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“Stripped of dignity” – Women in homelessness and their perspectives of healthcare services: A qualitative study

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ABSTRACT

Background: A much more substantial European evidence base on the accessibility of healthcare services among women experiencing homelessness across healthcare systems in Europe is warranted.

Objective: To give voice to women with experiences of homelessness, and to explore their perspectives of healthcare services in an EU country with universal healthcare.

Design: The study is part of a research program striving to promote equal healthcare through co-production with women in homelessness. An advisory board of women with lived experience of homelessness was established and a qualitative, interpretive and exploratory design was employed.

Participants: 26 women with experience of homelessness were interviewed. Their median age was 46 years (range 42) and 70% were roofless/houseless.

Methods: Data were analyzed with content analysis. Co-production and joint analyses were conducted by researchers and three women with experience of homelessness, using the DEPICT model for collaborative analysis.

Results: The analysis resulted in one overall theme: *Visiting healthcare from the outskirts of society*, comprising three sub-themes: Demand for a life in order - Exclusion in action; Unwell, unsafe and a woman - Multifaceted needs challenge healthcare; and Abuse versus humanity – power of healthcare encounters to raise or reduce. Women's experiences of care encounters were disparate, with prevalent control, mistrust and stigma, yet healthcare professionals that demonstrated respect for the woman's human dignity was described both as life-altering and lifesaving.

Conclusions: Women in homelessness live on the outskirts of society and have multiple experiences of exclusion and loss of dignity within healthcare services. The multifaceted care needs challenge healthcare, leading to women feeling alienated, invisible, disconnected and worthless. We urge registered nurses to take actions for inclusion health, i.e. focusing health efforts of people experiencing extreme health inequities. We can lead the way by speaking up and confronting discriminating behaviors, protecting and restoring human dignity in caring relationships, and framing healthcare services for *all* citizens.

Tweetable abstract: Women in homelessness have multiple experiences of exclusion and loss of dignity within healthcare services. Nurses must frame healthcare to include *all* citizens.

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What is already known

- Health and illness follow a social gradient: the lower the socioeconomic position, the worse the health.
- Unequal access to resources, capabilities and rights leads to large health inequities, signified by low uptake of preventative interventions, high prevalence of adverse events and multiple trauma, increased morbidity and premature death.

What this paper adds

- Women described loss of human dignity in encounters with healthcare services, i.e. feelings of alienation, insecurity, invisibility, and hopelessness, being disconnected, excluded, worthless, met with ignorance and impossible conditions.
- Women also described that healthcare services could offer respite, rest, and sanctuary during severe life circumstances.
- RNs must do more for right to health and to protect and restore human dignity for *all* members of the human family.

1. Background

Homelessness is one of the greatest manifestations of social injustice in countries with developed economy. Despite an annual average economic growth rate of 1.8 percent (Gross Domestic Product) in the European Union (EU) the last decades (European Commission, 2013), no member country has managed eradicate homelessness (The Foundation Abbé Pierre - FEANTSA, 2015). In fact, the number of individuals in homelessness has increased and it has been estimated that almost 4.1 million people face homelessness for varying lengths of time every year in the EU (European Commission, 2013). Recent data show that homelessness in Europe is far wider than suggested by official statistics, with a lifetime prevalence rate of almost five percent (Taylor et al., 2019). Thus, coupled with the well-established negative health impacts of homelessness, policies aiming to improve health services for people exposed to homelessness are warranted (Aldridge et al., 2018, European Commission, 2013, Fazel et al., 2014, Luchenski et al., 2018, Taylor et al., 2019).

Health and illness follow a social gradient: the lower the socioeconomic position, the worse the health (Marmot et al., 2012). Homelessness is a severe manifestation of social exclusion characterized by lack of access to adequate housing (Fitzpatrick et al., 2013), and linked to low income and poverty, but also to poor access to education, employment, and health services (Aldridge et al., 2018). In addition, experiences of crime, family breakdown, and incarceration are associated with social exclusion and these experiences often form part of an intergenerational cycle (Marmot, 2018). The unequal access to resources, capabilities and rights leads to health inequities, signified by low uptake of preventative interventions (Story et al., 2014), high prevalence of adverse events and multiple trauma (Fazel et al., 2014, Luchenski et al., 2018), as well as increased morbidity and premature death (Aldridge et al., 2019, Fazel et al., 2014). Consequently, individuals living in homelessness have high rates of acute healthcare use, including visits to emergency departments and inpatient admissions to hospital (Bharel et al., 2013, Hwang et al., 2013). This pattern is seen across countries irrespective of healthcare system; both in countries with and without universal healthcare insurance. The estimated healthcare costs ascribed to homeless people in one European country with universal healthcare, were approximately eight times greater than those of similarly aged housed adults, with threefold longer duration of hospital admissions (Department for Communities and Local Government, 2012). Despite the increased demand for healthcare, individuals living in homelessness tend to be neglected in international health strategies (Busch-Geertsema et al., 2016). An emergent approach trying to address these health inequities

is inclusion health (Aldridge et al., 2018, Luchenski et al., 2018, Marmot, 2018). The concept is defined as a service-, research-, and policy agenda that aims to close the extreme gap in health and life expectancy for socially excluded groups, by working across sectors nationally and internationally (Aldridge et al., 2018, Luchenski et al., 2018), in combination with engaging people with experience of social exclusion (Luchenski et al., 2018).

