

On Dying Alone in Prison and the Social Responsibility of Medicine - a pilot interview study with physicians caring for incarcerated patients

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Introduction and Background

We enter medical school, and our profession, promising that we will make no distinctions between human lives, that we will respect our patients and aim to serve humanity.

AS A MEMBER OF THE MEDICAL PROFESSION:
I SOLEMNLY PLEDGE to dedicate my life to the service of humanity;
THE HEALTH AND WELL-BEING OF MY PATIENT will be my first consideration;
I WILL RESPECT the autonomy and dignity of my patient;
I WILL MAINTAIN the utmost respect for human life;
I WILL NOT PERMIT considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient.

Part of the World Medical Association's Declaration of Geneva. WMA, "Declaration of Geneva", October 2017, <https://www.wma.net/policies-post/wma-declaration-of-geneva/>. Accessed 06 March 2022.

This declaration is a high ambition and far from the reality for a vast of patients. As a palliative care physician, however, one's aim is to care for anyone with a life-limiting disease and need for symptom control, regardless of their sex, gender, origin, language, race, political opinions or insurance status. During medical training and practice, it is rarely thought of people in prison and their specific needs. This, too, might be a consequence of systemic racism and xenophobia. More than half of Austria's prison population has no Austrian citizenship [1], and people of color are disproportionately more likely to be incarcerated in the United States, particularly Black men [2]. Locked away and out of sight, it is easy to look away and to not equally include incarcerated people into medical treatment consideration.

Reading the words of the hundreds of response letters that volunteers of the Mount Tamalpais College received after their project had provided thousands incarcerated men with care packages during the Covid-19 pandemic 2020 makes this omission intensely aware [3]. Especially Louis Anthony Crawford's letter raises awareness to the palliative care needs of incarcerated humans.

TO WHOM IT MAY CONCERN:

MY NAME IS LOUIS ANTHONY CRAWFORD WHOM IS NOW INCARCERATED AT SAN QUENTIN STATE PRISON. I AM ENTERING MY 34TH YEAR IN PRISON BEHIND BARS. YOU ONLY CAN IMAGINE THE STORIES I CAN TELL. PRISON HAS NEVER BEEN ABOUT THE PHYSICAL ABUSE AN INMATE GOES THROUGH. IT HAS ALWAYS BEEN ABOUT THE MENTAL STRESS OF BONDAGE. THE WORRIES ABOUT FAMILY AND FRIENDS PLAY A BIG PART IN ONE'S DETERIORATION BOTH PHYSICALLY AND MENTALLY. SINCE MY STAY IN PRISON I HAVE LEARNED THAT I HAVE HIV, HEP C, UNCONTROLLABLE HIGH BLOOD PRESSURE, A TUMOR AND CANCER. ABOUT EIGHT MONTHS AGO I HAD AN OPERATION FOR COLON CANCER THAT CAUSE ME TO LOSE MOST OF MY ABILITY TO FUNCTION NORMALLY. WHEN I WAS TOLD THAT I MAY HAVE ONLY A YEAR OR LESS TO LIVE, I LAID ON MY BACK FOR 24 DAYS WITH A MIND-SET THAT WHEN I WAS RELEASED I WOULD PROVE THEM ALL WRONG. FOR WEEKS STANDING WAS A DIFFICULT CHORE, THEN I SHOOK THE WHEEL CHAIR. I STILL USE A WALKER TO GET AROUND AND I AM CLOSE TO SHAKING IT AS WELL. I CAN WALK ON MY OWN FOR SHORT DISTANCES BUT MY EQUILIBRIUM IS WAY OFF. I HAVE DIZZY SPELLS AND BLACKOUTS. ALSO THE KERO BLOWS MY FINGER AND TOENAILS OFF. IT MAKES MY SKIN SO TIGHT THAT I CONSTANTLY FIND CRACKS IN MY SKIN. PAIN KEEPS ME COMPANY CONSTANTLY. I WRITE TO YOU NOT FOR MYSELF BUT IF I SHARE MY STORY IT MAY SAVE SOME POOR SOUL FROM THE TRAUMA THAT I HAVE ENDURED. I FEAR IT MAY BE TOO LATE FOR ME AND SHARING MY STORY EASES MY TROUBLED SOUL.

