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RESEARCH ARTICLE

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SEXUAL EXPERIENCES OF ELDERLY INDIVIDUALS WITH PHYSICAL DISABILITIES AND THEIR WELL-BEING[1]

Sexuelle Erfahrungen von älteren Menschen mit körperlichen Behinderungen und ihr Wohlbefinden

Fiziksel Engelli Yaşlıların Cinsel Deneyimleri ve İyilik Halleri

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ABSTRACT

Elderly individuals with physical disabilities (EIPD) are subject to the same rights and freedoms as the general population in the context of sexuality. However, the elements of social norms and religion may cause EIPD to experience sexuality differently. The approaches of health and social care institutions, the attitudes of families and caregivers, and the level of interest of the relevant occupational groups can affect the sexual well-being of the individuals. This study is a phenomenological research based on the personal experiences of EIPD. The results indicate that the participants consider themselves adequate or partiallyadequate with their knowledge on sexuality. The sexual well-being of the participants is negatively affected by aging and disability. The participants do not think they have freedom of expression and they experience discrimination from close circle. The study concludes that the sexual life of EIPD is limited or shaped by social norms, values, beliefs and religion.

Keywords: Elderly Individuals with physical disabilities (EIPD), sexual experiences, sexuality, well-being.

ZUSAMMENFASSUNG

Für ältere Menschen mit körperlichen Behinderungen (EIPD) gelten im Bereich der Sexualität die gleichen Rechte und Freiheiten wie für die Allgemeinbevölkerung. Die Elemente der sozialen Normen und der Religion können jedoch dazu führen, dass EIPD Sexualität anders erleben. Die Ansätze der Gesundheits- und Sozialeinrichtungen, die Einstellungen der Familien und Betreuer sowie das Interesse der jeweiligen Berufsgruppen können das sexuelle Wohlbefinden der Betroffe-

1 This article was produced from the master thesis of the first author.

nen beeinflussen. Bei dieser Studie handelt es sich um eine phänomenologische Untersuchung, die auf den persönlichen Erfahrungen von EIPD basiert. Die Ergebnisse zeigen, dass die Teilnehmer ihr Wissen über Sexualität als ausreichend oder teilweise unzureichend einschätzen. Das sexuelle Wohlbefinden der Teilnehmer wird durch das Älterwerden und die Behinderung negativ beeinflusst. Die Teilnehmer sind der Meinung, dass sie sich nicht frei äußern können, und sie erleben Diskriminierung durch ihr Umfeld. Die Studie kommt zu dem Schluss, dass das Sexualleben von EIPD durch soziale Normen, Werte, Überzeugungen und Religion eingeschränkt oder geprägt ist.

Schlüsselwörter: Ältere Menschen mit körperlichen Behinderungen (EIPD), sexuelle Erfahrungen, Sexualität, Wohlbefinden.

ÖZET

Fiziksel engelli yaşlı bireyler cinsel hak ve özgürlükler açısından eşit haklara sahiptir. Ancak toplumsal normlar, aile yapısı ve inanç ögeleri fiziksel engelli yaşlı bireylerin cinselliği farklı deneyimlemelerine sebep olabilmektedir. Özellikle bakım servislerinin ve sağlık kuruluşlarının yaklaşımları, aile ve bakım verenlerin tutumları ve ilgili meslek gruplarının ilgi düzeyi bireylerin cinsel iyilik hallerini etkileyebilmektedir. Bu çalışma, fiziksel engelli yaşlı bireylerin kişisel deneyimlerinden yola çıkan bir fenomenolojiyi yansıtmaktadır. Araştırma sonuçlarına bakıldığında, katılımcılar cinsel bilgi açısından kendilerini yeterli veya kısmen yeterli gördüklerini belirtmiştir. Katılımcıların cinsel iyilik halinin yaşlılık ve engelliliğe bağlı olarak olumsuz etkilendiği saptanmıştır. Katılımcılar, cinsel konularda ifade özgürlüklerinin olmadığını ve çevrelerinden ayrımcılığa maruz kaldıklarını belirtmiştir. Cinsel yaşantının toplumsal normlar, değerler ve inançlar tarafından sınırlandırıldığı veya şekillendirildiği katılımcılar tarafından belirtilmiştir..

