A group of people are kayaking on the ocean. The kayakers are wearing life jackets and are positioned in a line across the water. The sky is overcast and grey, and the water is choppy with whitecaps. The overall scene is somewhat desaturated and has a soft, hazy quality.

The effect of therapeutic adventure on the psychosocial adjustment and health-related quality of life of adolescents with cancer

A mixed methods research

Linda Paquette, Ph.D.

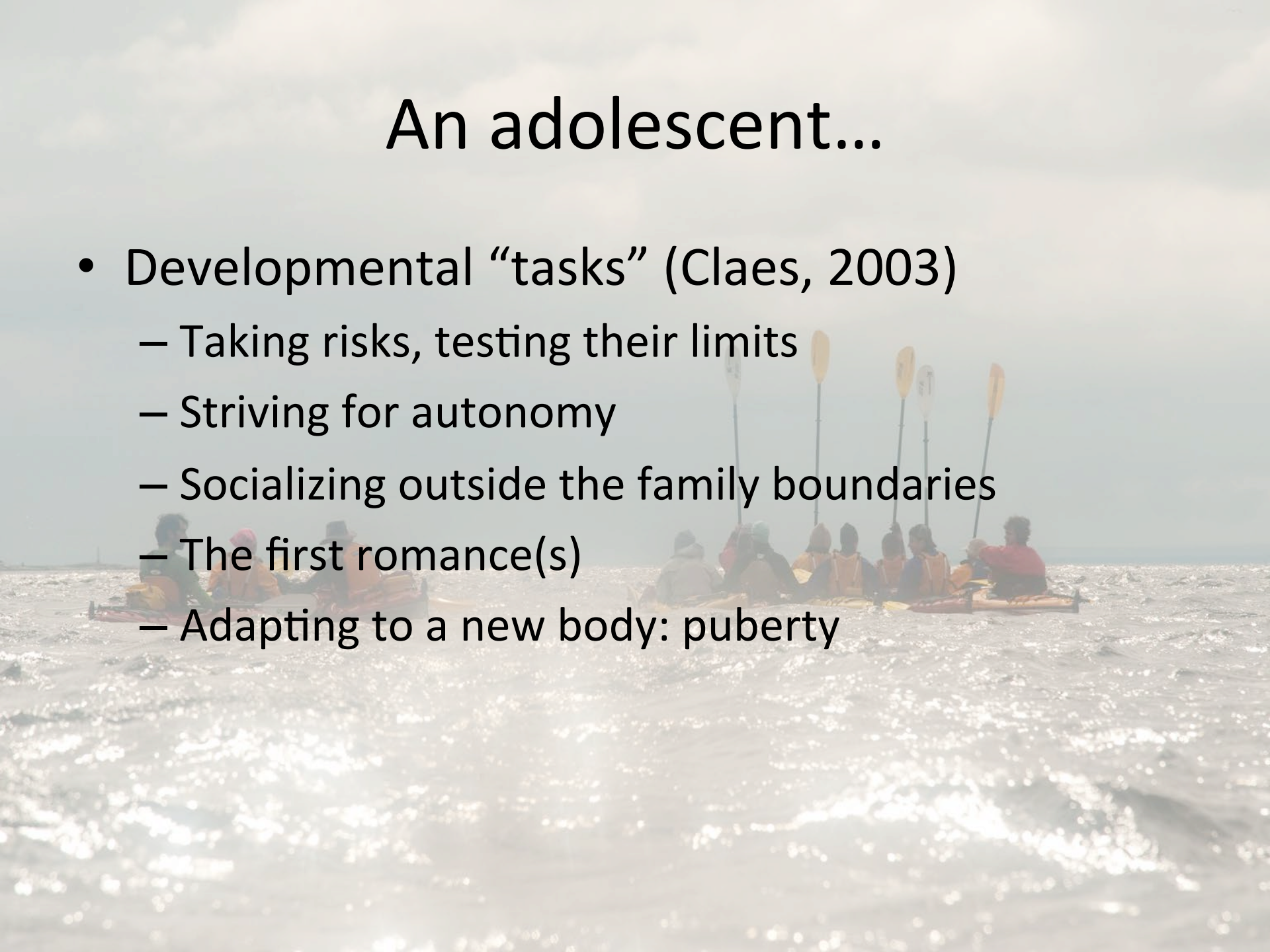
Université du Québec à Chicoutimi

INTRODUCTION



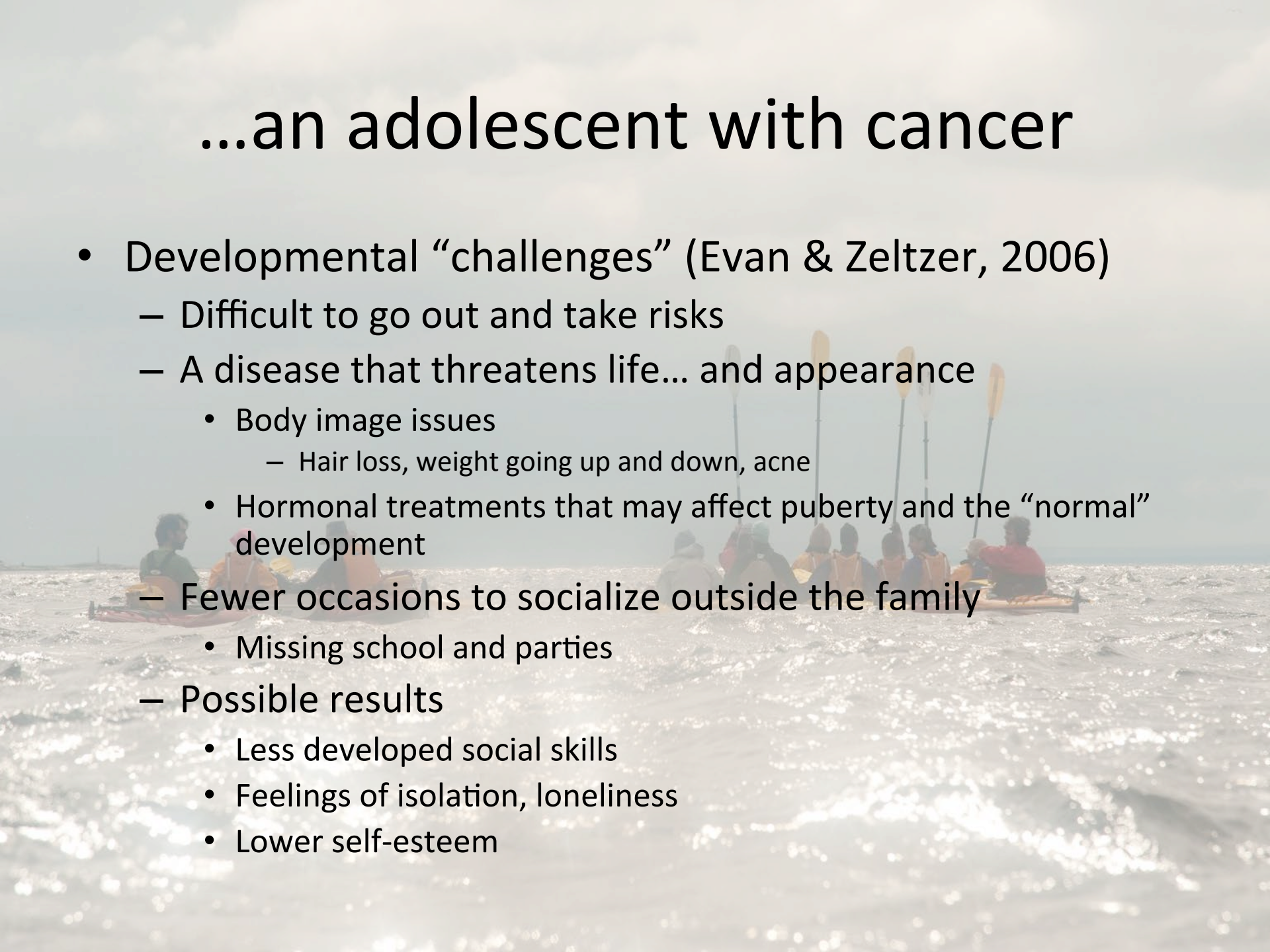
An adolescent...

- Developmental “tasks” (Claes, 2003)
 - Taking risks, testing their limits
 - Striving for autonomy
 - Socializing outside the family boundaries
 - The first romance(s)
 - Adapting to a new body: puberty



...an adolescent with cancer

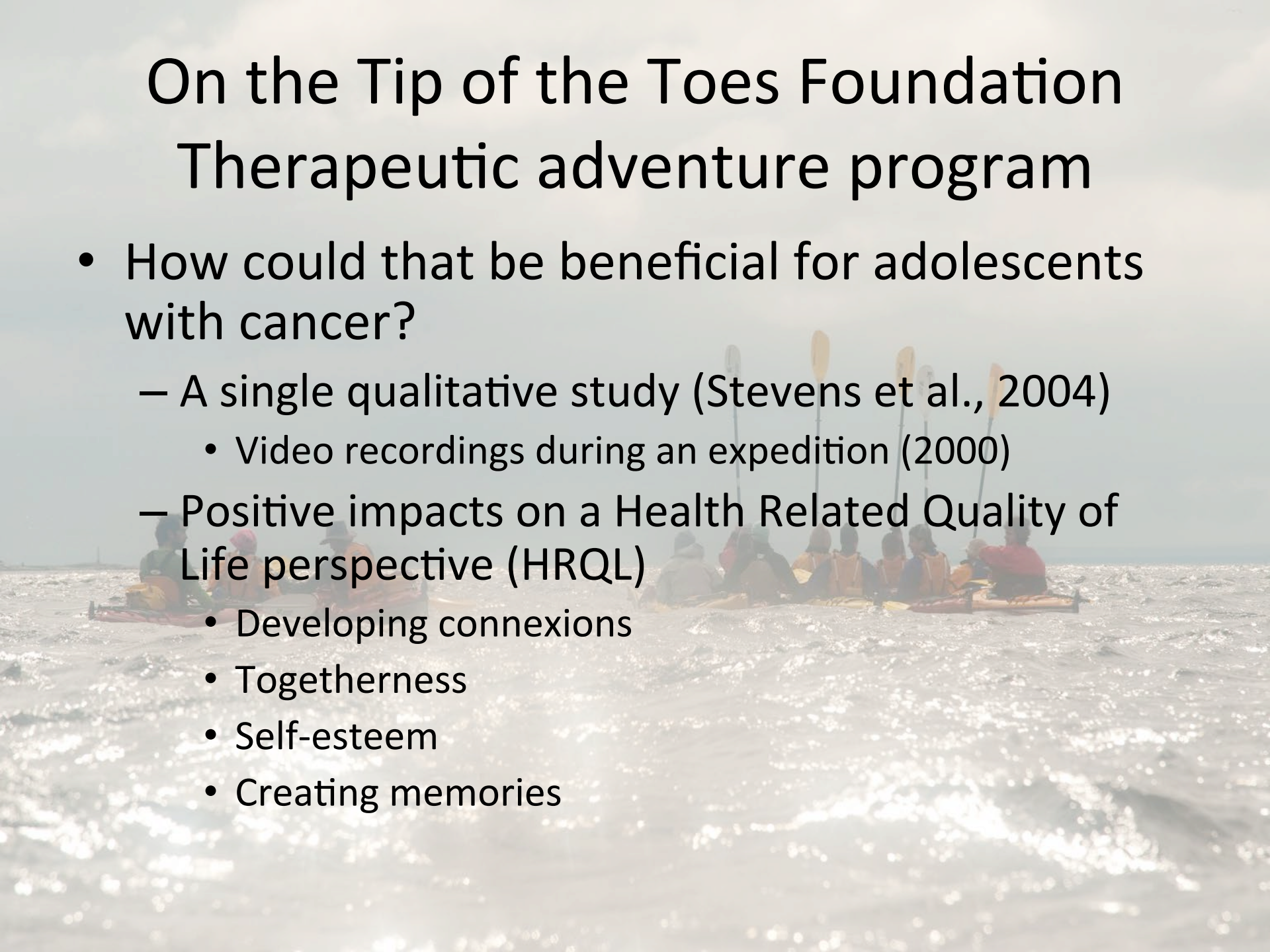
- Developmental “challenges” (Evan & Zeltzer, 2006)
 - Difficult to go out and take risks
 - A disease that threatens life... and appearance
 - Body image issues
 - Hair loss, weight going up and down, acne
 - Hormonal treatments that may affect puberty and the “normal” development
 - Fewer occasions to socialize outside the family
 - Missing school and parties
 - Possible results
 - Less developed social skills
 - Feelings of isolation, loneliness
 - Lower self-esteem



