

Monitoring, Disclosure, & Privacy Violation in Medical Contexts

Nancy Darling

Amber Borofsky, Chloe Howes, Huyen Kim,
Maille Kimble, Lorna Luo, Ariana Ofori, Stella Sears-Bicknell

Oberlin College

Monitoring Health

- 5% of adolescents experience a life-changing chronic pain.
 - Gold standard treatment: Pharmaceutical treatment combined with behavioral change
- Treatment plan:Adherence:Reporting Effectiveness <->
Rules:Obedience:Adolescent Information Sharing
 - Providers' ability to treat conditions effectively is entirely dependent on their ability to monitor treatment effects
 - Most adults don't adhere to behavioral treatment. Do adolescents? And would they tell the doctor if they didn't?



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Adolescent Information Sharing in the Context of Medical Adherence

- Does what we know about adolescents sharing information about rule disagreement and obedience in the context of parental monitoring generalize to the provider-patient relationship?
- Does what we know generalize to mothers disclosing information about their adolescents to the adolescents' providers?
 - The medical context involves 3 people: provider, parent, and adolescent
 - Primary relationship is provider:adolescent. Will they adhere and disclose?
 - Doctors prescribe but parents enforce
 - Conflict: Prudential v betraying adolescents' confidence



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Methods

- National Qualtrics Survey
 - 312 13-18 year olds & 301 mothers
- Watched a 5-minute video of a doctor visit
 - Adolescent with fibromyalgia (Alex) reported how the disease affected their life while their mother watched.
 - Their doctor prescribed medication and lifestyle changes.



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Measures: 1 pharmaceutical & 4 behavioral changes

Alex:

- Does Alex HAVE TO do what the doctor told them to do?
- Will Alex do what the doctor told them to do?
- Alex doesn't. Is it okay for them to hide that they didn't?
- Will Alex tell the doctor they didn't?
- Will treatment help?

Mom:

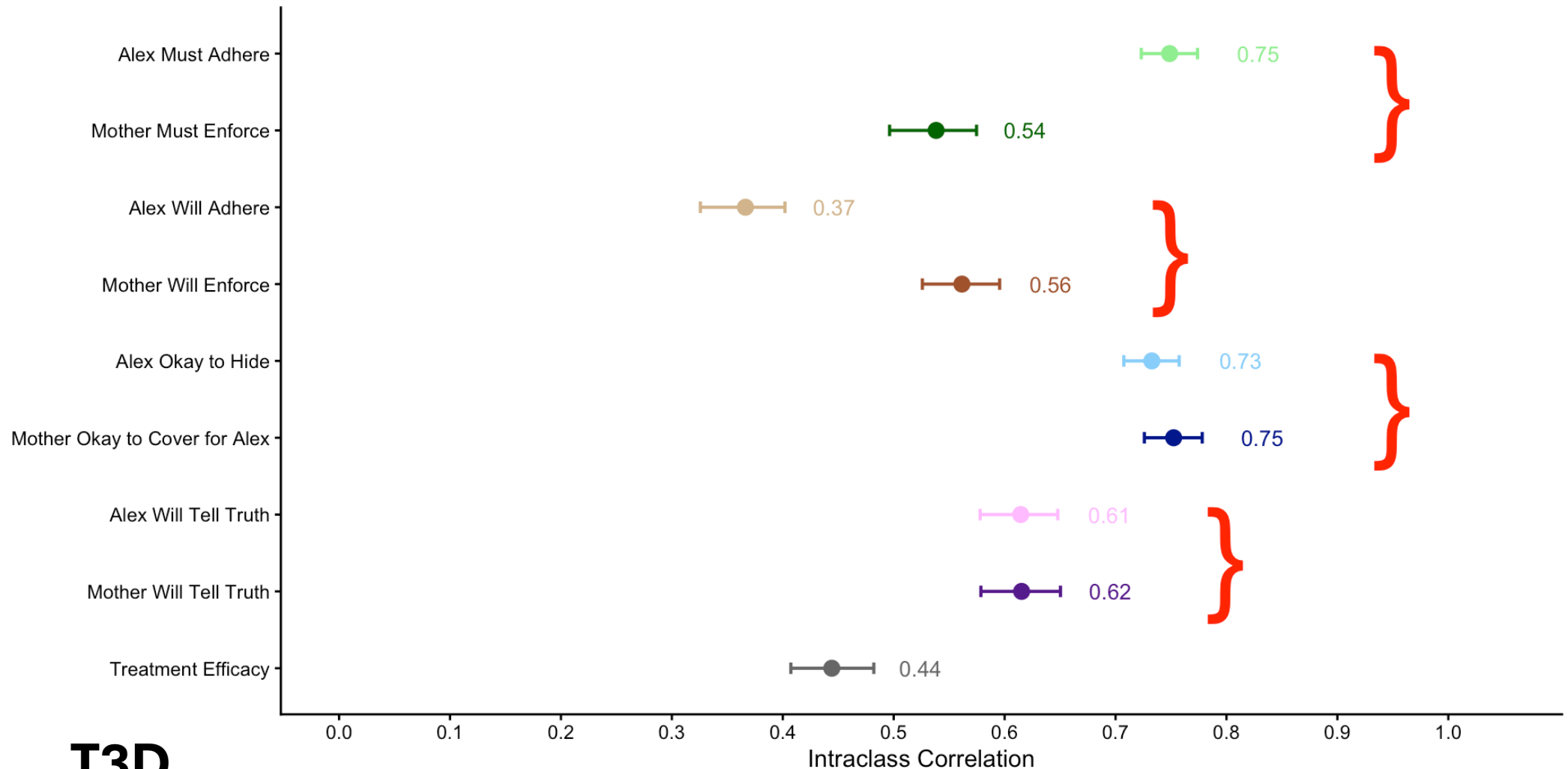
- Does Alex's mom HAVE TO make Alex do what the doctor told them to do?
- Will Alex's mom do what the doctor told them to do?
- Alex doesn't. Is it okay for Alex's mom to hide that from the doctor?
- Will Alex's mom tell the doctor they didn't?
- Will treatment help?