The profile of homelessness in EU is changing, and growing sub-groups are women and women with children (National Board of Health and Welfare, 2017, Vandentorren et al., 2016). The latter adds important intergenerational dimensions, as the effects of homelessness negatively impact generations to come (Nilsson et al., 2017). Traditionally, homelessness has been viewed as a male phenomenon, whereas women's homelessness has remained concealed because of the stigma attached to the 'unhoused woman' in the Western world (Wardhaugh, 1999). Thus, the available statistics in most countries almost certainly underestimate the number of women in homelessness. In fact, despite that the loss of home seems to have specific gendered consequences for women (Bretherton, 2020), the true extent of women's homelessness in Europe is unknown (Baptista, 2010, Pleace, 2016).

'Home' is a multidimensional and complex concept; however, it often represents a sheltered place where an individual can withdraw to feel freedom, peace, privacy and quiet (Hilli and Eriksson, 2019). It has been hypothesized that women's relationship with home is different to that of men (Wardhaugh, 1999). There is evidence that women, when becoming homeless, mobilize strategies to recreate 'home', e.g. rely on acquaintances, friends or relatives to find a temporary shelter of a home instead of accessing homelessness services (Mayock et al., 2015). Thus, women's search for existential and functional security render them invisible in society and may place them in situations where they are subject to further exploitations and/or abuse. For women, the loss of home appears to include a stigmatizing effect related to personal failure, accompanied by self-blame and shame (Wardhaugh, 1999). Although women's experiences of homelessness encompass severe forms of deprivation, e.g. child poverty, their specific needs have been disregarded in European housing policies, and in the development of policies on homelessness in general (Baptista, 2010, Busch-Geertsema et al., 2010). Furthermore, research regarding all aspects of the lives of women in homelessness in Europe is scarce (Baptista, 2010). Research on the health of European women facing homelessness is even more erratic.

Taken together, right to health is a core aspect of human rights. Internationally, a growing awareness of gaps in healthcare received by women versus men is highlighted, and a prioritized area for the United Nations is specific elimination of discrimination against women (United Nations, 1979). However, women in Europe who live without a shelter of a home are left behind (Baptista, 2010). Thus, the objective of this study was to give voice to women with experiences of homelessness, and to explore their perspectives of healthcare services in an EU country with universal healthcare.

2. Methods

2.1. Design

This study comprised a qualitative, interpretive and exploratory approach. The study is part of a research program striving to promote inclusion health among women in homelessness, by developing and implementing interventions to address healthcare inequities. In line with inclusion health (Aldridge et al., 2018, Luchenski et al., 2018, Marmot, 2018), we argue that health and well-being for all in society can only be achieved if groups outside mainstream society are heard, and their knowledge implemented in subsequent appropriate interventions. Thus, the inter-

views were guided by a narrative approach to engage the women in active, meaning-making dialogue (Fraser, 2004). Furthermore, the DEPICT model for collaborative qualitative analysis (Flicker and Nixon, 2015) was used to enhance rigor in the data analysis through collaboration with of women with experience of homelessness.

2.2. Setting and participants

More than 33 000 Swedish citizens or individuals who have temporary or permanent residence permits were reported homeless in Sweden during one week in April 2017 (National Board of Health and Welfare, 2017). Of those reported homeless, 38% were women with a mean age of 39 years. The number of individuals who were acutely homeless had increased compared to an earlier mapping in 2011, as had the number of women, women born abroad, and women with children under 18 years of age.

Data collection took place in a primary healthcare center in Stockholm, the capital of Sweden. The center is open on weekdays, caters to a population of individuals in homelessness within Stockholm county, population 2.4 million. A broad array of healthcare services is offered, without requiring pre-booked appointments nor formal identification. Visits are free of charge, and the center has close collaborations with social services, primary and psychiatric care, and services for treatment of substance use disorder. Around 1300 people, 40 percent women, are cared for by the healthcare center, with approximately 14 000 annual visits. A social services helpdesk and a social services unit, for example assisting with applications for financial aid and housing, are in adjacent rooms.

Participants were recruited in the waiting area of the healthcare center, using convenience sampling. One researcher (EM or AK, both females and registered nurses) and a female research assistant (previously employed at the healthcare center as an assistant nurse) were present in the waiting area. Potential participants were approached and informed about the study, i.e. that we were interested in interviewing women with experiences of homelessness about their perspectives on healthcare services. Inclusion criteria were women with experiences of homelessness, speaking Swedish or English. Exclusion criteria were women exhibiting severe distress or anxiety, manifesting as violent or abusive behavior. If a woman wanted to participate, further written and verbal information were provided in an adjoining room, where the interviews were conducted. The interviewers had experience and training in interviewing for research, however, no previous experience from working with women in homelessness. The research assistant acted as facilitator, with previous knowledge and experience from working with women in homelessness.

The four categories of the European Typology of Homelessness and Housing Exclusion (ETHOS) (Busch-Geertsema et al., 2016) were used to define homelessness: *roofless*, public space or night shelter; *houseless*, homeless hostel, temporary accommodation, transitional supported accommodation, women’s shelter accommodation, temporary accommodation/reception centers or supported accommodation for formerly homeless individuals; *insecure accommodation*, temporarily with family/friends; and *inadequate accommodation*, non-conventional building, temporary structure. Interviews were conducted with 26 women with experiences of homelessness which generated sufficient data regarding breadth and depth to capture a variety of experiences related to the research aim. Two interviews were conducted in English and 24 in Swedish.

See Table 1 for a presentation of the women’s self-reported socio-demographic characteristics.

The youngest woman interviewed was 23 years old, whereas the oldest was 65. The women’s median age was 46 years (range 42) and their mean age was 46.6 years (sd 11.2). All women

Table 1
Socio-demographic characteristics of the interviewed women (n=26).