Anahtar Kelimeler: Fiziksel engelli yaşlılar, cinsel deneyimler, cinsellik, iyilik hali.

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INTRODUCTION

In particular, due to the civil war in Syria, Turkey has been exposed to the largest mass migration In the 20th century, social scientists began to carry out important studies on the well-being of individuals (Diener & Biswas-Diener, 2005). After World War II, scales were developed, and studies were conducted by researchers to measure the well-being of individuals (Snyder & Lopez, 2002). However, because of the changing conditions and developments, the scope of the concept of well-being has changed and new criteria have emerged. One of these criteria was determined as sexuality. Especially in the 21st century, discussions on sexuality have increased significantly and the view that sexuality affects the well-being of individuals has been widely accepted (Lee, Fenge, & Collins, 2020). Nevertheless, the political, cultural and religious context in Turkey can be unwelcoming with regards to sex-related research and practices. Education and health programs largely avoid sexual elements. Although there are few experimental studies on the sexual life of EIPD, they are commonly considered to be asexual and absent from sexual activities (Bywater & Jones, 2007). This situation emerges as an important constraint on the sexual rights of individuals, which are an important part of their identities. Previous studies on the sexual experiences of EIPD reveal that individuals struggle with multiple personal and social constraints that directly and indirectly affect decision-making processes (Sinclair et al., 2015). In this sense, it is stated by the Sexual Information and Education Council (2012) that sexuality should be evaluated across multiple dimensions; namely biological, social, psychological, spiritual, ethical and cultural dimensions.

In addition, the media discriminates against EIPD and portrays them with traditional and different characteristics (Steinke, 1994). However, sexual rights have been recognized by many institutions and organizations and these rights are guaranteed by national and international regulations. The World Association for Sexual Health (2008) mentions the terms related to rights and freedoms such as "sexual freedom, sexual independence, sexual integrity and body safety, sexual privacy, free sexual relations, free and responsible choices about reproduction, scientific research-based sexual information, comprehensive sexual education and sexual health service" in the Declaration of Sexual Rights. Belief systems, cultural elements, and social norms can significantly affect open discussion about sexuality (Loe, 2004). Subjects such as engaging in sexual activities, discussing sexual preferences, showing erotic behaviours, and evaluating inter-gender relations have been tackled to a limited extent up to this century and even expressing sexuality has been difficult (Aggleton & Parker, 2010). This study is a pioneering work in Turkey since it is the first study regarding the sexual experiences of EIPD.

Well-being and Sexuality

The concept of well-being is a very broad term and is often referred to as quality of life and happiness in conceptual studies (Paim, 1995). With the development of debates on the necessity of a holistic approach to health, new definitions of health have been needed. As a result, explaining health only with consideration of its physical dimension is not sufficient (Greenberg & Dintiman, 1995).

The World Health Organization (2017) defines health as "the state of complete physical, mental and social well-being ". The concept of well-being has also been introduced as an umbrella term that is a holistic approach to health (Adams et al., 2000; Fahey et al., 2014). When the definitions of well-being are examined, different approaches to the term are apparent. Diener (2009), one of the pioneers of the conceptualization of well-being, states that well-being should be re-evaluated with regard to the existing conditions of the person and is a temporary and constantly changing concept. Dunn (1959) defines well-being as “the capability of an individual who is able to use his / her potential at the highest level to fulfil his / her functions in many areas of life”.

Sexuality is a basic need (Maslow, 1943) and an important part of life in terms of life satisfaction (Neufeld et al., 2002). Sexuality is not only a component of human existence, but also plays an important role in the formation of the individual's identity. Attitudes towards the concepts of sexuality, self-confidence, body image, and self also play a key role (Pangman & Seguire, 2000). For EIPD, chronic stress can occur due to problems associated with old age as well in addition to problems caused by disability (Bierman & Statland, 2010). Studies show that EIPD have lower self-esteem (Reitzes & Mutran, 2006) and more negative thoughts (Caputo & Simon, 2013) than non-disabled individuals. Woodard and Rollin (1981) state that sexuality comprises of five basic purposes which are reproduction, physical satisfaction, presentation of love, achieving integrity, and adaptation; moreover, sexuality is a criterion of holistic well-being.

