Journal Club: Genetic Counseling for Military Personnel

Moriah Edwards, MS, CGC

1/4/23

ORIGINAL ARTICLE

Are genetic counselors prepared to counsel active-duty service members? A survey of genetic counselors' self-efficacy, counseling techniques, and knowledge of military policy

Michael Kamen[1] | Lydia D. Hellwig[2,3] | Kristin A. Maloney[4] | Jessica Scott[5] | Clesson Turner[2] | Shannan Dixon[6]

Effects of Testing on Service Members

QUALIFICATION FOR SERVICE

AVAILABLE SERVICE ROLES/ MEDICAL DISCHARGE

PSYCHOSOCIAL IMPLICATIONS

GINA

Genetic Information Nondiscrimination Act of 2008

Protects people from health insurance discrimination and employment discrimination

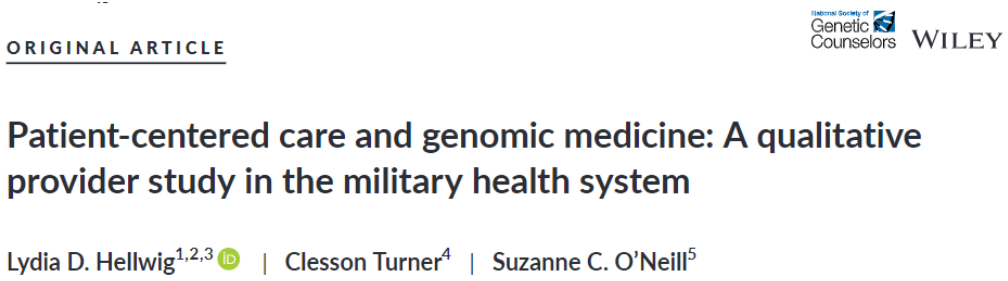
Does not apply to long-term care insurance, disability insurance, or life insurance; does not apply to small companies

Does not apply to military employment

- TRICARE: 9.6 million beneficiaries

Military HCP Preparedness

- Variable levels of knowledge and experience with ordering/interpreting genetic testing
- Variable opinions on implications of results on military career
- Often refer out to genetics, esp. for secondary findings



ORIGINAL ARTICLE

National Society of Genetic Counselors | WILEY

Patient-centered care and genomic medicine: A qualitative provider study in the military health system

Lydia D. Hellwig[1,2,3] | Clesson Turner[4] | Suzanne C. O'Neill[5]

Methods

- Participants: qualitative survey of 88 GCs on NSGC Student Research Projects listserv

- 4-part mixed-methods survey:
  - Demographics
  - Likert scale assessment of self-efficacy of ability to counsel active-duty service members (SMs) vs general population
  - Case scenarios testing knowledge of military policy
  - Case scenarios addressing military psychosocial concerns with open-ended responses

Methods

Q6.1.

Captain Jon Smith is an active-duty service member who sees you in a clinic outside of the Military Health System (MHS) for pre-test genetic counseling. There is a known disease-causing genetic variant in his family that may potentially disqualify him from service if he were to inherit it. He asks if you are required to share the results with the MHS.

You inform Captain Smith that...

(Please choose the best answer)

- ○ the genetic testing results are covered by the Genetic Information Non-discrimination Act (GINA) and will never be shared with any of the people who will decide if he is fit to continue to serve in the military.
- ○ he is required to have genetic testing for the disease-causing genetic variant. A medical board within the MHS reviews all genetic testing results.
- ○ the results will be part of his medical record and he is required to share these with the military. A medical board within the MHS may choose to review them, or not, based on their discretion and the rules of the particular service branch.
- ○ genetic test results are never disqualifying for service.
- ○ you are required to follow military policy and contact his commanding officer directly with the genetic test results.

Methods

- Participants: qualitative survey of 88 GCs on NSGC Student Research Projects listserv

- 4-part mixed-methods survey:
  - Demographics
  - Likert scale assessment of self-efficacy of ability to counsel active-duty service members (SMs) vs general population
  - Case scenarios testing knowledge of military policy (+ open-end responses)
  - Case scenarios addressing military psychosocial concerns (+ open-end responses)

Methods

Q7.1. During pre-test counseling, an 18-year-old client informs you that he plans to join the Reserved Officers' Training Corps (ROTC) program at his university next year. He is excited to follow in his mother's footsteps by entering the Army as a commissioned officer. He is concerned that he may have inherited a disease-causing *RYR1* variant, predisposing him to malignant hyperthermia, recently found in his father. Inheriting this variant may impact his ability to serve and he seems uncertain about whether or not to pursue testing.