Characteristics	n (%)
Age group	
20-30 years	2 (8)
31-40 years	4 (15)
41-50 years	9 (35)
51-60 years	7 (27)
61-70 years	3 (12)
Missing	1 (4)
ETHOS ¹	
Roofless	9 (35)
Houseless	9 (35)
Insecure	2 (8)
Inadequate	2 (8)
Missing	1 (4)
Providing	
Sick leave	9 (35)
Unemployed	8 (31)
Sick leave compensation ²	4 (15)
Income support	2 (8)
Pension	1 (4)
Prostitution	1 (4)
Missing	1 (4)

¹ Three women (12%) had been assigned own apartments through social services.

² Compensation Swedish citizens can receive between the ages of 19 and 64 if they will never be able to work, now or in the future, due to sickness or a disability.

had experiences of homelessness and a majority (70%) were roofless/houseless. Three women (12%) had been assigned own apartments through social services. Over half (66%) of the women reported that they were on sick leave or unemployed.

2.3. Data collection

An interview guide was developed with broad areas of interest aiming to elicit narratives (Fraser, 2004) regarding the experiences of seeking healthcare, i.e. what happened, how healthcare services functioned for women in homelessness, and what they appreciated as well as what they would wish for. With an exploratory design, the interview guide was used to provide a tentative structure to introduce topics for discussion (Riessman, 2008). Striving to build trust and a comfortable atmosphere, the interview guide was structured from more concrete to abstract (Price, 2002). Examples of probes used were: *Could you tell me more?, Would you please elaborate?, What happened next?, How did this make you feel?* Participants were encouraged to speak freely of situations and experiences that came to mind, with the interviewer striving to maintain an atmosphere of safe sharing, as opposed to interrogation (Fraser, 2004). Toward the end of the interviews, the interviewer asked if there was anything that participants felt was important to add to the discussion, if they had questions or wanted clarification of some kind. The interviews were audio recorded and lasted between 9 and 34 minutes, mean 22 minutes. As a token of appreciation, participants received a gift certificate (20 euros) valid in a national chain of grocery stores. Two researchers (EM and AK) spent about 20 days in total in the waiting area, and the interviews took place between August 26 and November 15, 2019.

2.4. Women advisory board for inclusion health

An advisory board of women with lived experience of homelessness was established in the Spring 2020; the Women Advisory Board for inclusion health. The purpose of the board was three-fold: to ensure public involvement in the research program; consult with researchers in the interpretation of research findings; and to gain methodological trustworthiness. The women lived in sheltered housing at Ersta Möjlighet in Stockholm that provides specialized, tailored long-term support. The unit has eight places and

Table 2
DEPICT steps, the roles of Women Advisory Board, and guiding questions.

DEPICT step	Member roles	Questions to answer
Dynamic reading	Individually review a subset of assigned and randomly chosen transcripts.	What aspects related to women's experiences of healthcare services seem to be crucial in these texts?
Engaged codebook development	Record notes on important concepts. Work together to list important ideas for categorizing data.	Do we have the right categories? Do we all understand what codes mean and how to apply them? Do codes require further refinement?
Participatory coding	Individually review and code a subset of transcripts.	Which sections of the transcript fit into which categories?
Inclusive reviewing and summarizing of categories	Working together to develop category summaries.	What are some key quotes?
Collaborative analyzing	Work together to depict main findings.	What are our most important findings?
Translating	Develop a knowledge translation and exchange plan for sharing research results to all relevant stakeholders.	How do we get the word out? Strategies and suggestions?

offers protection in safe and secure accommodation for women, who struggle with substance use disorder, as well as extensive male violence and abuse. Women were informed about the project and invited by staff. Those who expressed an interest in attending were invited to two-hour workshop(s), with two researchers (EM and AK) on a weekly basis. The constellation of board members was changeable, i.e. new women at the shelter were invited to participate consecutively, whereas women who were discharged had to leave the Board due to security reasons. Women were free to attend workshops weekly or more sporadically depending on their schedule, psychological well-being, treatments, interest, etc. Board members were paid per hour (temporary employment at Ersta Sköndal Bräcke University College) according to guidelines for patient and public involvement (INVOLVE, 2021).

2.5. Data analysis

All interviews were transcribed verbatim by a professional transcriber and analyzed using qualitative content analysis, as described by Graneheim and Lundman (2004) and Lindgren, Graneheim and Lundman (2020). The analysis process was iterative and conducted in close collaboration between researchers and the Women Advisory Board. Three women attended workshops and took part in the present data analysis. Eight weekly face-to-face workshops were held during September and November 2020, each comprising 2 hours. Two of the authors (EM and AK) facilitated the workshops, and the DEPICT model for collaborative data analysis (Flicker and Nixon, 2015) was used to guide and structure the process. The model includes six sequential steps: Dynamic reading; Engaged codebook development; Participatory coding; Inclusive reviewing and summarizing of categories; Collaborative analyzing; and Translating. See Table 2 for an overview of data analysis activities with the Women Advisory Board.

The first authors (ÅK and EM) read and re-read all de-identified transcriptions of interviews (n=26). Members of the Women Advisory Board individually reviewed entire transcripts of assigned (n=2) and randomly chosen (n=5) interviews as well as sections of most interviews.

Units of analysis were identified, i.e. interview text relevant to the study aim, and general reflections were noted. The de-contextualization and reflections were elaborated and discussed within the research group and in a Women Advisory Board workshop. Next, analysis continued with identifying meaning units, and labelling codes. The codes were compared, highlighting similarities and differences, and subsequently grouped into categories with shared commonality. The categories were labeled and discussed with the Women Advisory Board. These processes generated a first draft of the results with manifest content close to the interview

narratives (Lindgren et al., 2020). Re-contextualization started with formulating sub-themes close to the aim, i.e. experiences of healthcare services, and these sub-themes were created aiming to elucidate the unique experiences of women in homelessness. The Women Advisory Board identified main findings and chose key quotes related to each sub-theme. Further, to deepen the analysis, and to abstract and interpret latent content, in collaboration with the Board, an overall theme, embracing the three sub-themes and highlighting the underlying meaning within and beyond the text, was constructed aiming to make sense of the words in relation to the individual. See Table 3 for examples of analysis proceedings.