Attitudes towards the Sexual Life of EIPD

Sexuality is linked to many disciplines including history, anthropology, religion, philosophy, sociology and psychology. Individual and social views on sexuality are shaped in direct proportion to the development and the change of these disciplines (Parkes, 2006). This makes it necessary to discuss all aspects of sexuality according to different areas of expertise. Both when speaking to their families and with professionals, EIPD do not have the freedom of expressing themselves on the sexual matters and are mostly obliged to submit to pressure to remain silent on this topic (Coleman & Murphy, 1980). There are two main prejudices regarding the sexual life of EIPD. The first is the belief that individuals are asexual, and the second is the belief that sexual activities cannot be performed due to sexual dysfunction, even if they have sexual desires (DiGiulio, 2003). This situation both increases the stress levels of EIPD and limits the regulatory and developmental practices regarding sexual function (Chandani et al., 1989). However, since normalization philosophy became widespread, it has been stated that awareness on sexual rights has increased with the transition to the development process of the sexual rights of the EIPD (Aunos & Feldman, 2002). In spite of the increased awareness, the level of knowledge has not reached the desired level (Sinclair et al., 2015). In addition, despite this understanding that has developed up to now, sexuality is still not clearly grasped by families, institutions and healthcare professionals (Toubak, 2011). This situation may cause various forms of sexual violence to be experienced especially by individuals with disabilities (Healy, 2020).

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The attitudes and behaviours of families and those in the close environment towards EIPD have a direct effect on individuals' sexual expression and behaviour (Chou & Lou, 2011). The rate of participation of EIPD in the decision-making processes in the family regarding sexual matters has been found as 20% in a study (Evans et al., 2009). This shows that individuals in the close environment are an important obstacle in making individual decisions. In another study, it has been found that the family and close environment restrict disabled individuals and give negative messages because they think that disabled individuals are sexually inactive (Shuttleworth, 2000). In addition, roles such as being a grandmother, grandfather or an uncle in old age are common social roles for elderly individuals and these individuals can be considered asexual regardless of their masculinity or femininity (Penhollow, 2006).

The sexual histories, orientations and preferences of the individuals are ignored, and the individual applications to the healthcare institutions are standardized during the admission process (Haesler et al., 2016). There is no formal understanding of education on sexuality in the public sense and care professionals do not receive any type of education on sexuality (Lichtenberg, 2010). Leigh et al. (2004) state that professionals working in the care institutions, especially psychologists and social workers need additional training on sexuality. Social workers assume important responsibilities which includes the responsibility of meeting the needs of individuals and providing information on sexual matters to other staff at their institutions (Fairchild et al., 1996). In addition, in the report published by NASW (1996) with the title of “Ethical Principles”, it is emphasized that social workers should assume an advocacy role on matters regarding sexuality.

Stereotypes and prejudiced attitudes of healthcare professionals towards EIPD may cause individuals not to receive proper services from professionals. It is stated that the reason for this situation is the inadequate training of healthcare professionals providing services for EIPD and often results from a medical thinking (NCD, 2009). Strike et al. (2004) emphasize that the knowledge, awareness and skills of healthcare professionals on issues such as gender, sexuality and sexual well-being are insufficient, and that these skills need to be improved. In the study conducted by Haesler (2016), it has been found out that healthcare workers have negative attitudes. The attitudes and behaviours of healthcare professionals towards EIPD are grouped under three main problem areas: lack of knowledge about disabled people, discomfort with working with EIPD, and wrong perceptions and attitudes (Lam, 2010). These problem areas have a direct impact on the well-being of EIPD (Minihan et al., 2011; WHO, 2011). In studies examining the attitudes of doctors (Bauer et al., 2007; MH Dunn & Cutler, 2000), attitudes and behaviours of nurses and caregivers (Bouman et al., 2007; Maes & Louis, 2011; Mahieu et al., 2011), it has been concluded that professionals behave timidly about sexuality and do not have sufficient knowledge about sexuality and have personal stereotypes, while individuals refrain from discussing sexual activities and fantasies. This is directly related to the level of sexual education. In the international literature, it is stated that almost half (44%) of institutions providing medical education still do not have a sexual education program (Malhotra et al, 2008).

