

PALS Program at the UCI College of Medicine

Project Description

PALS is a UCI College of Medicine (COM) community service program that was initiated and run by first-year medical students as a pilot project from January to June 2003. The PALS Program, patterned closely after a successful program implemented by medical students at Stanford University, is a specialized adaptation of the national Big Brother/Big Sister Program. The overarching goal of the community service program is to foster relationships between medical students and chronically ill children and their families.

PALS also provides educational enrichment to participating medical students. The Department of Pediatrics at the UCI Medical Center (UCIMC) presents a structured bimonthly seminar series on issues pertaining to chronically ill children. Learning outcomes for medical students include:

- Increase empathy and sensitivity to the needs of chronically ill children and families;
- Increase specific knowledge and better understanding of issues relevant to child development, chronic pediatric illness, and impact of illness on family dynamics; and
- Increase awareness of pediatrics as a career and a deepening of professional commitment.

First-year medical students are paired individually with a pediatric patient (i.e., the index child) as “pals” who interact with each other on a regular basis for various activities. Examples of activities include taking the index child to the movies, attending a sports event, having an outing at a park, and participating in PALS group social events. Students also are encouraged to attend clinic visits with the index children and their families and to visit them in their homes. The intended community service benefits to families potentially include:

- Friendship and mentoring for an ill child from interacting with a medical student;
- Social support from having students become part of the chronically ill child’s support group and by participating in group events with other families facing similar issues; and
- Assistance in understanding medical problems and treatment.

A coordinating committee consisting of three first-year medical students (H. Richmond, T. Chang, & F. Staiti), Department of Pediatrics faculty sponsors (F. Waffarn, MD & P. Murata, MD), and the Director of UCIMC Child Life Services (E. Andrade, MS, CCLS) organized the program and vetted students who volunteered to participate in the PALS pilot project. Participation was not a required part of the COM curriculum; students were not evaluated or graded in any manner and no academic credit was granted. The families of the 10 index children were recruited, vetted and referred to the PALS Program by the UCIMC Director of Child Life Services. Family participation was totally voluntary and could be terminated by the family at any time. Index children varied by gender and age (range 6 – 16), presented with diverse chronic diseases, and came from a range of socioeconomic backgrounds. The coordinating committee also assumed responsibility for evaluating the pilot PALS Program.

Program Evaluation Data Collection and Analysis

Volunteer students ($n=10$) who were competitively selected for the pilot PALS Program completed brief (about five minutes) pre- and post-program written surveys to gauge their general impressions about personal expectations/accomplishments from participation in the program, per se, as well as perceived programmatic strengths and weaknesses. The survey data

consisted mostly of student ratings in response to either 11 (pre) or 9 (post) statements such as, “How much do you expect/did your interest in pediatrics increase?; “ How rewarding do you expect/was this program to you?”; and “How much do you think a child’s chronic illness affects his/her siblings?” All ratings were made on a 5-point scale, where 1=“Not At All/None,” and 5= “A Lot.” The remaining survey items were either two (pre) or three (post) structured questions requiring a brief narrative response that asked about expectations/what was gained or learning from being in the program and what were the expected /experienced difficulties and barriers.

Students were verbally informed prior to the post-program survey administration that there were no risks, their responses would be kept confidential, and the uses and benefits of the obtained data were solely programmatic—i.e., to improve the program, to support having PALS as a for-credit selective in the COM curriculum, and to achieve program visibility. All 10 students verbally consented; 10 and 8 students, respectively, provided useable pre- and post-program evaluation data. The evaluation data were collected by a student peer (H. Richmond) from the coordinating committee. Students recorded their names on the survey forms at the data collection stage to match their pre- and post-pilot program evaluation data. Once data collection was accomplished the student coordinator permanently removed individual student names from the evaluation survey forms. Then two COM faculty advisors (J. Boker, PhD & J. Shapiro, PhD), who were not on the coordinating committee and blinded to participating student identity, were recruited to perform both quantitative and qualitative data analyses aggregated across all responding students. The data provided to the latter faculty thus were anonymized because the survey responses were permanently de-linked from any personal identifiers. No copies of raw data were kept or viewed by student coordinators, faculty sponsors, or any other persons.