On the Tip of the Toes Foundation

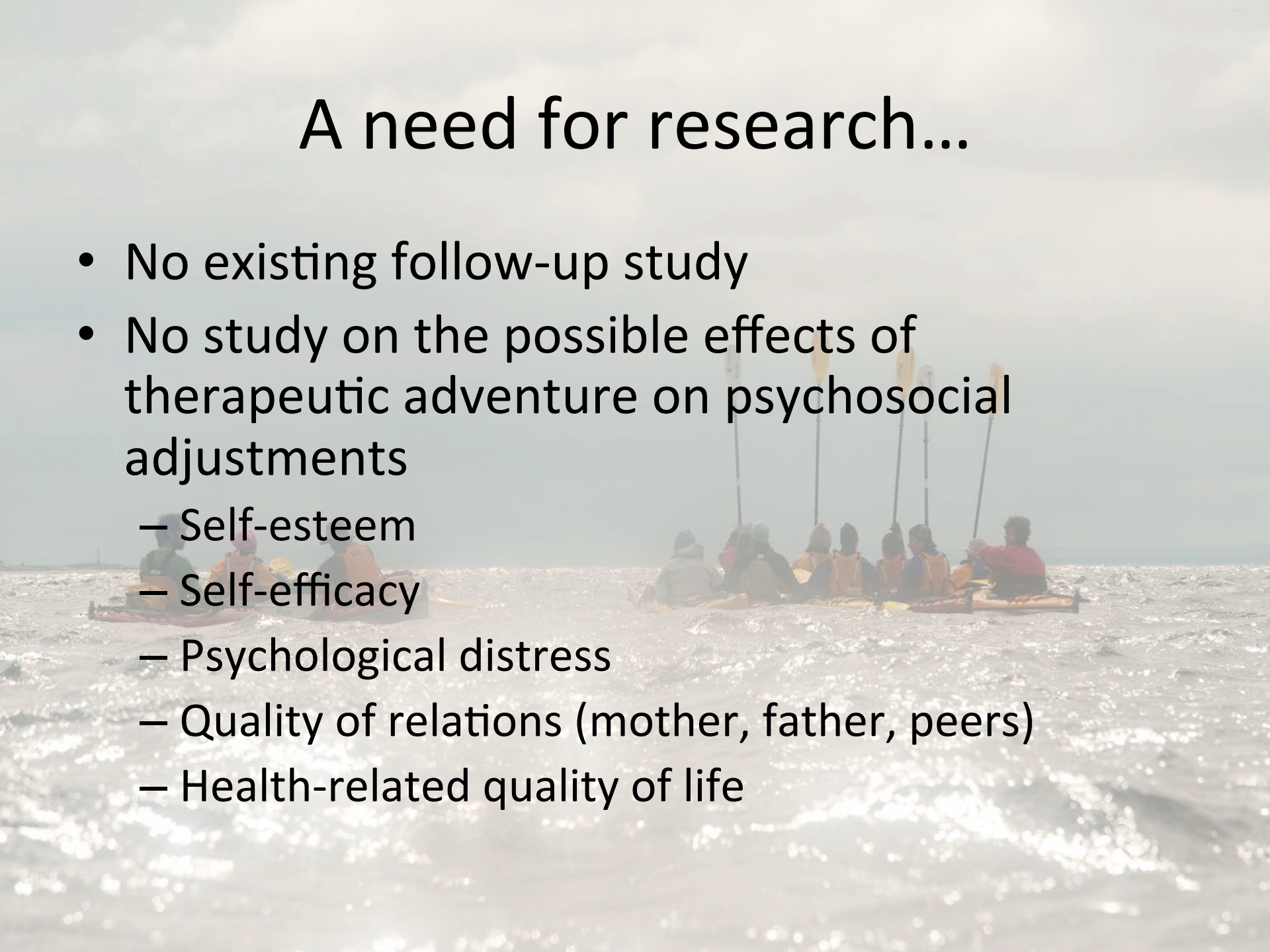
Therapeutic adventure program

- How could that be beneficial for adolescents with cancer?
 - A single qualitative study (Stevens et al., 2004)
 - Video recordings during an expedition (2000)
 - Positive impacts on a Health Related Quality of Life perspective (HRQL)
 - Developing connexions
 - Togetherness
 - Self-esteem
 - Creating memories



A need for research...

- No existing follow-up study
- No study on the possible effects of therapeutic adventure on psychosocial adjustments
 - Self-esteem
 - Self-efficacy
 - Psychological distress
 - Quality of relations (mother, father, peers)
 - Health-related quality of life



Research question

- Does the On the Tip of the Toes Foundation therapeutic adventure program affect/enhance the psychosocial adjustment and health-related quality of life of adolescents with cancer?

METHOD

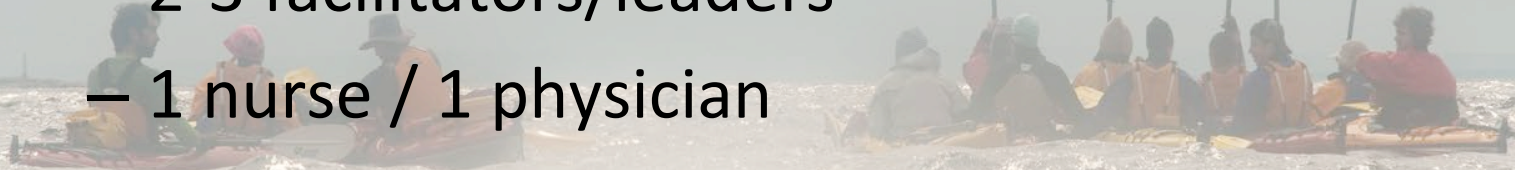


Participants

- Inclusion criterias
 - On the Tip of the Toes Foundation expedition participants
 - Ages 14 to 20
 - Cancer diagnosis with past or present treatment (ideally finished within the last year)
 - Being able to walk and/or kayak 4-5 hours a day
 - No personality or behavioural disorder
 - Having a functional limitation is not an exclusion criteria
 - Being the parent of a participant (mother and father)

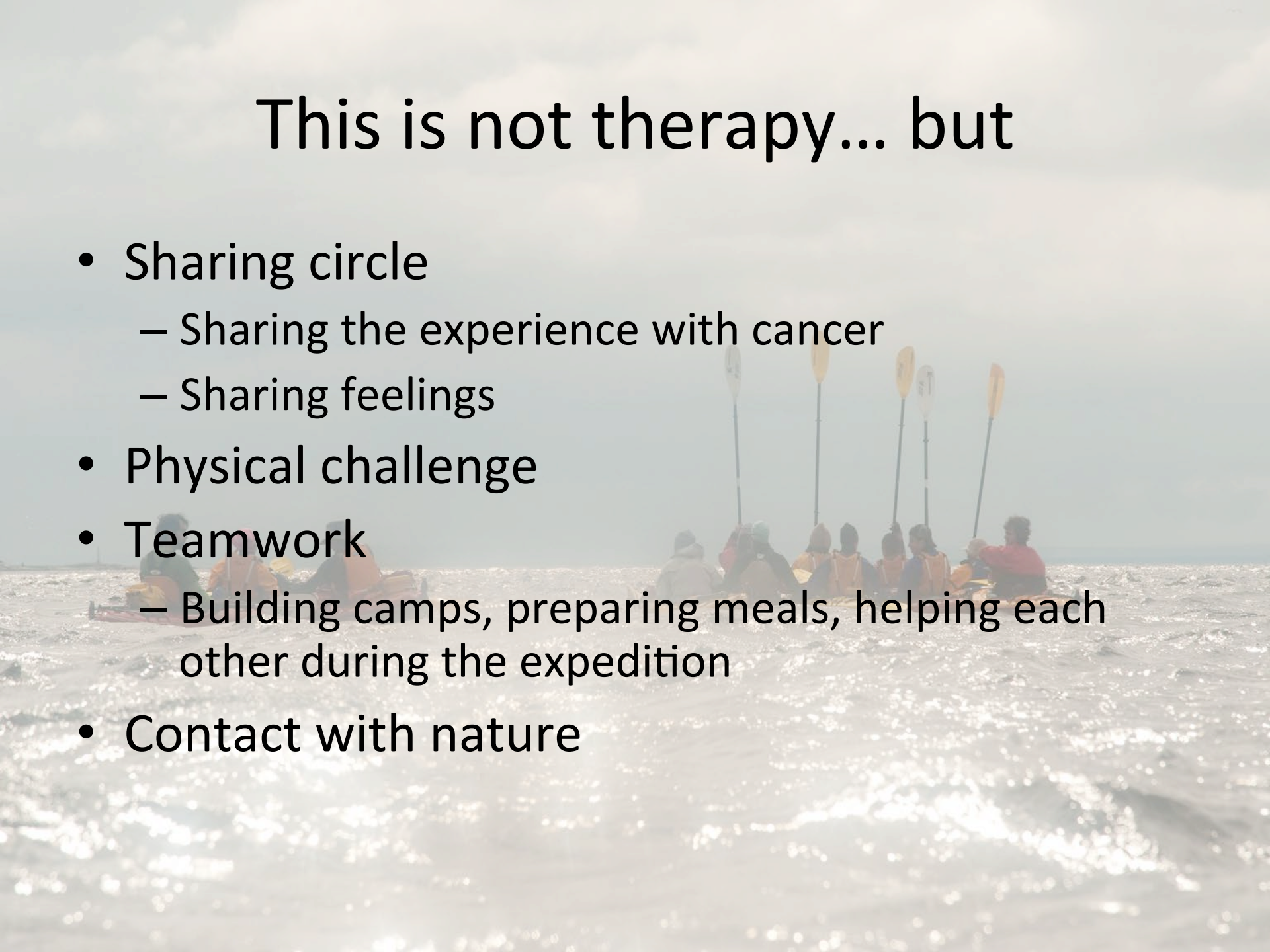
The expeditions

- 10 days
- Summer or winter context (2 X year)
- The Foundation Team
 - 2-3 facilitators/leaders
 - 1 nurse / 1 physician
 - 1 psychosocial facilitator
 - 1 blogger