The analysis procedure was conducted in several phases, including all authors and the Women Advisory Board with crucial, frequent discussions and reflection, aiming to strengthen the trustworthiness and the credibility of the emerging results, as described by Morse et al. (2002). This iterative process with discussions in the research group was conducted in face-to-face meetings, in phone conversations and in written text like emails. However, all discussions with the Women Advisory Board were conducted in face-to-face workshops coordinated by two of the authors (EM and AK). One woman was involved throughout the analysis process and in the preparation of the manuscript. She read the complete manuscript and approved it before journal submission. Two other women were involved in different parts of the analysis process, together with the first woman. In addition, a fourth woman joined the Board towards the completion of the article. She did not take part in the analysis but read the complete manuscript and provided comments to one of the authors (EM). All women (n=4) had Swedish as their mother tongue, and also had good to excellent skills in the English language.

2.6. Ethical considerations

All participants were offered written and verbal information about the study, and written consent was provided by all participants. Participants who did not want to divulge their names, signed the consent form with 'X'. No identifying personal information that could be connected to a specific woman was collected. Demographics like age, current housing status and occupation were recorded. All data were self-reported, and no medical files were accessed. Audio recordings and all written documentation of research data were stored on a password protected server, only accessible to the research group. Documentation was consecutively organized in folders, each folder contained: the audio file, the transcribed text, and the written consent form for that interview. Ethical approval was granted by the Swedish Ethical Review Authority, number 2019-02130.

Table 3
Analysis process examples.

Meaning unit	Condensed meaning unit	Interpretation	Sub-theme	Theme
<i>Sometimes they don't take you seriously and an addict does not have the same right to healthcare. I have a diagnosis, bipolar condition, both my mother and my grandmother took their own lives. And I don't get medication since I'm an addict. I still need medication. Why don't I have the same right to healthcare? Well, then it's easier to buy heroin to get some peace and take away the pain.</i>	An addict does not have the same rights to healthcare. Even though I have a bipolar condition, and my mother and grandmother committed suicide, I don't get the help I need and am entitled to. Taking drugs gives peace and takes away the pain.	Even though I have serious mental illness I do not get medication since I am an addict. I do not have equal rights to healthcare.	Unwell, unsafe and a woman – multifaceted need challenge healthcare	Visiting healthcare from the outskirts of society
<i>It's tragic that we need to take other ways into society. Everyone deserves a second chance... Staff need to be educated... to go and work in places with addicts, who are active users, so that they see that they are people too, not animals. Often animals are better treated than we are, I honestly think so. I told them last time I was in the hospital, but I'm branded already...</i>	We need different ways of joining society and everyone deserves a second chance. Staff need education to see that active users with addiction are people too. Animals are treated better.	Everyone deserves a chance. Staff are ignorant and mistreat patients. Homelessness and addiction equals stigma.	Abuse versus humanity – power of healthcare encounters to reduce or elevate	

We were conscious of the fact that women who live/have lived in homelessness have difficult experiences of life, possibly characterized by abuse, trauma and violence. The women may suffer from distress, post-traumatic stress, or mental illness. The interviews, as well as reading transcribed interviews, may trigger memories that cause significant distress for the interviewed women and women attending Women Advisory Board workshops. Thus, attention and concerted effort was focused on ensuring the women psychosocial support if needed in association with interviews and workshops.

3. Results

The analysis resulted in one overall theme: *Visiting healthcare from the outskirts of society*, comprising three sub-themes: *Demand for a life in order - Exclusion in action*; *Unwell, unsafe and a woman - Multifaceted needs challenge healthcare*; and *Abuse versus humanity – power of healthcare encounters to raise or reduce*. To summarize the overall theme, women described loss of human dignity in encounters with healthcare services, i.e. feelings of alienation, insecurity, invisibility, and hopelessness, being disconnected, excluded, worthless, met with ignorance and impossible conditions. Yet women also described that healthcare services could offer respite, rest, and sanctuary during severe life circumstances. Experiences were that the women did not quite belong to society like others but were allowed to “visit” as long as they remained cognizant of their place. Being met with compassionate care was a core positive attribute for the women in encounters with healthcare professionals.

3.1. Demand for a life in order - Exclusion in action

The women described that healthcare services came with conditions. Just as an intrusive visitor, they felt that they did not have the same qualifications to partake of healthcare services as others: both concerning having an organized life, but also compliance to policy, guidelines, or treatment. Their narratives attested that they needed to adapt to current policies and structures within the healthcare services, rather than the opposite. Thus, they perceived that the access to healthcare was conditional and included demands they had to conform, or at least relate to.

Demands for a fixed address and an identity card or electronic identification to access healthcare services were prevalent

in women's narratives. Failure to provide the requested information resulted in dismissal and denied care.

“The other places [healthcare centers], they don't understand the living conditions, and then it's like... Do you live somewhere [an address to enter in the system]?.. well no, I don't live anywhere. Then you can't come here, they said..” (P2)

Several women portrayed examples of how they felt excluded when encountering healthcare services because of not having a life in order nor being aligned with the ‘office hour norm’, or having an address. In addition, lack of money was described as an obstacle to receiving medical care.