Sincerely,
Louis A. Crawford D-59960

Crawford, Louis Anthony. "To whom it may concern", Voices from Inside: Full Library, Mount Tamalpais College, 17 July 2020, <https://www.mttamcollege.org/voices-from-inside-full-library>. Accessed 06 March 2022.

Objective

This pilot study aims to examine the experiences of physicians caring for terminally ill patients within prisons.

Materials and Methods

Three expert interviews were conducted in March and April 2021 with physicians working in carceral institutions in New York state and Austria. Interviewees were: A family medicine physician working in correctional facilities in New York, a palliative care physician working partly with incarcerated patients in a medical ward in a high security prison in Austria and in a special ward for incarcerated patients in a hospital, and lastly a psychiatry resident working in an Austrian prison that is at the same time a mental health institution. Two interviews were conducted via Zoom and one via telephone. The duration of the interviews ranged between 34-72 minutes. The interviews were recorded digitally and transcribed verbatim. The investigation is based on the qualitative methodology of thematic analysis.

Results

The interviews revealed that those who care for incarcerated people and accompany them through illness and sometimes even to death are left alone with concomitant difficulties. The findings show the struggle and lack of support and training of physicians within prisons. Different themes were identified and defined:

Provider-patient relationships seem hardly to be continuous. None of the interviewees were present at a moment of death within a prison. It became clear that they lost contact with their patients, this could be because of the end of a shift, a transfer of the terminally ill person to a facility with more medical resources, a transfer to a clinic, or early release.

Incarcerated people have very limited options of visits and saying their goodbyes. The architectural and security structure of a prison is not built for these situations. Visits are only possible within visitor rooms, but if the incarcerated person is too frail or ill to reach the visitor room, there are no alternatives.

Security remains the main concern. Safety measures are always first for everyone working with incarcerated persons. Aspects were mentioned that may seem absurd for a listener, such as having to shackle someone dying in a hospital bed or not informing families out of fear of an escape attempt or removing pens and name tags before entering the room of an incarcerated patient. What seems inhumane and inappropriate is explained by singular precedent experiences that led to caution and fear.

Rare possibilities of early release. The possibility of early release due to severe illness exists in both Austria and New York State but due to structural barriers to gaining early release this is hardly being applied.

Conclusion

These results present a starting point for further conversations and studies, as structural change is needed.

A broader awareness within the medical community could be a start and might also lead to more support for the physicians who are already working within prison environments. Furthermore, the attention of society and the government will be needed to finance and enable new structures and future homes for people with limited life expectancy to be able to leave prisons. Additionally, possibilities need to be created that allow visitors to the medical ward within prisons for those who choose to stay or who cannot be released.

Acknowledgments

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References

- [1] BMJ, Bundesministerium für Österreichische Justiz (Austrian Federal Ministry of Justice), "Insass*innenstand nach Staatsbürgerschaft", 1 April 2021, <https://www.justiz.gv.at/home/strafvollzug/statistik/insassinnenstand-nach-staatsbuergerschaft~2c94848542ec498101444595343b3e06.de.html>. Accessed 06 March 2022.
- [2] Sawyer, Wendy and Wagner, Peter. "Mass Incarceration: The Whole Pie 2020", 24 March 2020, <https://www.prisonpolicy.org/reports/pie2020.html>. Accessed 06 March 2022.
- [3] Voices from Inside: Full Library, Mount Tamalpais College, 17 July 2020, <https://www.mttamcollege.org/voices-from-inside-full-library>. Accessed 06 March 2022.