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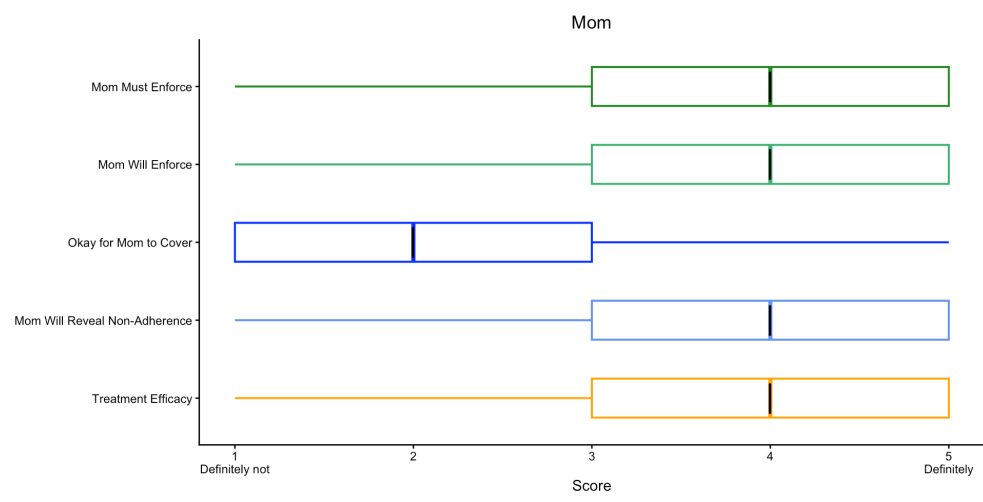
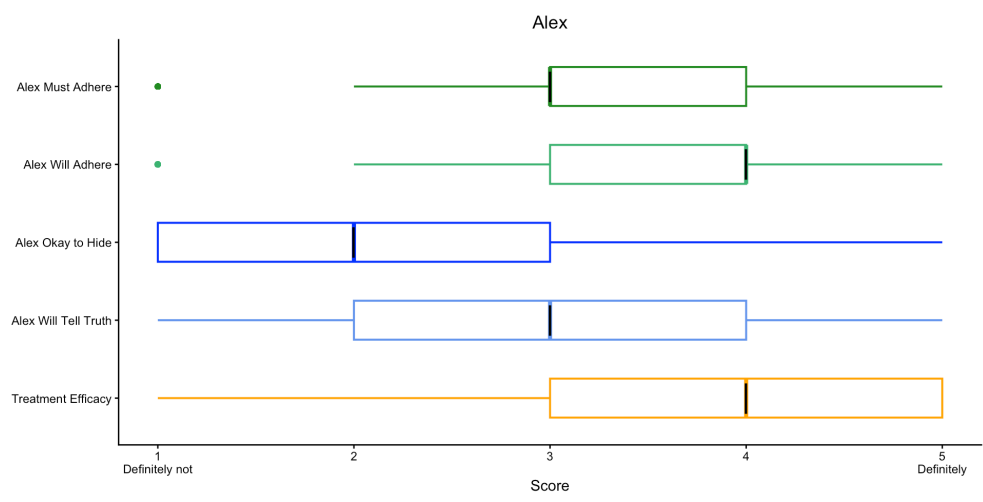
Different treatments are judged differently: ICCs .37 to .75