“I had an experience when I was on the street. I had a medical emergency and the police just sent me to the emergency room. But after being left in the emergency room and knowing that I have to pay, ...so I just left the hospital, yeah.” (P19)

Another example was the need for a telephone to contact healthcare services, which was described as a utopian ideal; to get hold of a telephone, remembering to call in the identified time frame, being met by a telephone queue, and subsequently being turned away and requested to try again tomorrow.

“A small thing, like contact hours can be really hard for many. And getting hold of a phone right then and being able to call, if that doesn't work, or the person is in a meeting, says call back at another time..., that becomes an impossible obstacle. No, I just can't do it, I don't have the energy. It's useless...” (P12)

The culled draft demonstrates the need to have a life in order to be able to access assistance from healthcare services. Moreover, rigid opening hours for clinics were challenging. For example, women stated that morning appointments for telephone and counseling may not be suitable.

“There was another girl there that was doing the same thing, you know she is a prostitute, and you know, ...the nights are so hard that by the time the morning comes maybe they are not thinking about going to a doctor.” (P13)

Instead, the women wished for flexibility, and drop-in clinics, preferably evenings and nights when they needed a safe haven anyway. Also, women suggested that outreach services, specifically targeted to women in homelessness, would improve access to healthcare.

"No, they would need to come back, to find people [in homelessness] on the streets and get them in here, for example unofficially for checkups and healthcare, or the mobile team could collect you and come along to the hospital, stuff like that." (P3)

The excerpt illustrates the women's longing for warmth in terms of compassion, commitment, and comfort in contrast to the coldness and detached environment on the streets. Descriptions that women might choose to abstain from collecting medication to avoid future side effects, if continuing treatment was impossible, were also present. Being in homelessness, often comprising a chaotic life, made it challenging to manage prescriptions and medications.

"As soon as you are homeless, your medication is stolen, and no one believes you." (P18)

Taken together, the women described that the organization of healthcare services contributed to making unreasonable demands on the women seeking care. Inability or failure to comply with the demands resulted in being discharged and denied care which put them in a position of being on the outskirts of society. Thus, social vulnerability significantly contributed to negative health consequences for women living in homelessness, in effect, being excluded within a universal healthcare system and stripped of dignity.

3.2. *Unwell, unsafe and a woman - Multifaceted needs challenge healthcare*

Failure to care for women in homelessness was present in the women's narratives. Their worry was that they were invisible to healthcare services and thus, the care was not tailored to their specific needs. Having complex needs with being unwell, feeling unsafe and being a woman was described as a vicious circle, perpetuating social vulnerabilities and declining health. The women described multifaceted care needs that challenged healthcare priorities and practice; adverse events during care delivery were also described.

Homelessness was described as a direct barrier to receiving preventive care. One woman said:

"I've actually never had a mammogram, and I'm 47, you know. I mean the basic routine of healthcare absolutely goes out the window when survival becomes the number one priority." (P13)

Furthermore, the women voiced that when being unwell, their needs for healthcare services must be addressed differently than healthcare needs of men in homelessness. Examples of expressed needs were contraception guidance, gynecological care and care as a result of male violence.

"So that, well after that I started bleeding and I didn't know why. Or I knew why, sorry. I was pregnant, I had an abortion, had an IUD inserted and then... this was last year in August, so I've been bleeding since August of last year." (P26)

The women found that healthcare services were not designed to meet their needs and instead deprived them of their dignity. Especially the needs of female victims of violence, living in homelessness, were not addressed, and women were left to fend for themselves.

"Here I come... I have a crack in my tibia, I am broken from abuse. I was... there was a rapist in the park. It happens all the time... When a woman has been raped, she crawls away, lies down on a bench and gets no help (sobs)." (P18)

In encounters with healthcare services, it was clear to women in homelessness that they do not fit in, which reiterated that they

were an anomaly, idling in the outskirts of mainstream society. Women described a parallel existence, being neither normal nor belonging. The quotes exhibit troubled feelings among women to seek healthcare services as 'outsiders'. In this sense, the women expressed an additional dimension of homelessness, that was not restricted to lack an address, but also a state of homelessness in society.

"First off, you don't really want to go to them [clinics] like everyone else [not homeless] because you feel odd sort of, you feel like you're not welcome, that's how it is." (P9)

"Regular people get annoyed, scared, angry and whatever else if you are in the same waiting area with them..., maybe you didn't shower for a month, ...whatever." (P12)

Experiences of being unwell in term of multiple illnesses, often a combination of poor physical health, poor mental health and drug use, were described. Complexity and co-morbidities challenged healthcare professionals in care encounters, and medical mistakes that resulted in unnecessary harm to the women were described.

"For example, once I had a stroke, but they thought it was narcotics and didn't discover the stroke, so I collapsed in the hospital... After two days I was sent home even though I've had no care in the hospital." (P6)

As embodied in the excerpts, the women have experienced situations in which they felt unsafe when being treated by healthcare, which threatened patient safety. Another dimension of multifaceted needs challenging healthcare was aspects of continuity.

"Yes, I think you need that as an exposed woman too, you need someone who knows who you are. 'I know her challenges' sort of. Rather than meeting new people and repeating the same life and the same mess over and over again. Eventually you get enough. There's no energy left." (P24)

As shown, the women stressed the importance of continuity of healthcare professionals in healthcare encounters. Continuity meant that someone could help with remembering your health history, so that energy could be focused on recovery instead of feeling hopelessness and giving up. However, adding to this, women also described that the scope of homelessness among women was unknown and met by ignorance among healthcare professionals.