The Sexual Function of EIPD

Although it is commonly thought that EIPD do not have an active sexual life, studies reveal that this is a misunderstanding (Lindau, Laumann, & O'Muircheartaigh, 2007; Starr & Weiner, 1982). The quality of sexual intercourse increases as age increases (Ferrini & Ferrini, 2008; Starr & Weiner, 1982). In addition, perceiving sexuality as only sexual intercourse may cause the other dimensions of sexuality to be ignored, such as love, passion and belongingness (Starr & Weiner, 1982). Lindau et al. (2007) have found that 50% of women (age 65 and over) and 70% of men are willing to participate in sexual activities. In the same study, the frequency of sexual activity has been found to be 73% in the 57-64 age range, 53% in the 65-74 age range, and 26% in the 75-85 age range by comparing sexual behaviours for twelve months. In other similar studies, it has been stated that individuals argue sexuality is a life-long activity and that their sexual desires continue (Arias-Castillo et al., 2009; Beckman et al., 2008; Camacho & Reyez-Ortiz, 2005; Trudel & Desjardins, 2000). In a study conducted with 2577 men and 3195 women aged 65 and over, it has been determined that sexually active individuals are happier than other individuals. In addition, the well-being scores of individuals who do not have a sexually active life are found to be lower than those who are active (Smith et al., 2019). In another study, life satisfaction and well-being scores of individuals who can talk about sexuality and act more freely than other individuals have been found to be higher (Schlesinger, 1996). It is also among the result of similar studies that the frequency of sexual intercourse is also important. In the study conducted by Moore (2011), it has been found that there is a correlation between the frequency of sexual activity and well-being.

METHODS

In the Turkish literature, no quantitative measurement tool has been found to demonstrate the sexual knowledge, understanding and experience of EIPD and their well-being. In this study, a qualitative research method has been used in order to examine the subjective experiences and opinions of the EIPD through in-depth interviews. The in-depth interview technique has been used in many social sciences and has made significant contributions to the qualitative research method (LeCompte & Goetz, 1982). The common purpose in all these disciplines is to "try to understand human behaviour in its environment and in a multifaceted way" (Yıldırım & Şimşek, 2013). Qualitative research aims to understand behaviours and their underlying causes in depth rather than a numerical proof purpose like mathematics (Creswell, 2014). Therefore, the qualitative research method is used for the understanding of sexuality which is a subject closed to public discussion and considered as taboo in Turkey.

In the study, the phenomenological approach has been used to accurately understand the experiences. This approach defends the view that "experienced knowledge reflects the truth" (Creswell, 2007; Creswell & Poth, 2018). Phenomenology is used to reflect the opinions, thoughts and different perspectives of individuals based on their life experiences regarding a phenomenon (Creswell,