This is not therapy... but

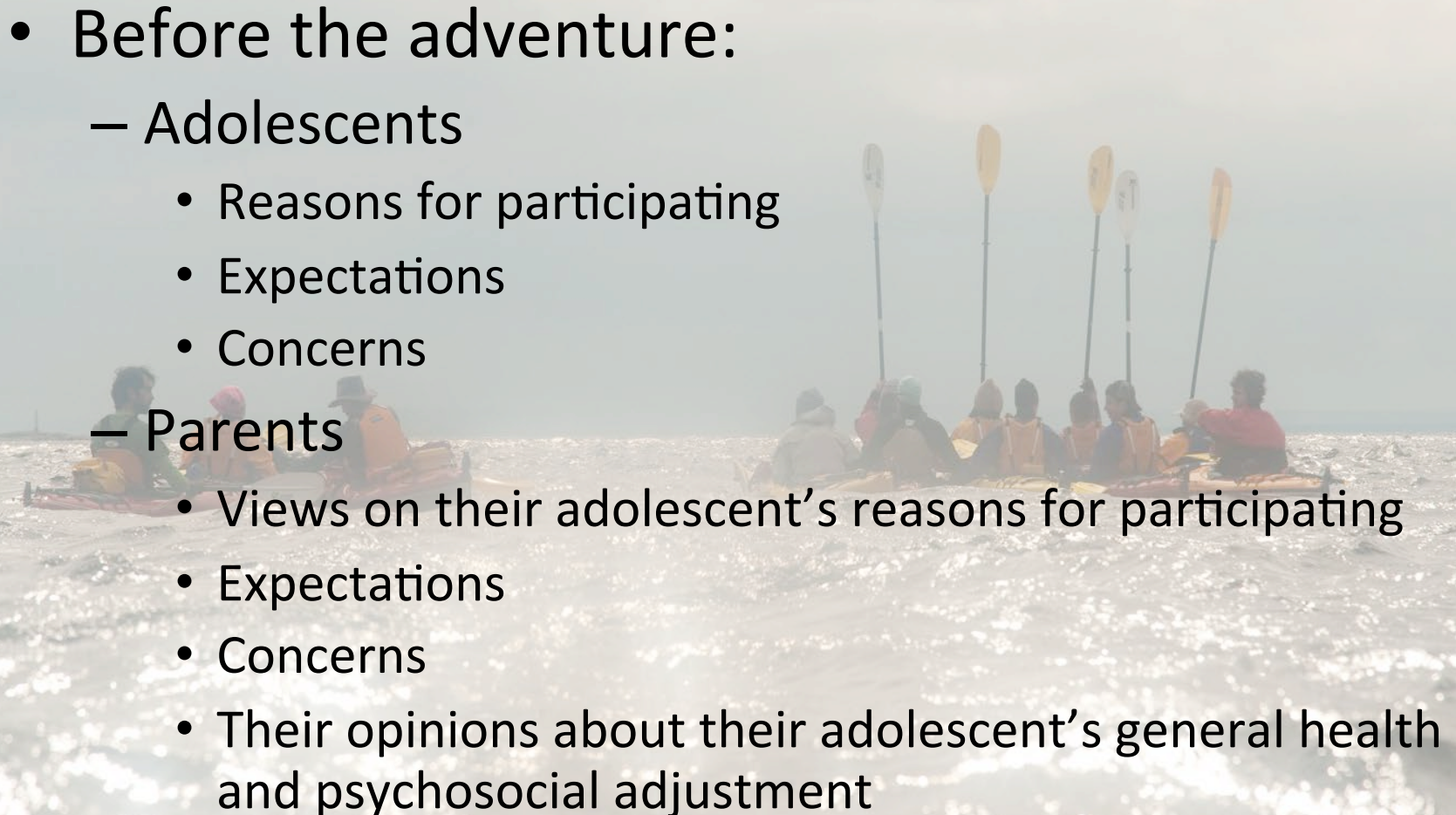
- Sharing circle
 - Sharing the experience with cancer
 - Sharing feelings
- Physical challenge
- Teamwork
 - Building camps, preparing meals, helping each other during the expedition
- Contact with nature



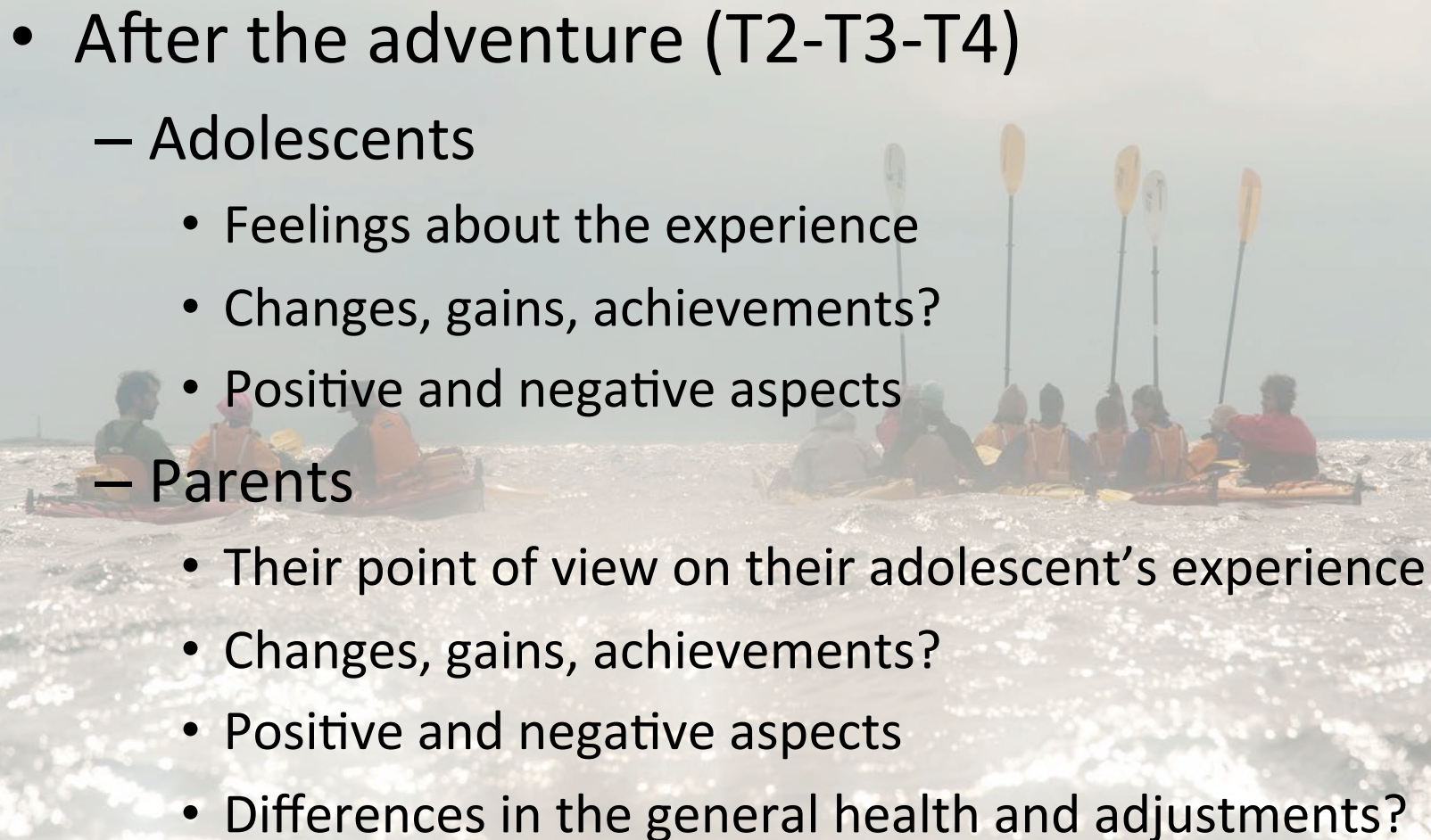
Research design

- Mixed methods pre-experimental design
 - T1 = 2 weeks before the expedition
 - T2 = 2 weeks after the expedition
 - T3 = 4 months after the expedition
 - T4 = 1 year after the expedition
- Qualitative and quantitative interviews
 - 15-45 minute interviews (qualitative)
 - Mother, father, adolescent
 - 45-minute quantitative self-reporting questionnaire
 - Adolescents only except for Quality of life (Kidscreen-52)

Qualitative interviews

- Before the adventure:
 - Adolescents
 - Reasons for participating
 - Expectations
 - Concerns
 - Parents
 - Views on their adolescent's reasons for participating
 - Expectations
 - Concerns
 - Their opinions about their adolescent's general health and psychosocial adjustment
- 
- A group of people are kayaking on the ocean. The kayakers are wearing life jackets and holding paddles. The water is choppy with small waves. The sky is overcast and grey.

Qualitative interviews

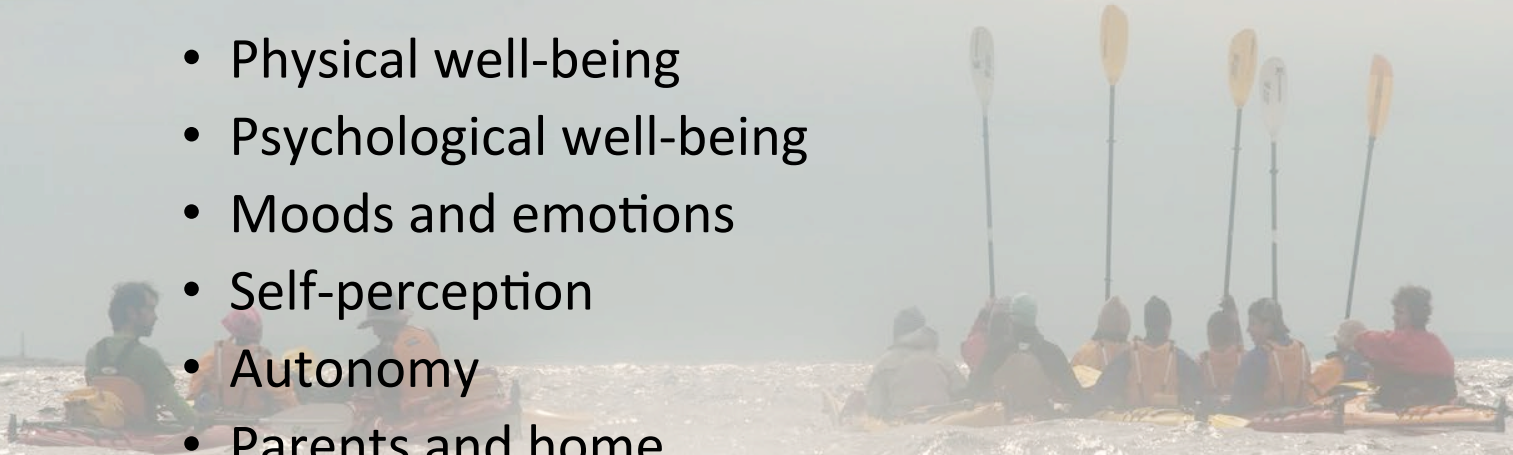
- After the adventure (T2-T3-T4)
 - Adolescents
 - Feelings about the experience
 - Changes, gains, achievements?
 - Positive and negative aspects
 - Parents
 - Their point of view on their adolescent's experience
 - Changes, gains, achievements?
 - Positive and negative aspects
 - Differences in the general health and adjustments?
- 
- A group of people are kayaking on the ocean. The kayakers are wearing orange life jackets and are holding paddles. The water is choppy with whitecaps, and the sky is overcast. The kayakers are arranged in a line, moving away from the viewer.

