' and categorized as 'Friends with Challenges'. However, in the category 'The Good Samaritan', the hospital environment was appealing for the applicants and for some it was even the main reason for applying.

Discussion

The results of this study show the feasibility of identifying classmates that can provide support to peers with cancer to facilitate rehabilitation from the point of diagnosis, even when pre-existing friendship is lacking. The presence of pre-existing friendship and emotional, social and academic resources were the predominant consideration in applying for the ambassadorship. The ability of classmates and their parents to recognize the needs of children with cancer and their strong motivation to actively address the need offers new perspectives for organizing health care of critically ill children experiencing extensive hospital stays.

The Classmate Support Model's 'Best Friends Forever' archetype may demonstrate a faithfulness to the child with cancer and a willingness to maintain a close relationship in both sickness and in health [28]. Based on ethical and societal norms and individual feelings of loyalty to the child with cancer, those classmates categorized as 'Friends with challenges' may experience a feeling of failure for not applying for ambassadorship [28]. Parents, researchers and schoolteachers should be aware of this potential stress factor and provide the necessary emotional and psychological support

in future studies on paediatric rehabilitation during treatment that use classmate ambassadors.

Age has a major influence on the ability of classmates to understand and on the content of the ambassador role. A seven-year-old ambassador may offer support by bringing food or a gift while a 16-year old may provide heart-to-heart dialogues and share emotional experiences [29]. Both actions can be perceived by the child with cancer as an expression of support to counteract feelings of loneliness and social marginalization.

Some parents assisted their child to complete the open-ended question. These parents reflected their child's motives by quoting them verbatim. The parents often elaborated on their child's motives by adding their own reflections, e.g. in Theme 1, parents confirmed recognizing the need for support had their own child been the one affected by cancer. The fact that some parents assisted their children in replying may influence their motives; however, it is not possible to say to what extent in the current study. The strength of this study lies in the fact that all of the classmates participated in the cancer education presentation and all were exposed to having a classmate diagnosed with cancer. This in turn gave authenticity to their reflections on friendship, and the inner resources they could offer to support as ambassadors. Furthermore, both genders and all age groups from 6–15 years were represented; however, this range and variation were not stipulated in advance of the intervention due to the consecutive sampling strategy applied. The study was somewhat limited by the fact that approximately one third of the classmates failed to respond and no information was available from non-responding classmates. However, because of the option of answering anonymously, there was no reminder procedure. The advantage of answering anonymously was to allow the classmates and their parents to answer openly and honestly when confronted by a difficult situation and when considering a sensitive matter. The 'Classmate Support Model' is developed based on decision-making patterns of classmates to 10 children with cancer. As such, the social position of the child with cancer in the class could influence the number of applicants and their statements. However, because the study both included applicants and non-applicants, the perspectives of both positions were represented.

Although it is claimed that 'peer-relationships are powerful socialization agents contributing well beyond the collective influence of family, school and neighbourhood to child and adolescent social, emotional and cognitive wellbeing and adjustment' [30], this has not been explored in-depth in children with life-threatening or severe, chronic disease. Contemporary health care could benefit from various forms of active and targeted inclusion of classmates in supporting paediatric patients and in facilitating back-to-

school rehabilitation. With 69 of 72 (96%) consecutive eligible patients having entered the RESPECT study and no subsequent dropout of ambassadors, the 'Classmate Support Model' indicates that the motivation and expectation characterizing the classmates that volunteer are met only once they actually engage in peer-based rehabilitation for children with cancer. This information may be useful for healthcare professionals, schoolteachers and parents to classmates and children with cancer when developing peer support programmes. Still, classmates and parents may respond differently when faced with diseases other than childhood cancer and results yielded by this study need to be validated in other disease settings. In the post-modern society, friendships tend to be lifelong and bring the lifespan together [31]. Therefore, including active friendship roles, e.g. ambassadorship, as a component in the future treatment of paediatric patients is essential.

Conclusion

School-aged children are highly motivated to support classmates with cancer. The Classmate Support Model identifies characteristics of the classmates willing and able to support the child with cancer. In perspective classmates as ambassadors during extensive hospital stays may offer a radically novel approach to promote quality of life and back-to-school rehabilitation for the child with cancer, from the point of diagnosis to reintegrating with peers in the school setting.

Conflicts of interest

The authors declare no conflicts of interest.

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Data sharing statement

The qualitative coded data set can be made available by the corresponding author on request.

Ethical approval

The Regional Ethics Committee for the Capital Region approved the RESPECT investigation (H3-2012-105). Protection of subject data was approved by the Danish Data Protection Agency (file. 2007-58-0015/nr.30-0734).

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