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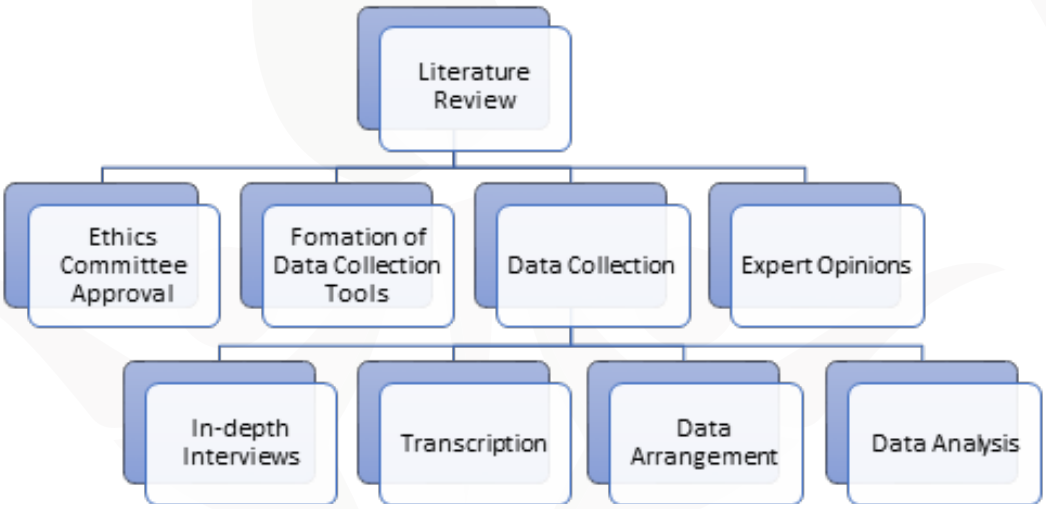
2014). This understanding reveals that the subjective assessments of EIPD reflect a phenomenology based on many different experiences and knowledge rather than reflecting a single truth (Salice & Schmid, 2006). This method used in this study provides the opportunity to obtain more in-depth information about the situation and previous experiences obtained directly from individuals with physical disabilities (IPD) and to interpret the reflected feelings more accurately. In addition, the experience and observations of the researcher in qualitative research contribute to the phenomenology experienced by the individuals (Mertens, 2009). In this context, the second author's twenty years of nursing home management experience and first author's five years of experience as a social worker in a nursing home contribute to the interpretation of the participants' sexual experiences from an expert perspective.

Figure 1: Research Pattern



In Figure 1, the stages of the research from the preparation of semi-structured interview form based on previous research and expert opinions to the data analysis process are indicated. This research pattern is a widely used method in qualitative research processes (Creswell, 2007; Yıldırım & Şimşek, 2013).

Qualitative research, unlike quantitative research, does not aim to generalize and reflect the entire universe. The qualitative research tradition is mostly aimed at reaching the entire universe (LeCompte & Goetz, 1982). In this context, there is no conviction that the population should reflect the general inferences, considering that everyone has different knowledge and experiences regarding sexuality.

This study has been carried out with 23 individuals (F: 13, M: 10) who have physical disabilities and are 65 years old and older. The criterion sampling method has been used in the study. In the purposeful sampling method, a research opportunity is obtained that allows for in-depth discussion of the subject according to the criteria determined by the researcher and to evaluate the phenomenon with all its details rather than generalizing the sample to the population, (Creswell, 2007; Creswell

& Poth, 2018). The purposeful criterion sampling method is a method that uses pre-determined criteria for the subject and group to be researched. The criteria determined by the researchers are listed as follows:

1) Being 65 years of age or older,

2) Having a physical disability

3) Not having any obstacle to verbal communication,

4) Not having any psychological or psycho-pathological diagnosis.

During the research process, 30 EIPD who were previously selected based on the above criteria have been interviewed. However, 3 of the participants were not included in the research group as it was determined that they did not meet the fourth criterion since they had Alzheimer's disease. In addition, 4 of the participants were excluded from the research group due to ethical concerns, because the individuals stated that they did not want to participate in the study after the interviews were completed. As a result, the research was completed with 23 individuals.

Data Collection

No positive feedback was received when the aim to conduct research on sexuality was communicated to the institutions and organizations where the EIPD are under care. In Turkey, especially sexuality, sexual health, abuse and neglect are the areas that are closed to discussion and research and support is quite limited. This has been experienced once again during the data collection process of this study. Social workers who work in private institutions such as nursing homes were contacted to reach out to the EIPD. Social workers reported that the supervisors of the institutions were not favourable on the subject and that they could help if there was another topic rather than sexuality. After negative feedback received from private institutions, associations and foundations were contacted, but the reaction was similar.

After it became clear that obtaining permission from the institutions where the EIPD reside collectively was not possible, the process had to be carried out on individual bases. Thanks to the qualitative research structure that allows researchers to reach out to groups (Creswell, 2007), based on the report "Disabled and Elderly Bulletin" (2019) published by Republic of Turkey, the Ministry of Family, Labour and Social Services, Mersin province was selected because of its disabled and elderly population ratio.