Quantitative interview

- Same measures T1-T2-T3-T4
 - Self-esteem
 - Self-esteem questionnaire (Rosenberg, 1965) 10 items
 - Psychological distress (short PSI, Ilfeld, 1976)
 - Inventory of parent and peer attachment (Greenberg & Armsden) 75 items
 - Three dimensions:
 - Mother
 - Father
 - Peers
 - Three sub-dimensions
 - Trust
 - Communication
 - Alienation

Quantitative interview

- Health-related Quality of life = Kidscreen 52 items
- Parent et child version (adolescent, mother, father)
- 10 scales
 - Physical well-being
 - Psychological well-being
 - Moods and emotions
 - Self-perception
 - Autonomy
 - Parents and home
 - Financial resources
 - Peers and social support
 - Bullying
 - School environment (removed)



Analyses

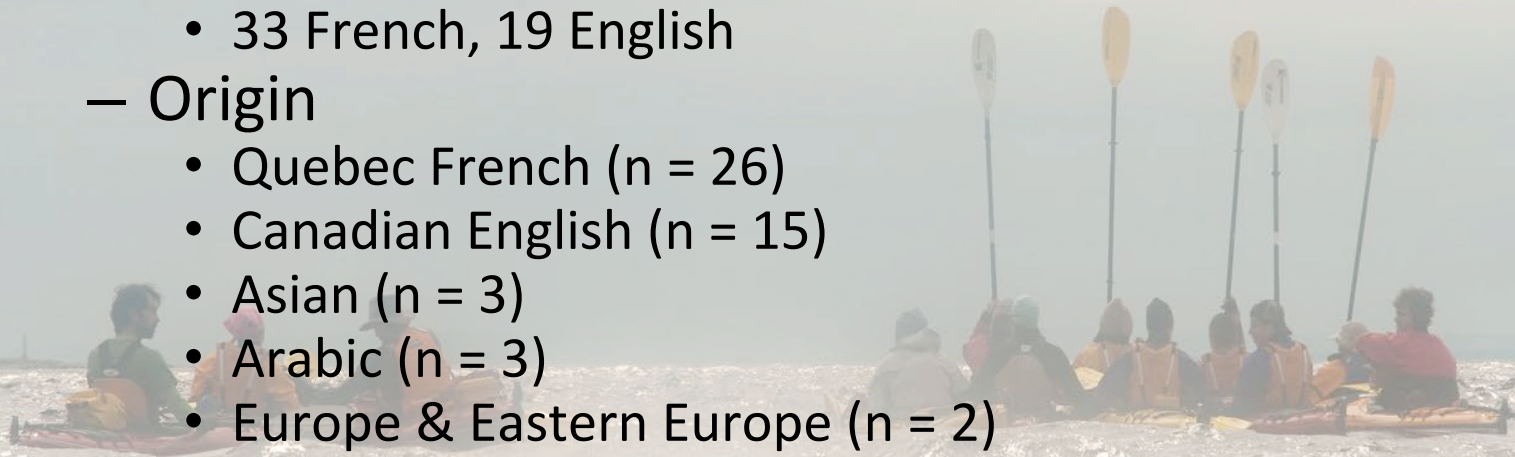
- Qualitative content analysis (Saldana, 2013)
 - Verbatim transcription
 - First cycle : Nvivo codification (descriptive, evaluative and process coding)
 - Second cycle : Condensation : principal themes
- Quantitative statistical analysis
 - Descriptive statistics
 - Repeated measures covariance analysis (ANCOVA)
 - Control variables : Gender, language, cohort
 - Covariate : social desirability

Results



Participants

- Adolescents N = 52
 - Gender
 - 30 boys, 22 girls
 - Interview language
 - 33 French, 19 English
 - Origin
 - Quebec French (n = 26)
 - Canadian English (n = 15)
 - Asian (n = 3)
 - Arabic (n = 3)
 - Europe & Eastern Europe (n = 2)
 - Native American (n = 1)
 - Age : 14 - 20 years (m = 16.56 years)
- Parents N = 100
 - 51 mothers et 49 fathers



Participation rate by cohort

Cohorts	Expedition participants (n)	Research participants (n)	Research participation rate (%)
July 2011 Georgian Bay, Ontario Sea kayak	9	8	88,9 %
March 2012 Baie James, Quebec Snowmobile	11	9	81,8 %
August 2012 Assiniboine Park, Alberta Hiking	10	7	70,0 %
March 2013 Sentier des caps, Quebec Snowshoe	7	5	71,4 %
August 2013 Missinaibi River, Ontario Canoe	10	7	70,0 %
March 2014 Algonquin Park, Ontario Dogsledding	12	9	75,0 %
Juillet 2014 Voie Maritime, Quebec/East Sailing	11	7	63,6 %
Total	70	52	74,3 %

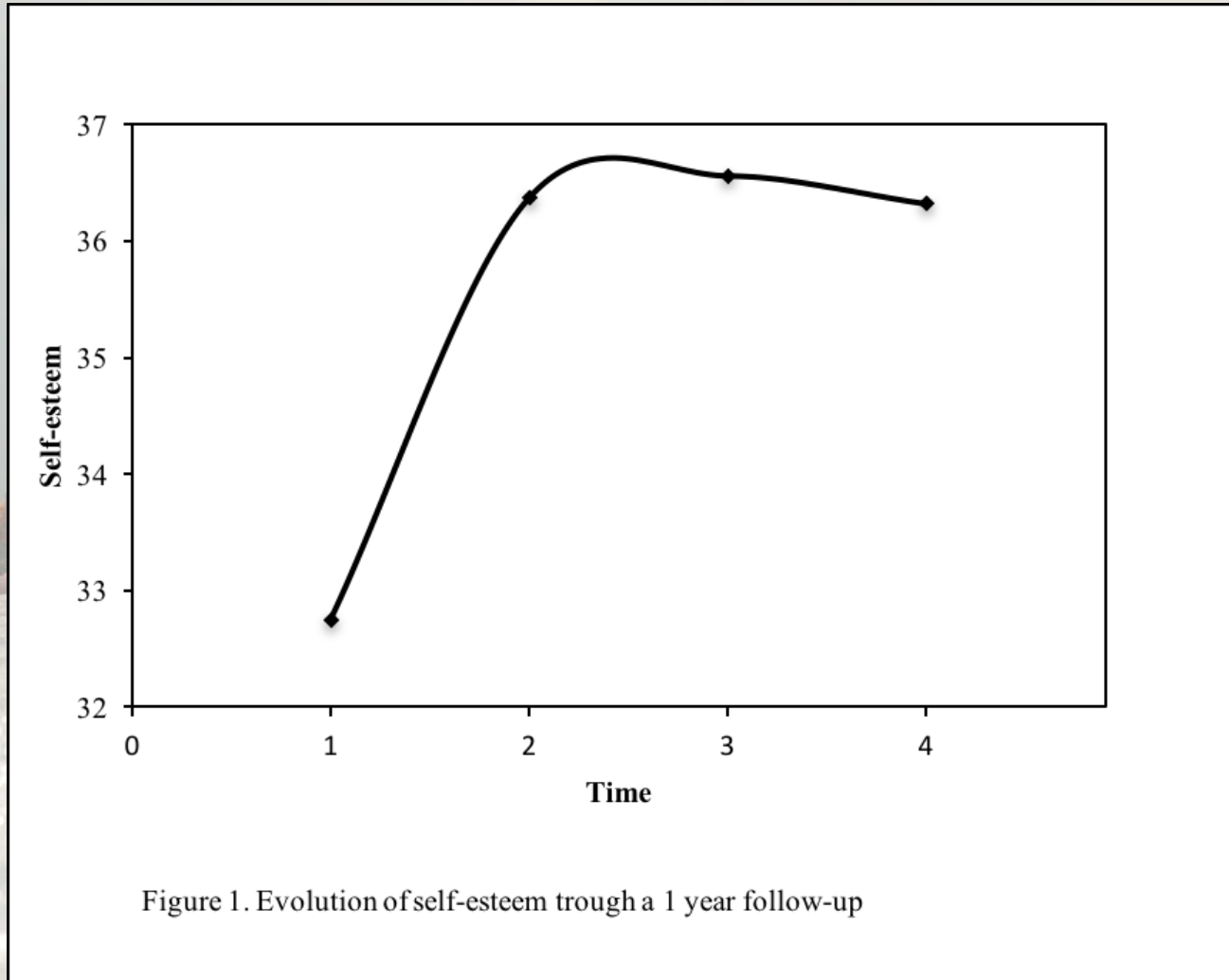
Preliminary analysis

- Attrition rate (26,9%)
 - Similar to what is found in pediatric studies (32% Karlson & Rapoff, 2009)
 - Family income significantly lower if attrition (effect 13%)
 - Self-esteem (T1), significantly lower if attrition (effect 13%)
 - No other difference if attrition
- Cohort effect
 - Small differences in mean age
 - Small differences in mother's mean age
 - No differences in any psychosocial variable
 - Not included in ANCOVAs

Quantitative results

Psychosocial adjustment	T1	T2	T3	T4	* $p < 0.05$
	N = 52	N = 50	N = 43	N = 38	Effect %
Self-Esteem	32,75	36,37	36,56	36,32	*37%
Psychological distress	23,65	19,67	21,38	20,63	*32%