Interviews with one adult from each of the participating families were conducted at the end of the pilot program to provide a further program evaluation focus from the family perspective. A structured interview protocol was developed by the coordinating committee and presented the following five questions requiring a brief, verbal narrative response:

1. What were your expectations for the program, and were they met?
2. How did you feel that PALS benefited your child?
3. What were the weaknesses of the program, and what suggestions would you offer to improve it?
4. Would you recommend PALS to other families?
5. Do you want to continue in PALS next year? Would you want the same student or a different one?

Because English was not the language spoken in some homes, the coordinating committee recruited and trained interviewers/translators to administer the family interviews. The interviewers/translators were blinded to the identity of the families and recorded only brief, written summary notes about responses to the interview questions obtained from their interactions with adult family members. The summary interview notes were recorded anonymously; there were no audio recordings made. No personal family or health-related data were sought or obtained. The interviews lasted less than five minutes on average. Adult family members were approached by the interviewers/translators at a final program event in June 2003; were shown the interview questions and verbally told that all recorded data were anonymous summary notes of their responses; and were verbally informed about the purpose, risks (none),

and programmatic benefits (same as for the students). All in attendance at the final event verbally consented, and the interviews were conducted away from the group where confidentiality could be assured. Six family interviews produced useable data. The anonymous summary notes were then qualitatively analyzed across the aggregated six families by the same faculty advisor (J. Shapiro, PhD) who performed the qualitative analysis of student data.

Summary of Program Evaluation Results

Students pre-program (n=10). Most students (n=7) anticipated developing a relationship with the index child that they variously described as friendship, mentor, or helper; one student also expected to develop a relationship with parents and siblings. All expected to acquire new knowledge, skills, and attitudes. The largest number (8) expected learning about the effects of chronic illness on the child, and a smaller number expected to learn about coping mechanisms. A similar number (5) anticipated learning about family effects. One student mentioned learning about the interaction of culture and illness, while one each expected to learn more about pediatric illness and about the specialty of pediatrics. Students hoped to improve communication skills, both with children and generally. Attitudes were only mentioned by one student, who wanted to develop increased compassion. Anticipated difficulties focused on language (5) and cultural barriers (2), relational difficulties with either child (5) or parents (2), and structural and scheduling problems (2). Two students either expected no difficulties or weren't sure.

Students post-program (n=8). Students noted as benefits developing a relationship with the child (n=8) and family (4); a renewed enthusiasm for medicine (2); a deepening of their commitment to pediatrics (6); a better sense of perspective (3); and improved self-understanding, being of use, and "making a difference" (2). All reported learning about the effects of chronic illness on the child. The range and specificity of the knowledge and insights gained included deepening awareness and understanding of subjective experience, meaning, and coping mechanisms associated with pediatric chronic illness. Much was also learned about family effects and coping. While positive family coping predominated, a few also mentioned stresses and dysfunction in the family unit. Generally, students expanded their knowledge of difficulties facing families of low socioeconomic background. All reported improved communication skills, and all reported some change in attitude as a result of being in the program. The latter included understanding the importance of the family in health care and treating the whole family; appreciation for the uniqueness of each patient; valuing connection between doctor and patient; accepting limitations; forming a more empathic view of noncompliance; and increasing compassion and empathy.

The largest number of students cited structural and scheduling difficulties. Although several students had anticipated relational or communication difficulties with the child, only two reported actually encountering such problems, and only two mentioned such difficulties with parents. Two students noted language barriers, and none referred to cultural impediments. Two expressed concern about the lack of clinical relevance, while one referred to disappointed expectations. The summary statistics for the rating scale items, shown in the attached table, reflect these qualitative program evaluation results from the students' perspectives.