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There are higher expectations for Moms



Predicting Alex's Responses

Predicting Alex's Adherence & Disclosure of Non-Adherence		
	Adherence	Non-Adherence Disclosure
Mother v Adolescent	-0.41***	-0.20*
Med v Lifestyle	0.49***	0.11**
Obligation to Adhere	0.29***	0.09***
Okay to lie		0.16***
Efficacy	0.17***	0.16***
ICC	0.40	0.59
Note. N = 3057 observations from 613 participants. * $p < .05$. ** $p < .01$. *** $p < .001$.		

Predicting Mom’s Responses

Predicting Mom’s Enforcement & Revealing Alex’s Non-Adherence		
	Enforce Adherence	Reveal Non-Adherence
Mother v Adolescent	-0.11*	-0.06
Med v Lifestyle	0.15***	0.12***
Obligation to Enforce	0.28***	0.21***
Okay to lie		-0.10***
Efficacy	0.19***	0.14***
ICC	0.56	0.59
Note. N = 3065 observations from 613 participants. * $p < .05$. ** $p < .01$. *** $p < .001$.		

Conclusions

- Parents and adolescents share similar beliefs about adherence and disclosure.
 - Both believe that there is a higher obligation to adhere to pharmaceutical treatments than to behavioral changes and that disclosing non-adherence of behavioral change is more discretionary.
 - Beliefs about treatment efficacy are important predictors of adherence and disclosure.
- Mothers are more pragmatic about adherence than adolescents are.
 - Expect less adherence and less disclosure of adherence from Alex
 - Expect mother's to enforce less, although no difference in disclosure



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Conclusions

- Does what we know about monitoring & sharing information generalize to the provider-patient relationship?
 - **Yes.** Beliefs about obligation to adhere and disclose predict both medical adherence and disclosure of non-adherence.
- Does what we know generalize to mothers telling doctors that their adolescents didn't follow the treatment plan?
 - **Yes.** Mothers and adolescents had similar beliefs about Mom's obligation to enforce the treatment plan and that she should disclose Alex's non-adherence to the practitioner.
- Efficacy beliefs are important predictors of adherence and disclosure.



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Implications

- Fewer than 20% of men who just had a heart attack follow doctors' treatment instructions about behavioral change.
- Our lab has shown that most adolescents believe that behavioral interventions are not legitimate areas for health practitioners to regulate and that it is fine to lie to them about not doing it.
- Doctors cannot treat patients when they do not get accurate information from them.
- Addressing both parents' and adolescents' beliefs about how and why lifestyle changes will improve the adolescents' health is critically important for increasing adherence and improving communication.



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