Self-Esteem



Psychological distress

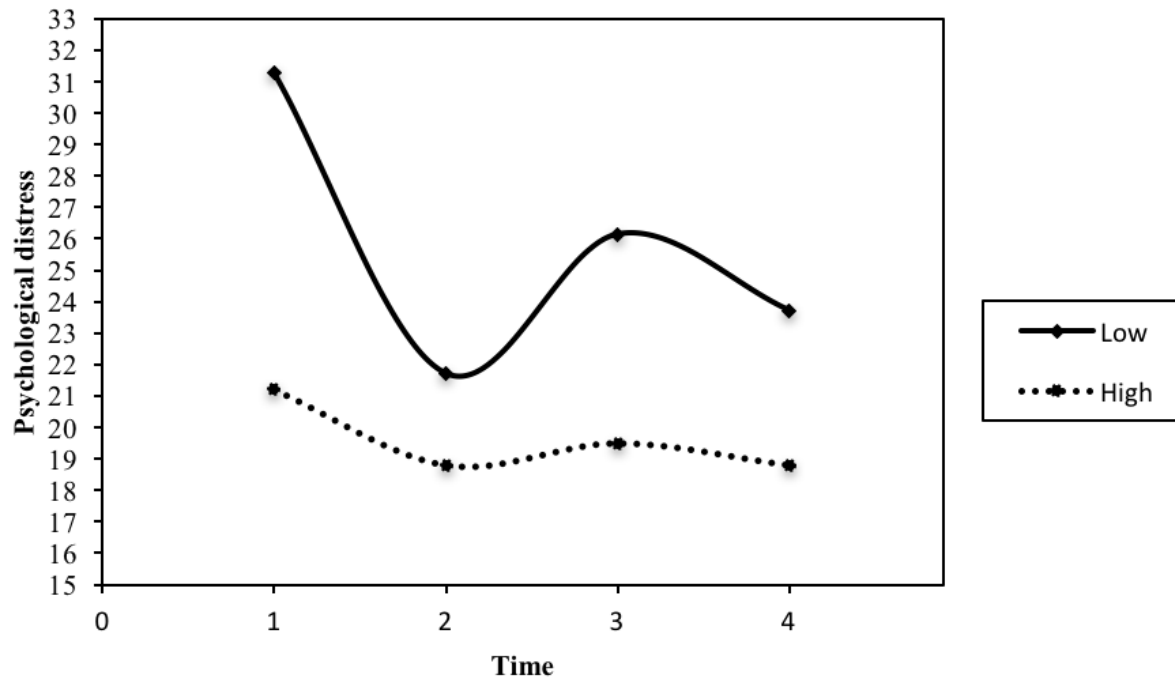
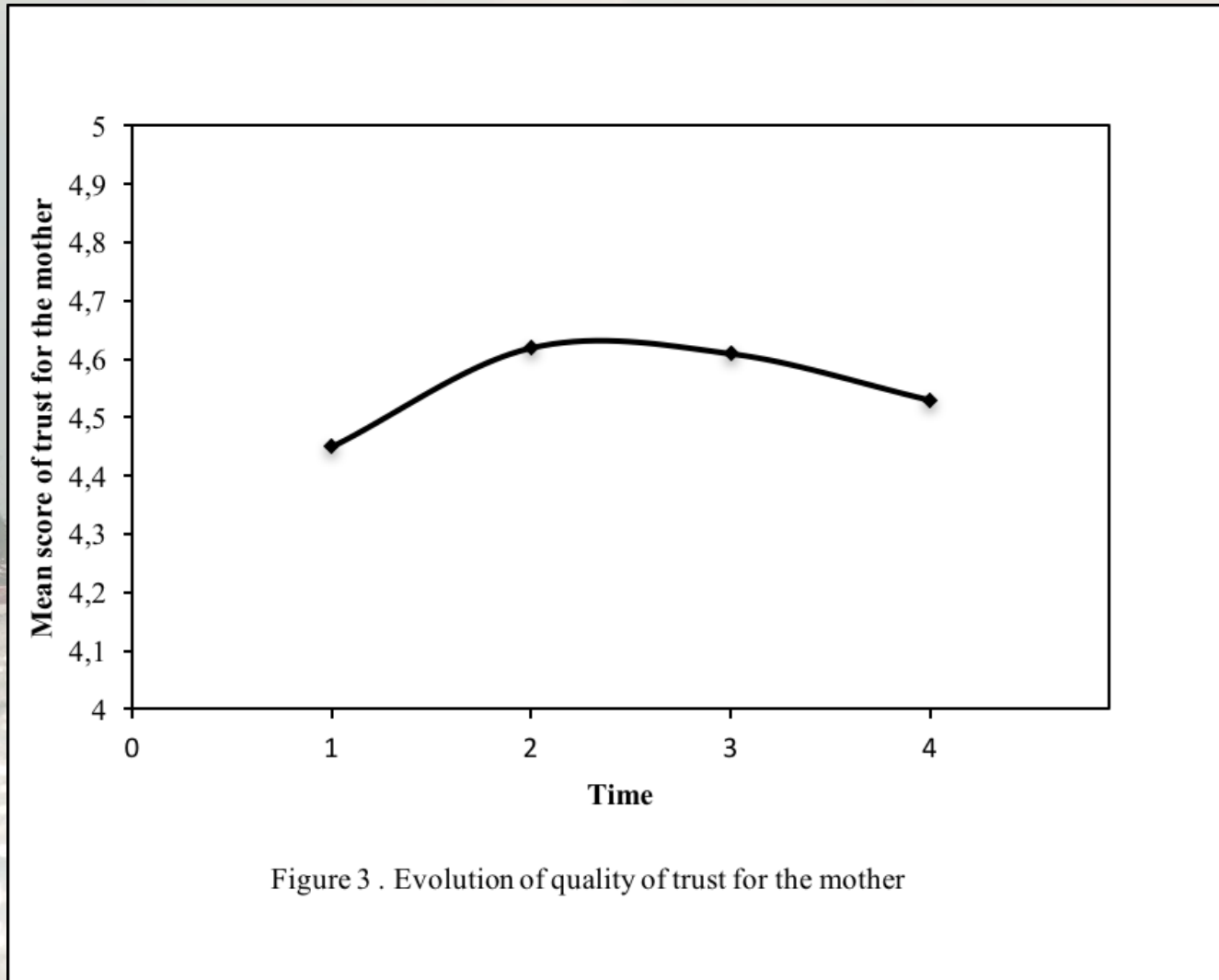


Figure 2 . Evolution of psychological distress for high or low social derirability

Quantitative results

Quality of relationships	T1	T2	T3	T4	* $p < 0.05$
	N = 52	N = 50	N = 43	N = 38	Effect %
Mother : Trust	4,45	4,62	4,61	4,53	*28%
Mother : communication	4,06	4,17	4,20	4,10	n.s.
Mother : alienation	4,23	4,43	4,40	4,39	n.s.
Father : Trust	4,35	4,52	4,53	4,39	*25%
Father : communication	4,70	4,96	4,97	4,83	n.s.
Father : alienation	4,10	4,35	4,31	4,20	n.s.
Peers : Trust	4,26	4,40	4,34	4,34	n.s.
Peers : communication	3,77	3,96	3,94	3,91	*36%
Peers : alienation	3,69	4,02	4,07	4,03	*30%

Relationship with the mother : Trust



Relationship with the father : Trust

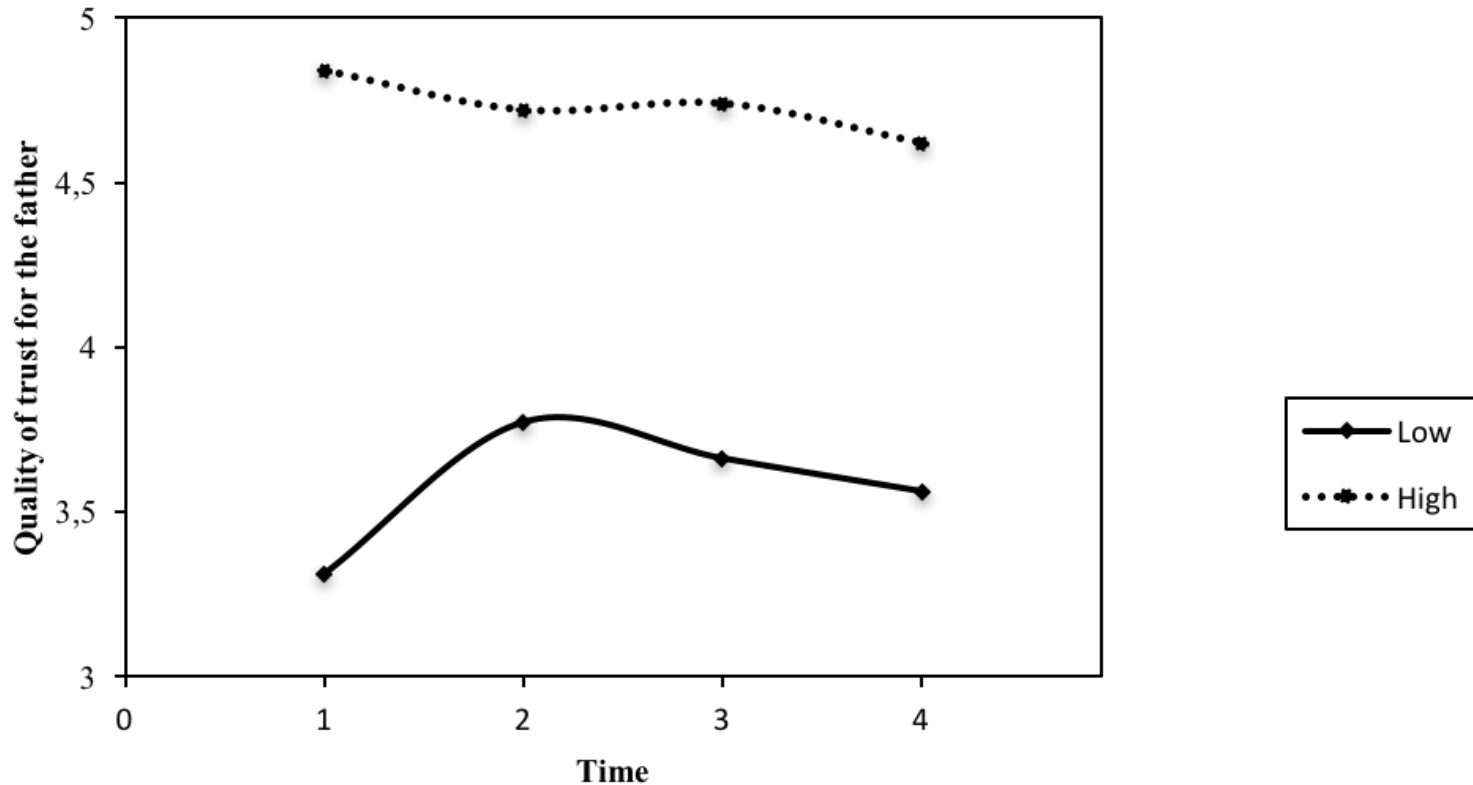


Figure 4. Evolution of the quality of trust for the father for high and low social desirability