Families post-program (n=6). Parental expectations universally looked for friendship, mentoring for the target child. One parent each mentioned the program as a break from medical routine, and an opportunity for the student to learn about the child. All parental expectations were either met

or exceeded. All parents except one case felt the child benefited from the program. The majority of parents pointed to the beneficial effects of the relationship formed between the student and child, and four mentioned specific positive behavioral changes that they attributed to the student. One parent also mentioned as a benefit the help the family as a whole had received with problems. In general, parents did not identify weaknesses, although a few suggested it would be more convenient for the student to be able to drive the child places. All would recommend the program to another family, wanted to continue next year, and wanted to keep the same student.

PALS Pilot Program: Summary statistics obtained from medical students' ratings on pre- and post-program evaluation surveys¹.

Survey rating item content	Mean	S.D.
Past experience with children ²		
Pre	4.1	.9
Post	---	---
Past experience with chronically ill children ²		
Pre	2.7	1.5
Post	---	---
Ability to relate to patients		
Pre	4.4	.7
Post	3.6	.7
Ability to relate to chronically ill child		
Pre	4.4	.5
Post	3.8	.7
Clinical skills improvement		
Pre	3.3	1.0
Post	2.5	.8
Interest in pediatrics		
Pre	4.0	.8
Post	4.0	.8
Participation in program rewarding		
Pre	4.9	.4
Post	4.6	.8
Impact of chronically ill child on siblings		
Pre	4.8	.5
Post	4.9	.4
Important to include siblings in patient contact		
Pre	4.5	.8
Post	4.6	.7
Difficulty in establishing emotional connection		
Pre	2.5	1.1
Post	2.8	1.1
Impact on own view of chronic illness		
Pre	4.0	.8
Post	3.6	.9

¹p > .05 by Wilcoxon Signed Ranks Test comparing pre- and post-ratings on items; n=8 for all comparisons.

²Asked only on pre-program survey; n=10.

PALS PROJECT QUALITATIVE DATA: THEMES

STUDENT DATA PRE (N=10)

Summary: The largest number of students (N=7) anticipated developing a relationship with the target child that they variously described as friendship, mentor, or helper. Only one student also expected to develop a relationship with parents and siblings. All students noted hoped-for learning in terms of knowledge, skills, and attitudes. The largest number (8) expected learning about the effects of chronic, serious illness on the child, and a smaller number thought they would learn about coping mechanisms. A similar number (5) anticipated learning about family effects. One student mentioned learning more about the interaction effects of culture and illness, while one each expected to learn more medically about pediatric illness and about the specialty of pediatrics. In terms of skills, students hoped to improve communication skills, both with children and generally. Attitudes were only mentioned by 1 student, who wanted to develop increased compassion. Anticipated difficulties focused on language (5) and cultural barriers (2), relational difficulties with either child (5) or parents (2), and structural and scheduling problems (2). Two students either expected no difficulties or weren't sure.

Benefits/Learning

Develop a relationship/mentor/help child

Help someone get through difficult time

Have fun as mentor to child II

Establish a relationship/make friends IIII

Develop a relationship with family

Get to know family

Develop specific knowledge

Better understanding of issues related to chronically ill children

Better understanding of social/medical/familiar issues related to chronically ill children