During the data collection process, 5 of the EIPD were interviewed in the home environment while 18 people were interviewed in various public spaces. The family members of the interviewees were contacted in the home environment and the meetings were held at the specified hours. Before the interviews, it was agreed that family members should not be in the room where the interview was

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being conducted. In addition, in the interviews held outside the home, the physical environment was made suitable for the interview and the participants' views were only heard by the researcher. Before starting the in-depth interview, the “Consent Form” was read to the participants and their approval was obtained. In accordance with the purposeful sampling method, statements were also received to confirm that they comply with the criteria determined by the researcher.

Before the interview started, consent for voice record was obtained from the participants and they were informed that the records would be destroyed within 2 years after the research was published. Initially, all the participants gave their consent for recording, but after the interviews were completed, 4 participants requested that the recording be deleted because they thought it would not be appropriate (thinking their answers would be disclosed). Since the research was based on voluntary participation, these records were deleted, and 4 participants were not included in the study in line with ethical principles. Thus, 23 interviews in total were conducted and the data collection process has been finalized.

Considering the possible inappropriacy of a male researcher interviewing women regarding sexual matters and the socio-cultural structure of Turkey, Social Worker E. G (female) offered support during the interviews with female participants. In addition, since the possibility of the participants being timid in providing their information could affect the reliability of the research results, getting support from a female professional was considered necessary. E. G is a social work professional and has academic and practical experience, which was commented as ethically positive decision by the Ethics Committee. However, 4 of the female participants stated that they would be uncomfortable with the voice recordings and that they could be given to the researcher in writing. Social Worker E.G. accepted the concerns of the participants and upon the request of 4 female participants, the audio recordings were deleted and archived in a written form.

Data Analysis

The data analysis process includes the processes of “making the necessary arrangements (prearrangement, naming), coding and categorizing the data, and interpreting the data according to the research results after the data is collected (Creswell, 2007). The analysis process has not included any correction of the participants' answers since qualitative research findings should be used by directly quoting (Yıldırım & Şimşek, 2013). A thematic analysis method has been used in the study. In this research model, the method of creating codes according to the answers, not coding the answers in accordance with the predetermined themes, is realized (Ezzy, 2002). Thus, the participants were given the opportunity to reflect their knowledge and experiences that are not included in the literature. The data have been themed with the help of the NVivo 12 program which is a package program that is widely used in qualitative research and analysed by coding.

RESULTS

In this study, it is aimed to understand the sexual knowledge, attitudes and behaviours about sexuality of EIPD and subjective evaluation of sexuality in Turkey through the eyes of EIPD. Research questions are listed below:

What is the level of sexual knowledge of EIPD?

How do EIPD experience sexuality? What are the sexual attitudes and behaviours of EIPD?

What are the expectations of EIPD regarding sexuality? What is the current situation regarding their education and policy planning on the matter?

How are EIPD perceived by the family and society?

The subjective knowledge, experience and expectations of the EIPD in line with the above questions will be discussed in the findings section. In this way, it is aimed to clarify the ideas of individuals about sexuality from their own point of view. In addition, it is among the aims of this study to reveal false or unknown information about the personal expectations and desires of the EIPD on the part of the families, society and policy makers.