Relationship with peers : communication

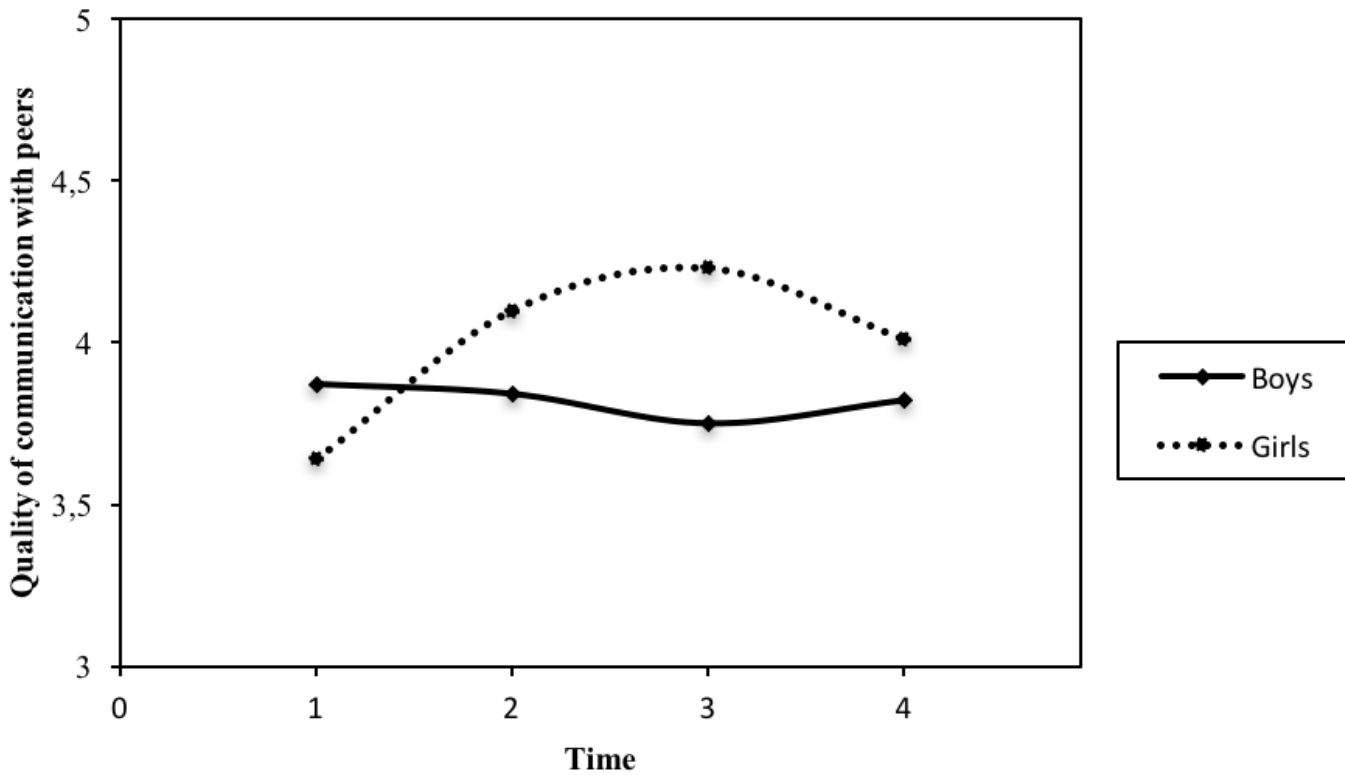
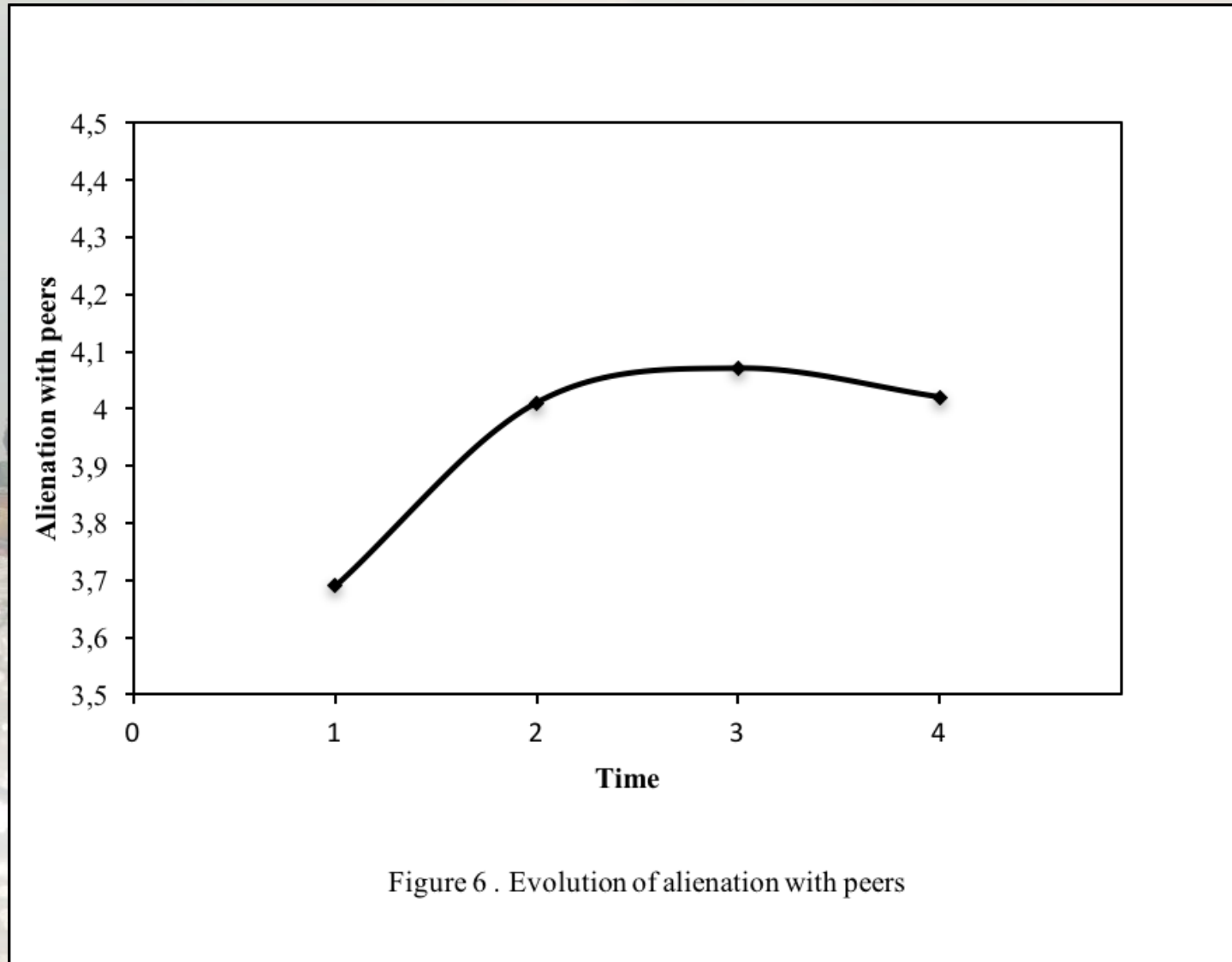


Figure 5. Evolution of quality of communication with peers for boys and girls

Relationship with peers : alienation



Quantitative results

Quality of life (adolescent)	T1	T2	T3	T4	* $p < 0.05$
	N = 44	N = 42	N = 35	N = 30	Effect
Physical well-being	17,55	18,34	18,49	18,59	n.s.
Psychological well-being	24,34	25,83	25,94	25,44	n.s.
Moods and emotions	29,02	32,68	31,46	32,18	n.s.
Self-perception	19,93	22,02	21,66	21,74	n.s.
Autonomy	18,20	20,37	20,00	19,71	n.s.
Parents and home	25,41	26,32	26,83	25,74	n.s.
Financial resources	11,93	13,15	13,26	13,15	n.s.
Peers and social support	20,11	21,60	22,31	21,91	n.s.
Bullying	14,3	14,76	14,77	14,80	*17%

Quality of life : bullying

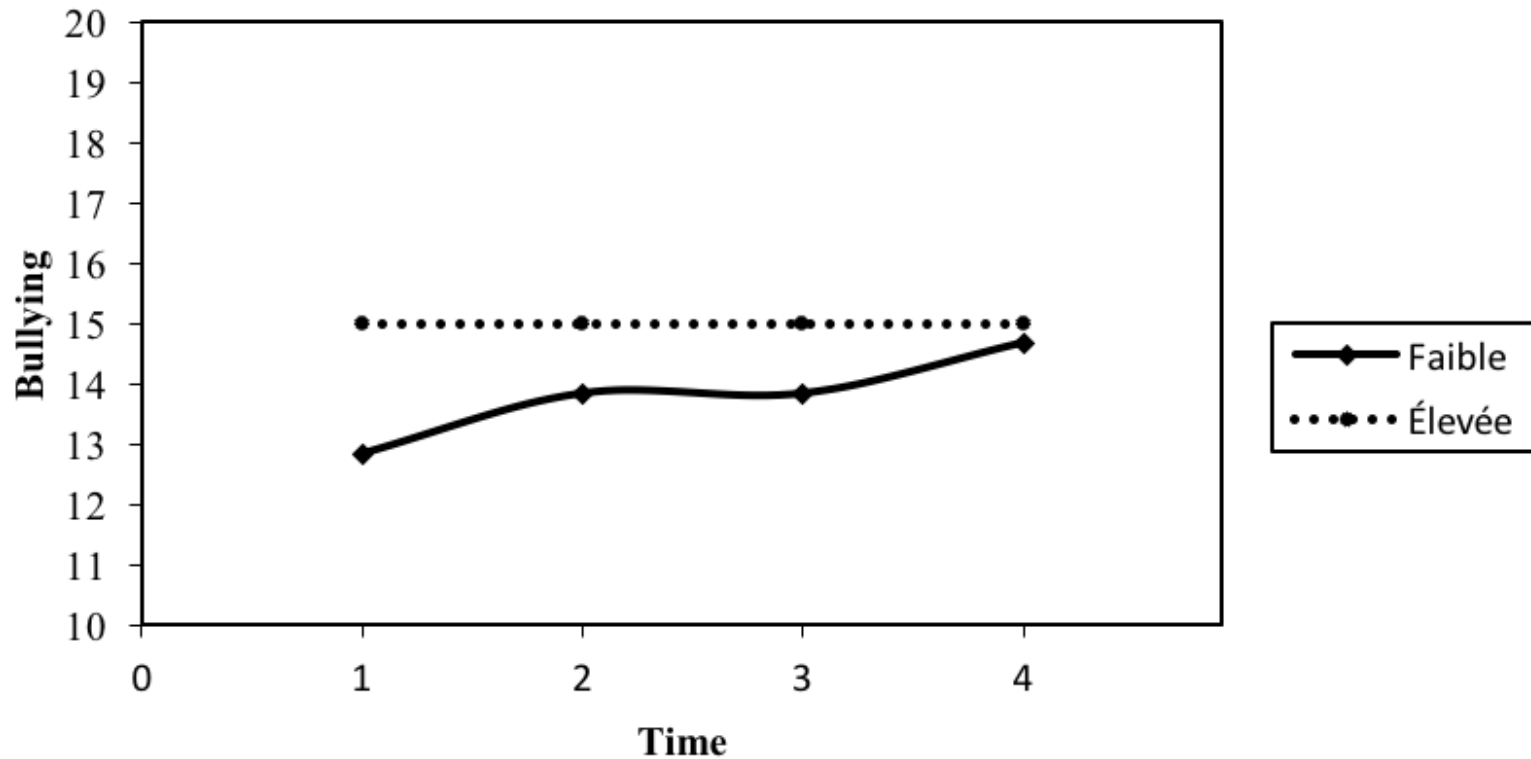


Figure 7. Evolution of bullying for high and low social desirability

Quantitative results

Quality of life (mother)	T1	T2	T3	T4	* $p < 0.05$
	N = 44	N = 42	N = 35	N = 30	Effect
Physical well-being	16,21	17,10	17,00	17,72	n.s.
Psychological well-being	22,81	24,51	24,25	24,50	n.s.
Moods and emotions	28,65	31,62	31,25	31,72	*13%
Self-perception	19,00	20,16	20,03	20,53	*10%
Autonomy	18,36	19,58	20,08	18,41	n.s.
Parents and home	24,38	25,13	25,53	25,22	n.s.
Financial resources	11,90	11,79	12,78	12,53	n.s.
Peers and social support	16,71	18,84	19,39	20,16	*40%
Bullying	14,50	14,80	14,80	14,70	n.s.

Quantitative results

Quality of life (father)	T1	T2	T3	T4	* $p < 0.05$
	N = 44	N = 42	N = 35	N = 30	Effect
Physical well-being	16,24	16,88	17,31	16,97	n.s.
Psychological well-being	22,41	24,29	23,19	23,19	n.s.
Moods and emotions	30,19	32,03	31,19	31,53	*26%
Self-perception	19,27	20,29	19,94	19,94	n.s.
Autonomy	18,73	20,35	20,13	19,00	n.s.
Parents and home	24,65	24,56	24,09	24,19	n.s.
Financial resources	12,32	12,35	12,72	12,81	n.s.
Peers and social support	17,36	18,82	18,00	19,47	n.s.
Bullying	14,05	14,70	14,56	14,63	n.s.