"Well, firstly I feel that they [healthcare professionals] aren't aware of how many women there are out there in homelessness, because they don't show themselves. Only a small fraction is visible." (P9)

Taken together, the women found that healthcare services were tailored for mainstream society and the average citizen, from which they were marginalized, or even excluded. The complex interplay between medical care needs and social vulnerabilities was a threat to patient safety, and a violation on their dignity, exemplified by unintended or unexpected harm during the provision of care, as evident in the women's narratives.

3.3. *Abuse versus humanity – power of healthcare encounters to reduce or elevate*

The women described that they avoided seeking healthcare. Reasons given were: not being treated with respect by healthcare professionals, fear of being branded as an addict, feelings of shame for being in homelessness, and not being able to manage personal hygiene, in combination with descriptions of previous abusive incidents in healthcare provision. In contrast, a strong

patient-professional relationship in healthcare, where women felt respected, safe, and secure, was experienced as the foundation of good quality care by the women in this study.

Prevalent in the narratives were women's experiences that their history and social circumstances determined which services were offered, instead of the current needs. The women described misconceptions among healthcare professionals that individuals in homelessness *always* have a substance use disorder, and further that this substance use is at the root of whichever issue is at hand.

"Abuse occurs every day there, and its' about half the staff against you, ...and they really are against you. There isn't..., f*ck it, we shouldn't have to take..., just because we are using...even though I have a medical condition, they don't even read the papers. They judge you and say that, well..., she just wants meds." (P24)

Women described a controlling atmosphere where healthcare professionals were restrictive, suspicious and asked a lot of questions. For the women, this signaled that the healthcare professionals did not care for them, and that positive reinforcement for the constant ongoing struggle was absent. One woman described her feelings:

"It goes so far that... you're used to it, you back out of the line, get in last and then everyone else does not have to hear... that I have to wait. Basically, you put yourself down. You get last in line even if you were first. ...Sure, go ahead, I'm not as much of a person as you are." (P10)

Similar descriptions were common in the narratives resulting in feelings of resignation and loss of dignity. Abuse was often perpetuated by healthcare professionals or even taken for granted, according to the women, while illness could remain undiagnosed. Descriptions of violations of personal integrity by healthcare professionals were clear in the women's narratives, which was perceived as devastating for a caring, health promoting relationship.

"And then I also show the doctor my bruises and he looks very eager to help. He also...so he took a lot of photos of my bruises and said that he would write me a report. But as of today, I still haven't seen a report with the photos, and he took the photos with his [personal mobile] camera, so I feel like...he got my personal data, my information, but he didn't give it back to me." (P19)

The description demonstrates abuse of power from the physician's hegemonic position in which the woman felt violated – totally stripped of dignity. This example illustrates our interpretation that encountering healthcare service can result in a feeling of being public property. A more flexible and open approach was described in how women were approached in healthcare services specifically targeted to people in homelessness. Women described a caring culture with greater understanding and compassion for individuals in homelessness, this was also reflected in administrative and security personnel at the unit. To be able to go there even if you have been through a rough patch, and meeting someone who understands that it was tough, just getting there.

"I'll put it like this, you recognize all the staff here because it is a warm place, no one throws sh*t around whatever you do, ...even if you are under the influence of alcohol, they don't close the door on you." (P3)

To be listened to was experienced as crucial in care encounters, being allowed to cry and feeling that someone cared. The women stressed the importance of feeling secure, seen and treated with respect. The interviewed women wanted to be seen as individuals, taking current circumstances into account while acknowledging the challenges and needs they struggled with.

"Since I ended up here the first time it changed, I mean really changed. People listen here. Doctors listen, the staff listen, and they ask how I am doing. I feel like they see me." (P4)

"You need more humanity..., here they see us as individuals." (P14)

The excerpts demonstrate the profound need for entering the cottage warmth from their everyday experiences of being on the cold outskirts of society. Healthcare services were also described as providing respite and sanctuary in severe life circumstances, together with a chance to recuperate. To be able to relax, knowing that food and shelter have been taken care of, and being able to take a shower, provided a sense of comfort and self-worth.

"It was pretty luxurious there [in the hospital], they had dessert that you could order from a menu. I had my own menu, and whichever food I wanted..., my goodness, I ate tons! And felt like... actually worth something..." (P1)

Taken together, women's experiences of care encounters were disparate, with prevalent control, mistrust and stigma, yet healthcare professionals that demonstrated respect for the person and human dignity were described both as life-altering and lifesaving.

4. Discussion

The synthesis of our findings from 26 interviews with women having lived experience of homelessness provides a comprehensive compilation of their perspectives of healthcare services in an EU-country with universal healthcare. The women attested that encounters and relationships with healthcare professionals are of great importance during times of homelessness. Being treated with respect, feeling safe and secure were core values for the women when seeking care. However, their shared perspectives from the outskirts of society, carried experiences of being an intrusive visitor. The healthcare system was perceived as confrontative, excluding, unable to maintain care quality, threatening patient safety, and comprised healthcare professionals who have abandoned standards of ethical practice. Our interpretation is that women meeting healthcare services were treated as coming in from the outskirts of society and successively stripped of their dignity.

Our interview study adds to the growing evidence that social determinants of health represents extreme health inequities that call for prompt action and shifting foci in healthcare delivery (Aldridge et al., 2018, Luchenski et al., 2018, Marmot et al., 2012). Consequently, we urge registered nurses (RNs) to take actions to promote inclusion health, i.e. focusing health efforts on people in extremely poor health due to marginalization, multimorbidity, and poverty. RNs have responsibility to *do something*, *do more* and *do better* to frame healthcare services for all citizens, which in turn is crucial to achieve sustainable development of societies (Marmot et al., 2012). Consequently, the forthcoming discussion aims to direct RNs towards this end.