Medical

Learn more about childhood illnesses

Effects on children/coping

Learn about how illness affects children and how they cope IIII II

Learn more about struggles of others

Effects on family/coping

Learn about impact of illness on families/siblings IIII I

Learn more about how families cope

Understanding of interaction of culture and illness

Learn about cultural aspects of illness

Learn more about pediatrics as a specialty

Deepen exposure to pediatrics

Develop specific skills

Interaction, communication skills with child

More interaction with children

General communication skills

More effective communication skills

Helping skills

How to apply medicine on an individual basis

Learn better how to help

Develop specific attitudes

Learn to be a more compassionate doctor

Difficulties

Structural/scheduling

Intermittent contact, being there every time

Setting up appointments II

Language/cultural barriers

Language barriers IIII I

Cultural barriers II

Relational/communication difficulties with child

Trouble connecting with child II

Getting child to open up III

Relational/communication difficulties with family

Confusion/miscommunication with family

Trouble interacting with child's family

Expect no difficulties/not sure

Expects no difficulties

Not sure

STUDENT DATA POST (N=8)

Summary – Benefits: Students noted as benefits developing a relationship with the child (N=10) and family (4); a renewed enthusiasm for medicine (2) and a deepening of their commitment to pediatrics (6); a better sense of perspective (3); improved self-understanding, being of use and “making a difference (2);” and simply “having fun” (2).

Benefits

Develop relationship with child

Developed relationship with child; becoming closer to pal; bond with someone going through difficult experience IIII II; became confidant about school problems, other children

Developed relationship with family

Developed relationship with family III

Felt welcomed by family

Renewed commitment to medicine

Renewed enthusiasm for being a physician II

Deepening of professional commitment

Learned these are the kinds of kids Pal wants to spend time with in future practice II

Learned about chronic pediatric care III

Will be better able to help future patients of low ses background

Learned about Child Life program

Created perspective

Put studying/school into perspective II

Gave perspective about what truly matters in life

Increased self-understanding

Developed perspective on self

Making a difference (particularly in relation to child/family experience of medical profession)

Made a positive difference; gave a positive experience with medical profession

Program provided aid for some, respite for others, still others fun, friend, source of support

Enjoyable and valuable

Had fun

Experience was unique, and satisfying emotionally and intellectually

Summary – Learning: All participants reported learning about the effects of chronic illness on the child. The range and specificity of the knowledge and insights gained were impressive. These included deepening awareness and understanding of subjective experience, meaning, and coping mechanisms associated with pediatric chronic illness. A great deal was also learned about family effects and coping, although initially this had not been a goal for many students. While much of what students reported had to do with positive family coping, a few also mentioned stresses and dysfunction in the family unit. On a more general level, students also expanded their knowledge of the difficulties facing families of a low socioeconomic background. Eight of the 10 students also reported improvements in their communication skills, although this area of development was only mentioned by one student in the pre-program assessment. Similarly, while only one student anticipated attitudinal change, in fact all students reported some change in attitude as a result of participating in the program. These changes included understanding the importance of the family unit in health care and treating the whole family; appreciation for the uniqueness of each patient; valuing connection between doctor and patient; accepting limitations; forming a more empathic view of noncompliance; and increasing compassion and empathy.

Learning

Knowledge

Learned about effects of chronic illness on child

Saw effects of chronic illness on daily life of child III
Learned how chronic illness changes people, their interactions with others, and their perspectives
Learned about coping with a chronic illness on a daily basis
Learned about strength of child
Learned how child overcomes daily obstacles to lead more “normal” life II
Saw what it was like to be lonely and afraid
Learned what it means to live with chronic illness
What hospital can represent to chronically ill child
 Second home
 Staff like family
 Claiming ownership of floor (understanding of how system works)
Learned about meaning of “physical difference”

Learned about effects of chronic illness on families

Learned about healing power of laughter and hugs
Learned how love of mother/family can help child deal with illness and despair
Learn about effects of chronic illness on other children, and on family II
Learned that families can adapt to chronic illness and not be consumed – families of chronically ill are “normal” people
Learn about interactions of sibs and target child (protection, providing assistance)
Saw how chronic illness can bring family closer
Learned about flaws and imperfections within families

Learned about difficulties of low ses (generally and health-specific)

Learned more about difficulties of kids/people from low ses backgrounds II; learned a lot about living conditions of people from low ses
Learned about difficulties in accessing healthcare for kids from low ses
Learned about dynamic of community support toward family within apartment complex