How do you assist your client through the decision-making process?

Results

- 75% scored perfectly on military knowledge
- High levels of reported self-efficacy in counseling SM

- 57% of open-ended responses showed low confidence of military policy
- 70% lacked training in military-specific issues

Military Use of Genetic Information

- Remains identification
- Genetic screening for enlistment, e.g. sickle cell trait and G6PD deficiency
- Medical review for impactful results

Disqualification from Service

1. CONGENITAL CONDITIONS
2. ACQUIRED CONDITIONS
3. ADULT-ONSET CONDITIONS?
4. SECONDARY FINDINGS?

DoD Instruction 6130.03, Volume 1

Medical Standards for Military Service: Appointment, Enlistment, or Induction

---

DoD Instruction 6130.03, Volume 2

Medical Standards for Military Service: Retention

How To Counsel a Service Member

- Identify primary concerns
- Risks and benefits (informed consent)
  - Career repercussions
  - Impact of diagnosis on safety of self and team
  - Impacts on medical benefits and dependents
  - GINA
- Genetic screening and reporting requirements
- Patient motivations and values for testing
- Informational resources and referrals
- Mental health support

Clinic Application

PRIMARY DIAGNOSIS

SECONDARY FINDINGS

RESEARCH

Military Initiatives in Genetic Testing

- **MilSeq Project**
- **American Genome Center (TAGC)**
- **APOLLO Network**
- **DoD/NASEM Committee**

Conclusions

- Military service members have special considerations for genetic testing
- More education needed for genetics professionals to address military-specific concerns
- Ongoing development of military use of genomic information

References

- https://www.genome.gov/about-genomics/policy-issues/Genetic-Discrimination
- De Castro M, Biesecker LG, Turner C, et al. Genomic medicine in the military. npj Genomic Medicine. 2016/01/13 2016;1(1):15008. doi:10.1038/npjgenmed.2015.8
- De Castro MJ, Turner CE. Military genomics: a perspective on the successes and challenges of genomic medicine in the Armed Services. Molecular Genetics & Genomic Medicine. 2017;5(6):617-620. doi:10.1002/mgg3.335.
- Department of Defense Instruction 6130.03: Medical standards for appointment, enlistment, or induction into the military services. U.S. Department of Defense 2018. Available at https://www.esd.whs.mil/Portals/54/Documents/DD/issuances/dodi/613003_vol1.PDF?ver=7fhqacc0jGX_R9_1iexudA%3D%3D; accessed December 28, 2022
- Department of Defense Instruction 6130.03: Medical standards for Military Service Retention. 2020. Available at https://www.esd.whs.mil/Portals/54/Documents/DD/issuances/dodi/613003_vol02.PDF?ver=vx1spUpNVLcc-0-rov00Sg%3D%3D; accessed December 28, 2022.
- Hellwig LD, Turner C, Manolio TA, et al.. Return of secondary findings in genomic sequencing: Military implications. Molecular Genetics & Genomic Medicine. 2019;7(2):e00483. doi:10.1002/mgg3.483.
- Hellwig LD, Turner C, O'Neill SC. Patient-centered care and genomic medicine: A qualitative provider study in the military health system. Journal of Genetic Counseling. 2019;28(5):940-949. doi:10.1002/jgc4.1144.
- Helm BM, Langley K, Spangler BB, Schrier Vergano SA. Military Health Care Dilemmas and Genetic Discrimination: A Family's Experience with Whole Exome Sequencing. Narrat Inq Bioeth. 2015 Summer;5(2):179-86. doi: 10.1353/nib.2015.0059. PMID: 26300150.
- Mehlman MJ, Parasidis E. Predictive Genetic Testing by the U.S. Military: Legal and Ethical Issues. Military Medicine. 2021;186(7-8):726-732. doi:10.1093/milmed/usab011