Quality of life (mother/father) moods and emotions

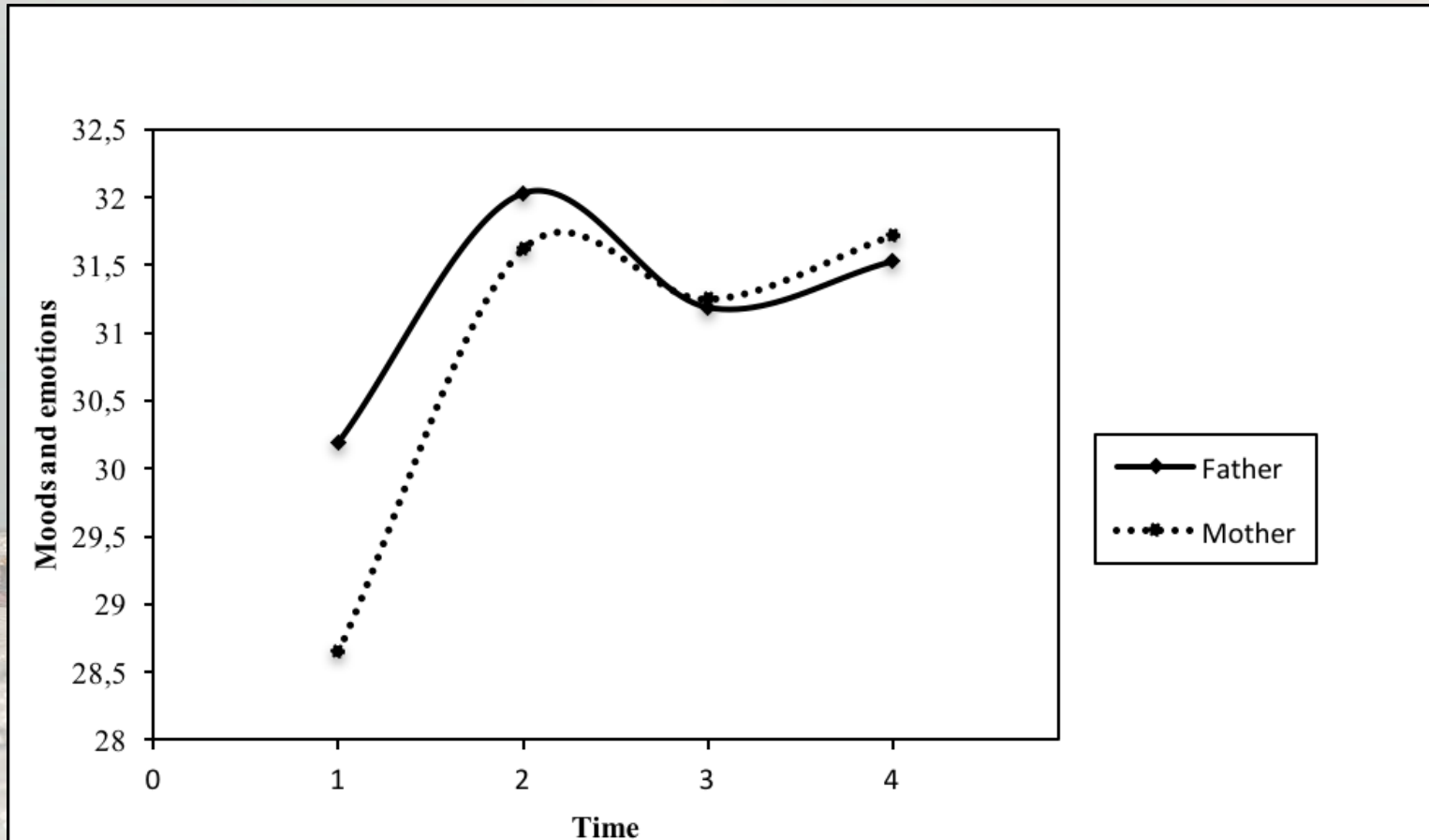
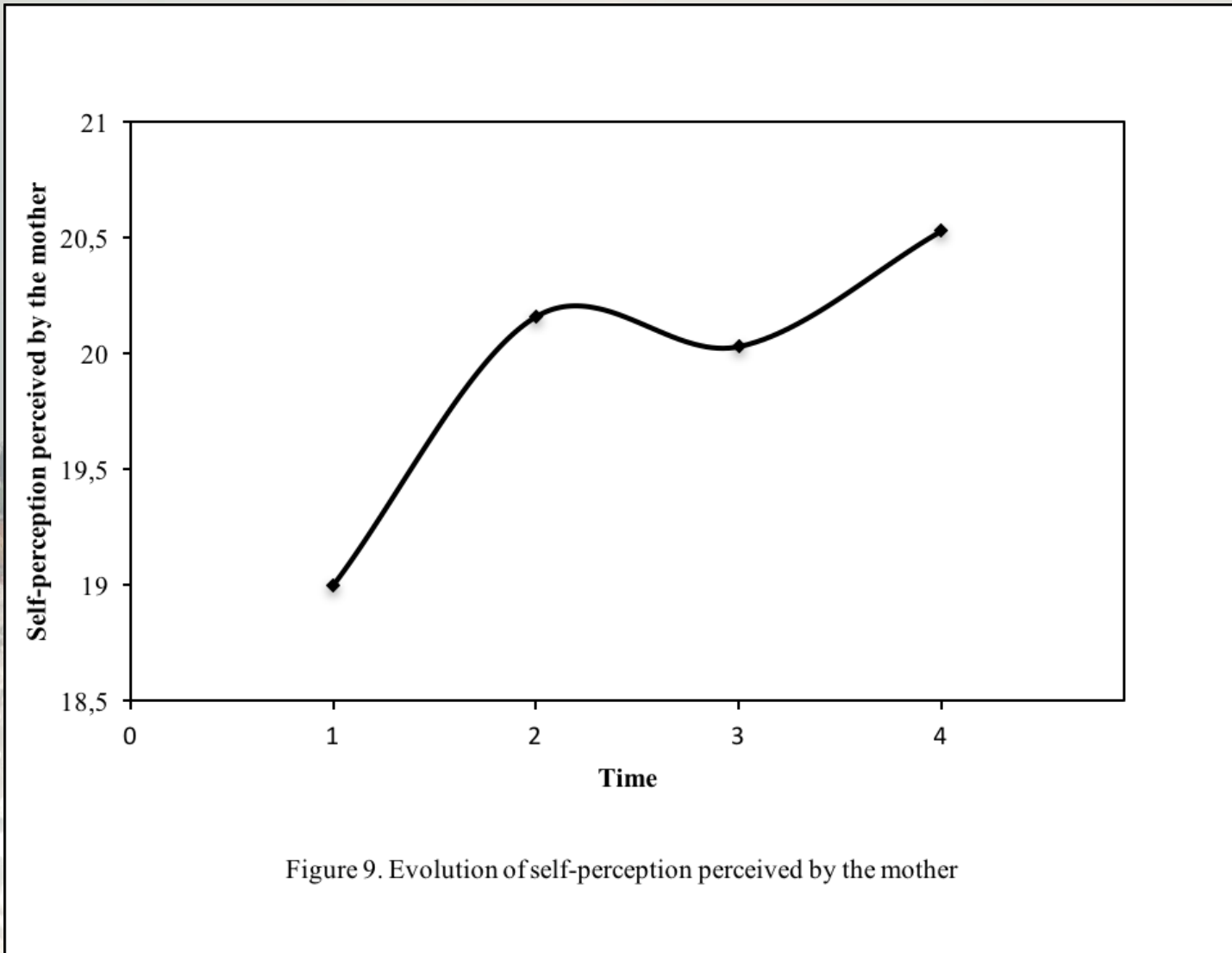


Figure 8. Evolution of moods and emotions according to the mother and the father

Quality of life (mother) self-perception



Quality of life (mother) peers and social support

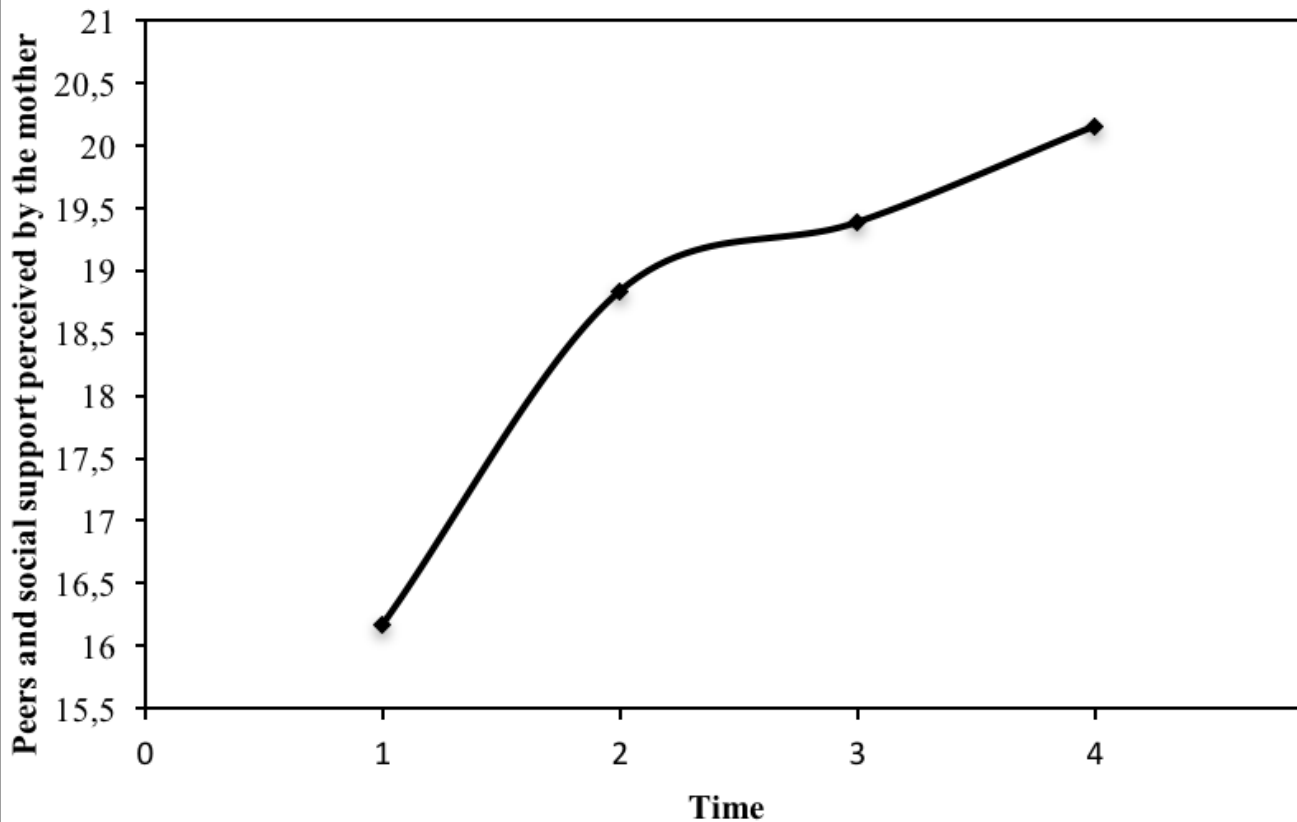
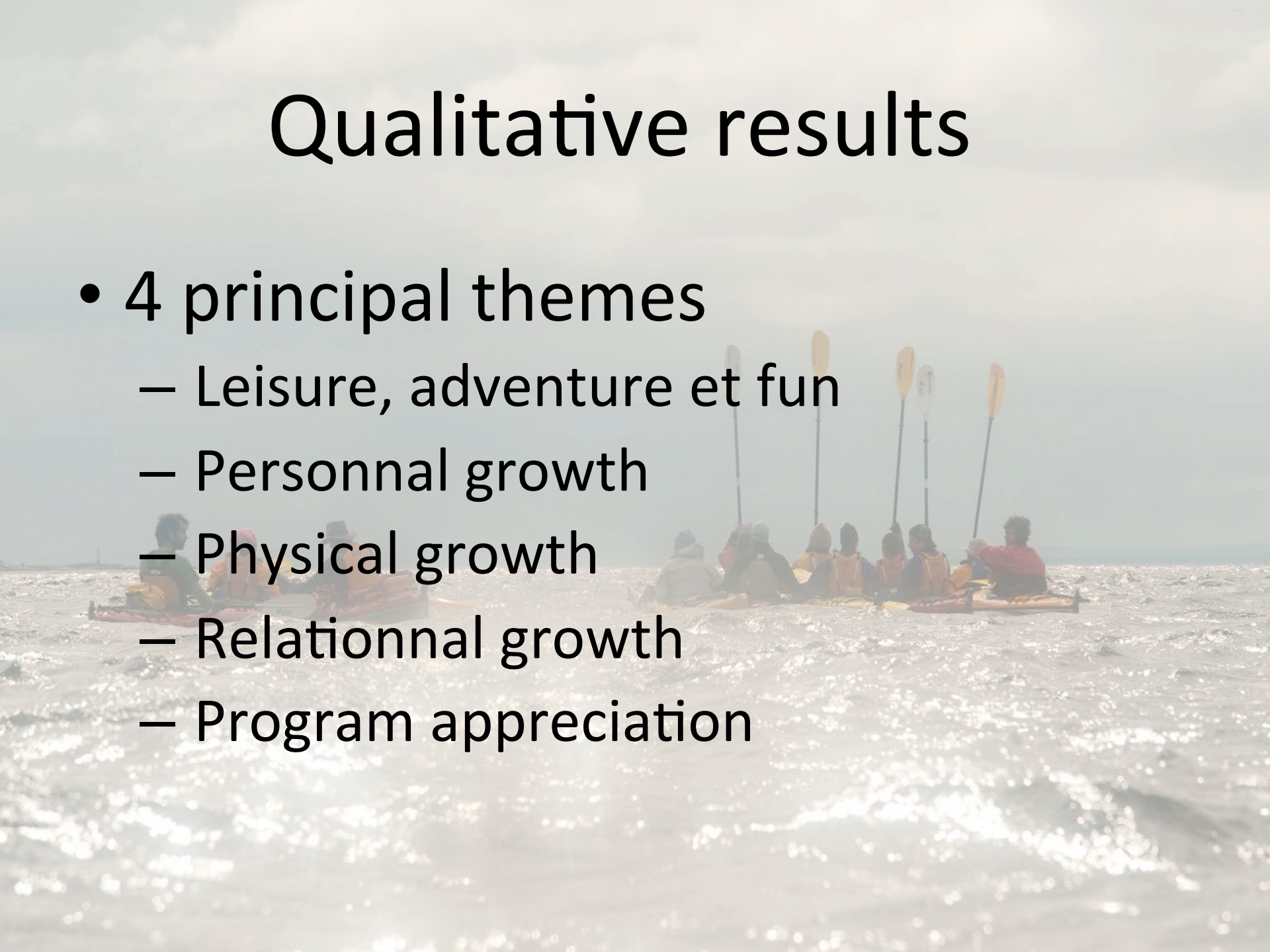