Skills

Developed skills in communication
Learned to set boundaries
Learned about how to interact/communicate with children II
Learned how to relate to parents and children as a unit and as individuals
Learned about how to interact/communicate with children II
Learned to express views on problem management diplomatically to parent

Attitudes

Learned how to relate to parents and children as a unit and as individuals
Learned to keep a sense of perspective
Learned to enjoy experience for what it was
Learned greater empathy and compassion II
Learned importance of connecting with child before trying to be a part of their lives
Learned importance of showing concern for family
Importance of treating entire family
Learned every child is unique
Making a meaningful connection with child harder than it seems

Developed insights into noncompliance

Summary – Difficulties: The largest number of students complained of structural and scheduling difficulties. Although several students had anticipated relational or communication difficulties with the child, only two reported actually encountering such problems, and only two mentioned such difficulties with parents. Only 2 students noted language barriers, and none referred to cultural impediments. Two students expressed concern about the lack of clinical relevance, while one referred to disappointed expectations.

Difficulties

Structural difficulties

Difficult to go anywhere or take child places II

Hard to coordinate meeting times II

Hard to find as much time as student wanted to spend with pal

Difficult to get messages to pal because of large number of people living in household

Hard to make initial contact

Hard to terminate visit – feelings of guilt (limit-setting)

Relational/communication difficulties with child

Difficulty getting pal to open up; getting to know child

“Reading” pal – when wanted student to be around and when wanted student to leave

Relational/communication difficulties with family

Disagreements with mother about how to approach problem

Communication with parents

Moved without notifying Pal; would not return phone calls; failed to show up at events; parents seemed unsupportive of program

Language barriers

Language barrier was problem II

Problem with role/lack of clinical relevance

More of a babysitter – not doing anything clinically relevant

Didn't get to observe child in healthcare setting or interact with the child's physician

Disappointed expectations

Expectations (of child?; of student?; of family?) are hard to meet

FAMILY DATA (N=6)

Summary: What were your expectations and were they met?

Expectations: Parental expectations looked for friendship, mentoring for the target child (N=6). One parent each mentioned the program as a break from medical routine, and an opportunity for the student to learn about the child. All parental expectations were either met, or in one case, exceeded. Except in one case, all parents felt the child benefited from

the program. The majority of parents pointed to the beneficial effects of the relationship formed between the student and child, and 4 mentioned specific positive behavioral changes that they attributed to the Pal. One parent also mentioned as a benefit the help the family as a whole had received with problems. In general, parents did not identify weaknesses, although a few suggested it would be more convenient for the Pal to be able to drive the child places. All would recommend the program to another family, wanted to continue next year, and wanted to keep the same Pal.

Friendship/mentoring

Someone to begin friendship with child llll; someone to help mentor child and help him understand his problems ll;

Remove from medical routine

Take kids out of hospital routine

Student learning about child

Pal would learn something of their daily life

Expectations met llll l

Exceeded expectations l

Child put up barriers

How did PALS benefit child?

Benefited from activities

Enjoyed activities

Benefited from relationship (generic)

Benefited from friendship

Pal supportive of child

Behavioral improvements

Child became less shy

Improved child behavior

Child doesn't let people get too close, so his behavior didn't change much

Motivated child to continue treatment

Made child more likely to speak with relatives

Benefits to family

Helped with family problems

Children (all, not just target) enjoy the attention from Pal

What were weaknesses of program, and suggestion for improvement?

None llll l

Limitations in location

Wish child could go places (outside home) with Pal

Would like Pal to come to home

Pals can't drive kids anywhere

Would want Pal to be able to see child without parent always present

Would you recommend program to other families?

Would recommend llll ll

Do you want to continue program next year?

Continue llll ll

Would you like to keep same Pal or get a new one?

Same Pal llll ll