4.1. Do something

RNs need to acknowledge that during times of homelessness, the home, and feelings of being at home, may have a significant meaning to women in relation to their health and well-being (Wardhaugh, 1999). It has been hypothesized that the deep meaning of feeling at-home has important implications to nursing care (Hilli and Eriksson, 2019), i.e. nurses have the power to invite women into caring relationships, through creating *at-homeness*. However, our result revealed that when the atmosphere in care encounters was experienced as negative by women, this led to reinforced feelings of low worth and belonging to the outskirts of society. It is sad to conclude that this is in line with numerous

studies (Omerov et al., 2020), presenting that healthcare professionals are failing to provide for the complex needs of individuals in homelessness with care and compassion. These are identified barriers to inclusion health as groups experiencing health inequities avoid and delay seeking health care (Luchenski et al., 2018), resulting in extensive human suffering (Aldridge et al., 2018) and significant healthcare costs (Department for Communities and Local Government, 2012). Therefore, all RNs need to grasp and adhere to the fundamental principles of ethical conduct for RNs (International Council for Nurses, 2012), here supported by a quote from Indira Gandhi, the first female Prime Minister of India: "Tolerance and compassion are active, not passive states, born of the capacity to listen, to observe and to respect others". Thus, every RN is obliged to act against stigma and discrimination in healthcare.

The literature suggests that RNs are more likely to adopt ethically sound practice if they feel that their peers do the same (Deshpande and Joseph, 2009). Given this, we urge RNs to speak up, address, and confront discriminatory behavior from healthcare professionals against women in homelessness, or other individuals or groups. Discrimination has no place in nursing practice and healthcare. We think of words and language as non-neutral, so use of words and language create and foster an ethical foundation of (workplace) culture. Your words are powerful and have profound effect on co-workers as well as the ethical climate in your workplace. In addition, use your voice as a professional RN to address health inequities through involvement in public debates, conferences, panels, policies and reports.

Although individual nurses have the power to contribute to equal healthcare, we must never forget that RNs work within a healthcare system that has significant impact on the care that women in homelessness receive. The social determinants of health must be addressed in wider social and economic spheres to achieve greater health equity (Aldridge et al., 2018, European Commission, 2013, Luchenski et al., 2018, Fazel et al., 2014, Marmot, 2018, Marmot et al., 2012). Health policies, healthcare structures and management, as well as economic arrangements, distribution of power, gender equity, and societal values are all key components in building sustainable societies.

4.2. Do more

Based on our results we conclude that, even in a system with universal healthcare, social vulnerabilities contribute to negative health consequences for women in homelessness. Civil, political and social rights are inherent in inclusion health and democratic citizenship (Marshall, 1950). Unfortunately, initiatives to accomplish inclusion health, and by association strengthen civil, political and social rights, as well as representation and participation for women in homelessness, are insufficient both in research and in clinical practice (Pleace, 2016). To democratize approaches to equal healthcare, concerted efforts from RNs are needed.

Firstly, removal of barriers to access and uptake of healthcare services can be accelerated by collaborating with people who have experience of social exclusion (Luchenski et al., 2018). Women with experiences of homelessness must be included both in research and practice development, i.e. co-production of healthcare (Luchenski et al., 2018, Marmot et al., 2012). As a RN, you may hesitate or even despair at achieving such social inclusion. Nonetheless, co-creation and partnership with women, experts through experience of homelessness, are essential to ensure health equity, acceptability, and relevance of healthcare services (Luchenski et al., 2018, Marmot, 2018). As a means towards this end, working with inclusion health target populations requires active engagements and may need health professionals going beyond what might be expected from their role (Luchenski et al., 2018). Trained community nurses in collaboration with peer workers, i.e. individuals with

experience of homelessness, might be best suited for engagement and outreach.

Secondly, preserving dignity must be a core dimension in healthcare services for women in homelessness. Our study identified crucial experiences that constitute loss of human dignity for the women. We argue that the loss of human dignity that women in homelessness experience, undermines the most fundamental ideas embodied in the Universal Declaration of Human Rights, the foundation of our modern societies. Thus, women in homelessness represent a case of extreme health inequity that threatens both the legitimacy and the functionality of publicly funded welfare systems (Marshall, 1950). Addressing health inequities, leaving no one behind, is one of the biggest challenges of the 21st century. RNs must do more to protect and restore human dignity for *all* members of the human family. This approach will build human capital by empowering groups experiencing health inequities to influence delivery of healthcare services and take their place as equal members of the society (Marmot, 2018, Marmot et al., 2012). Healthcare providers, administrators and nurse managers have key roles in creating and maintaining a sound ethical climate in the workplace, as well as identifying and implementing mechanisms to manage, change and improve ethical climate in nursing/healthcare settings (Koskenvuori et al., 2019).

4.3. Do better

The complex interplay between social vulnerability and healthcare needs, that women in homelessness described, calls attention to infra-structures in healthcare beyond those traditionally recognized. It has been put forward that flagrant gaps and inequities in health persist both within and between countries partly because of the so-called tribalism of the professions, i.e. the tendency of various professions to act in isolation from or even in competition with each other (Frenk et al., 2010).