Figure 9 . Evolution of peers and social support perceived by the mother

Qualitative results

- 4 principal themes
 - Leisure, adventure et fun
 - Personnal growth
 - Physical growth
 - Relationnal growth
 - Program appreciation



Leisure, adventure and fun

- Contact with nature, « Awe »
- Fun during the trip and adventure
- Escaping from the ordinary, entertainment
- Creating memories / uniqueness
- (adolescent) « The landscape that we saw was really amazing, it was a once in a lifetime experience for me, the people that I met were so nice and I had so much fun being with them. »
- (parent) « Fishing, seeing bears in nature and hiking mountains, and the landscape. She was talking about it as if it was paradise, so I think that she was amazed by this experience. »

Personnal growth

- Feeling of achievement ,pride related to the challenge
- Better mood, more positive, calm
- Learning of outdoor skills
- Indentity growth/ autonomy
- (adolescent) « I think that this trip helped me to realize that cancer will always be a part of me, but it doesn't mean that it is the only part of me, it doesn't mean that it will define my character for the rest of my life, and I think that this trip really helped me to realize that. »
- (parent) « Well, dealing with her own things, without us, mom and dad, always there, protecting her. I feel that she got back her own energy, her own things, that she can now do things all by herself. »

Relational growth

- New social skills
- Feeling of connexion with others, creating new friends
 - Keeping contact (facebook group)
- Better openness to others, sharing the experience
- Breaking the isolation (contact with others journeying with cancer)
- (adolescent) :« I feel more comfortable now with the idea of myself going through all the cancer thing. Before I was not comfortable with the idea of not wearing a wig, for an example, because my hair is very short. But now, I feel like a young person among other young persons who are going through the same thing, I guess it helped me to get more comfortable with that. »

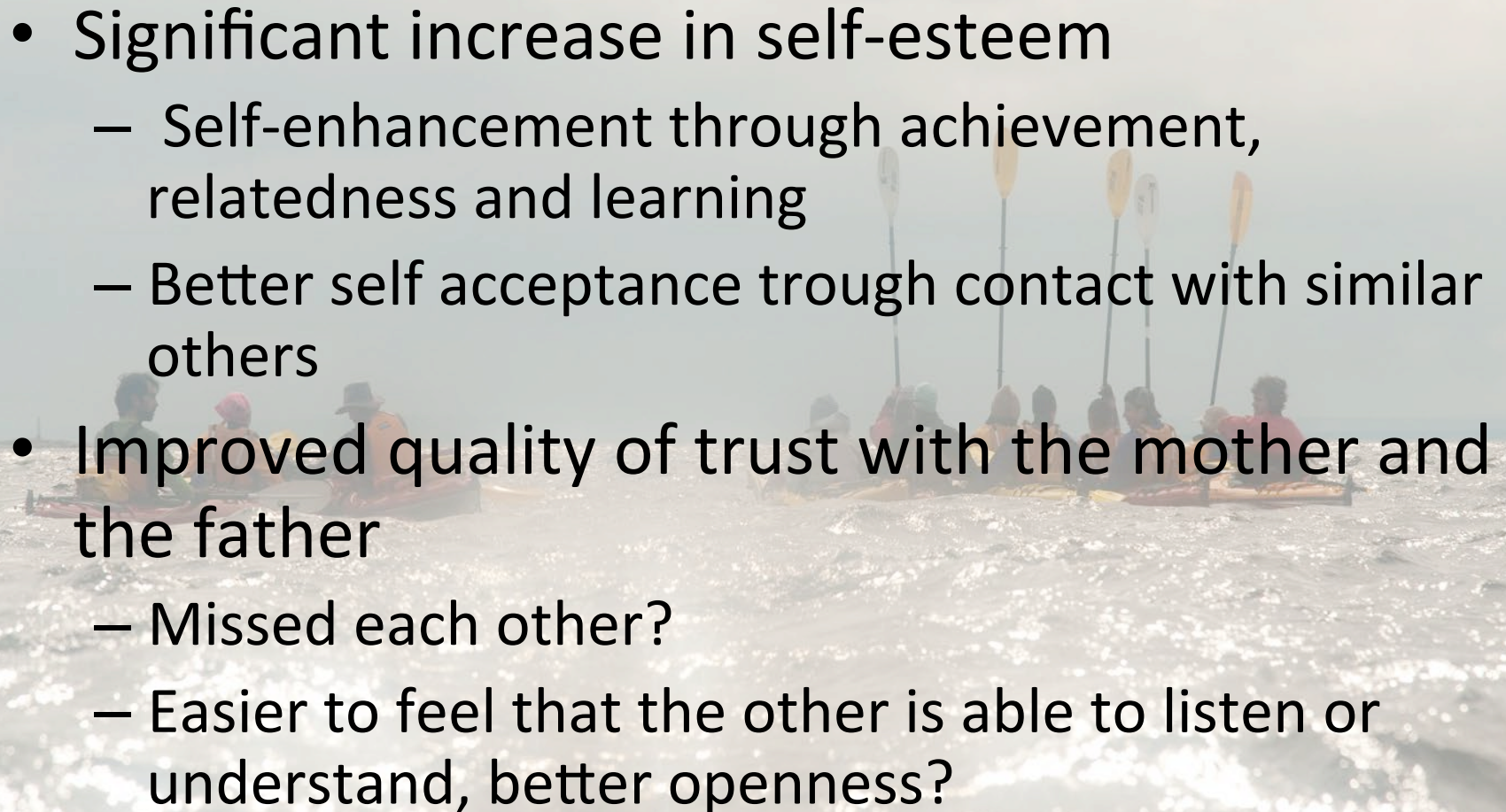
Physical growth

- Physical challenges (fatigue, endurance)
 - Surprising to be able to do all that
 - Challenge related to outdoor discomforts (mosquitos, weather)
 - Frequent association between the challenge and the pride.
- Motivation to practice physical activity
 - Realizing that the capacity is there
- Physical activity / training / better shape after
- (adolescent) « The biggest challenge for me was hiking the mountains, because it was really difficult physically, you know, the guys were always tired, lost their breath all the time, and my legs were always tired, so it was the main challenge I think. »
- (parent) « We saw him coming back at the airport and he looked a little bit tanned and a little bit stronger. Yes, he looked in a better shape. He is stronger now, his friends and him went to the gym and they said that he is stronger. »

Program appreciation

- Positive comments about the blog
 - Parents et adolescents
- When asked about negative aspects
 - Language issues (French/English) (n=8)
 - Difficult to be apart for 10 days (mostly parents)
 - The all process brings back difficult memories (parents)
 - Very hard to quit the group after 10 days (adolescents)
 - Cohort 1 (summer 2011)
 - TV mass media seen as intrusive (n=3)

Discussion

- Significant increase in self-esteem
 - Self-enhancement through achievement, relatedness and learning
 - Better self acceptance through contact with similar others
 - Improved quality of trust with the mother and the father
 - Missed each other?
 - Easier to feel that the other is able to listen or understand, better openness?
- 
- A group of people are kayaking on the ocean. The kayakers are wearing life jackets and holding paddles. The water is choppy with whitecaps, and the sky is overcast. The kayakers are positioned in a line, moving away from the viewer.

Discussion

- Increase in the quality of communication with peers, especially in girls
 - Do they suffer more in their friendships because of cancer? (ex. Physical appearance, values, goals?)
 - Easier to share after the experience?
 - New friends?
 - More self-esteem and acceptance = better social skills?
 - Relatedness gains applied to friendships?

Discussion

- Integrative model reminiscent of the self-determination theory (Decy & Ryan)
 - Autonomy, competence, relatedness
- Words in the sharing circle
 - Inspired, genuine, reborn... something spiritual, flow experience? (Csikszentmihalyi)
- Shortcomings
 - No comparison/control groups, no physiological variables, impossible to “isolate” the nature factor

Your ideas about the project?