For women in homelessness the problems with healthcare services are structural: episodic encounters rather than continuous care, mismatch of competences to meet their needs and poor teamwork. RNs are encouraged, or even required, to develop and utilize new discourses of professionalism to meet the complexity of healthcare challenges related to homelessness and social vulnerabilities. We must continue to develop and expand the knowledge base of professional nursing, while at the same time fostering understanding, respect and deep valuing of other professionals. Only by capitalizing on the synergies between medical, nursing, psychological and social models of care can we counter health inequities stemming from social determinants (Aldridge et al., 2018, Fazel et al., 2014, Frenk et al., 2010, Luchenski et al., 2018, Marmot et al., 2012). This is imperative when caring for women in homelessness who often suffer from tri-morbidity, i.e. a combination of poor physical health, poor mental health and drug/alcohol misuse as well as violence. The ability to deliver seamless health- and social care services for individuals living on the outskirts of society is a key indicator of quality in inclusion health. However, such services need to be supported by information systems that can provide data for continuing advocacy, guide service development, and monitor the health of socially vulnerable populations over time (Aldridge et al., 2018). If we successfully adopt collaborative approaches that reach beyond the silos of individual professions, we enable women in homelessness to move from invisibility to visibility in receiving safe, quality healthcare services and healing.

4.4. Limitations

There are a number of caveats to consider. The literature suggests that monetary incentives in research studies are a useful

strategy to increase the response rate among vulnerable populations (Knoll et al., 2012). In our study, it is likely that the gift certificate facilitated the recruitment of study participants. Our impression is that the women regarded the payment as a sign of respect; their time and contribution were valuable. This in turn, may have facilitated building trust in the interviews.

The interviews with women in homelessness entailed meeting a heterogeneous group with multiple healthcare needs. Alcohol/drug misuse, mental health illness, and neurodevelopmental disorders are factors that may have contributed to relatively short interviews (range 9–34 minutes). However, the women candidly described their experiences when seeking healthcare, and the 26 interviews generated rich and varied data.

We planned to conduct the interviews in co-production with women with own experience of homelessness. Initially, we had contact with two women that were interested in taking an active part in the data collection. But one woman got severely ill and was hospitalized for a long time, and the other woman had a relapse to addiction. Due to commitments to funders, we decided to do the interviews solely with researchers. Four months after data collection was completed; we started our collaboration with the Women Advisory Board. To conclude, we miscalculated the time needed to build an infrastructure for the involvement of women with experience of homelessness in the project. We have learned that strong infrastructures, e.g. collaboration with civil society organizations, are needed to succeed with co-production in research with vulnerable populations.

The co-production with the Women Advisory Board included both ethical and practical considerations. We performed three initial meetings with the women and the staff at the shelter, with the purpose to carefully plan for the workshops. Finding a suitable and safe venue for the workshops needed special attention as the women lived under active threat. Furthermore, we agreed that all face-to-face meetings were to be performed only with two of the authors (EM and AK) to protect the women's identities. Other practical problems were resolved by the Human Resources Administration at the university college (the employer), for example how to get the salary without an identification card or bank account.

The atmosphere in the workshops was characterized by respect and trust for each other's experiences and skills. Sharing power and interpretative control resulted in active mutual involvement in the analysis process. The DEPICT model for collaborative qualitative analysis (Flicker and Nixon, 2015) was a valuable tool to guide the process. The model was found flexible and represents a democratic approach to enhance rigor in the analysis through inclusion of women with lived experience of homelessness. However, implementing a collaborative, inclusive qualitative research analysis included challenges for all involved. One example was difficulties keep up with each other during the analysis process, as we were unable to have joint meetings. To anchor the discussions held in workshops to the other authors was time-consuming. Another challenge was the changeable nature of the Women Advisory Board. We started the analysis process with one woman and over time two new women were added to the Board. However, the latter women left the shelter before the analysis was completed. Protecting new Board members' identities was a prerequisite for our collaboration, as the shelter must meet legal requirements in line with national standards of security and confidentiality. Thus, the women who were discharged from the shelter had to leave the Board as well. We tried to maintain a parallel board with women who had left the shelter, but failed to maintain contact. Taken together, continuity of members in the Board over time was difficult, or even impossible, to accomplish. Instead, we acknowledge and value each woman's unique contribution to parts of the research process. A strength of the present study is that one woman from the board took part in the whole data analysis and

the preparation of the manuscript. Other strengths are that additionally two women contributed to parts of the data analysis and a fourth woman read and commented on the final manuscript.

Furthermore, reading and processing stories of violence and abuse was taxing for women with their own experiences, however, all involved found that the experience helped with perspectives and finding a voice to speak up. Working with the manuscript, in co-production, was seen as deeply meaningful by all. Including women with lived experience on our analysis team enriched the data analysis and provided more nuanced understandings of the complexity of navigating through a universal healthcare system, as a woman without the shelter of a home. Our take home message is to embrace co-production at the very start of any future research project to benefit from the strength of lived experience throughout the research process.

Finally, it is important to bear in mind that the interviews were conducted before the Covid-19 pandemic in 2020. One may assume that the pandemic has made circumstances for women in homelessness even more difficult.

5. Conclusions

Women in homelessness live on the outskirts of society and have multiple experiences of exclusion and loss of dignity within healthcare services. The multifaceted care needs and frequent trimorbidity challenge healthcare, leading to women feeling alienated, invisible, disconnected and worthless. However, women also described healthcare services as respite, rest and a sanctuary. We urge registered nurses to take actions for inclusion health, focusing health efforts of people experiencing extreme health inequities due to marginalization and poverty. We can lead the way by speaking up and confronting discriminating behaviors, protecting and restoring human dignity in caring relationships, and joining forces with other professionals and stakeholders, like women in homelessness. This is imperative to frame healthcare services for *all* citizens and to promote sustainable development of societies globally and highlighting ethical nursing conduct in line with professional standards of ethical practice.

CRedit authorship contribution statement

Åsa Kneck: Writing – review & editing. **Elisabet Mattsson:** Conceptualization, Methodology, Writing – review & editing. **Martin Salzmänn-Erikson:** Writing – review & editing. **Anna Klarare:** Conceptualization, Methodology, Writing – review & editing.

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Conflict of interest

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