Brief Introduction to the Participants

Individuals from different age groups have been interviewed to reflect the diversity of the research sample. The age range of the participants is 66-93 and the average age of the participants is 77.08. One of the participants is literate (without a school degree) (F = 1), eight are graduates of elementary school (F = 5, M = 3), ten hold a high school degree (F = 4, M = 6), and four are university (F = 3, M = 1) graduates. The professions of the participants are as follows; fifteen participants are retired (f = 5, M = 10) and used to work as mechanical engineer, driver, actor, soldier, farmer, teacher, broker, government official, customs counsellor, and trader. Six female participants are unemployed and describe themselves as housewives (F = 6) and two people are business owners (F = 2). When the statements of the participants regarding their income levels are examined, it is seen that twelve participants perceive their income level as sufficient (F = 8, M = 4), five of them perceive it to be partially sufficient (F = 1, M = 4), and six report their income as insufficient (F = 3, M = 4). 3). Fourteen of the participants have nuclear families (F = 10, M = 4) and nine of them have large families (F = 3, M = 6). Furthermore, ten participants live in Mersin (F = 5, M = 5), the remaining live in Italy (Padova), Ankara, Istanbul (Sarıyer), Adana, Izmit, Antakya, Elazığ, Kayseri, Kars. All but one of the participants have married once, one participant has married twice. Eight of them are currently married (F = 3, M = 5), two participants are divorced (E = 2), twelve are widowed (F = 10, M = 2). When it comes to the age of marriage of the participants, it has been found that the age of marriage is between 19-31 and the average age of marriage is 24.45. The participant who has never married is not included in this average regarding the age of marriage. .

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Detailed Information on the Participants

Information about the participants is indicated below in the Table 1. It has been found that all the participants have become disabled during later stages of their lives and the majority suffer from orthopaedic disabilities. It is also among the findings that all participants have at least one chronic disease.

Tablo 1: Information on the Participants

Participants	Type of Physical Disability	Percentage of Physical Disability (%)	Did disability occur at birth or later?	Mobility	Illnesses	Addictions
Participant 1 (M)	orthopaedic	60	later	partial (with the help of a walker)	prostate disorder, diabetes, hypertension	nicotine and alcohol
Participant 2 (F)	orthopaedic	80	later	partial (with the help of a walker)	diabetes, high blood pressure, osteolysis	none
Participant 3 (M)	hearing	40	later	yes	diabetes	nicotine
Participant 4 (M)	orthopaedic	40	later	partial	colon cancer	recovered (nicotine and alcohol)
Participant 5 (F)	orthopaedic	60	later	partial (with the help of a walker)	high blood pressure, obesity	none
Participant 6 (F)	orthopaedic	52	later	partial	diabetes, high blood pressure	none
Participant 7 (M)	orthopaedic	65	later	partial (with the help of a walker)	cardiac insufficiency, high blood pressure	none
Participant 8 (F)	orthopaedic	No answer	later	yes	diabetes	none
Participant 9 (F)	orthopaedic	80	later	partial (with the help of a walker)	diabetes, high blood pressure	none
Participant 10 (F)	hearing	46	later	yes	cardiac insufficiency	none
Participant 11 (M)	orthopaedic	60	later	partial (one leg is amputated)	kidney failure	recovered (nicotine and alcohol)
Participant 12 (M)	orthopaedic	20	later	partial	diabetes, high blood pressure	alcohol

Participant 13 (F)	orthopaedic	30	later	partial	Parkinson's disease, high blood pressure	recovered (nicotine and alcohol)
Participant 14 (M)	orthopaedic	32	later	partial (with the help of a walker)	high blood pressure	none
Participant 15 (F)	orthopaedic	60	later	partial (with the help of a walker)	epilepsy	nicotine
Participant 16 (F)	orthopaedic	25	later	partial	Parkinson's disease	none
Participant 17 (F)	orthopaedic	No answer	later	yes	cardiac insufficiency	none
Participant 18 (F)	visual	56	later	yes	diabetes	recovered (nicotine and alcohol)
Participant 19 (F)	hearing	38	later	yes	high blood pressure	nicotine and alcohol
Participant 20 (F)	orthopaedic	45	later	yes (with rare exceptions)	high blood pressure	recovered (nicotine and alcohol)
Participant 21(M)	hearing	50	later	yes	diabetes, high blood pressure	nicotine
Participant 22 (M)	orthopaedic	No answer	later	yes	cardiac insufficiency, high blood pressure	recovered (nicotine and alcohol)
Participant 23 (M)	orthopaedic	90	later	partial (on a wheelchair)	diabetes	nicotine and alcohol

Information on the Sexuality of the Participants

While the participants stated that they see their sexual knowledge status sufficient or partially sufficient, some participants stated that they are not sure about their sexual knowledge level. It has been found that their sexual knowledge is generally based on post-marital experiences:

P1: I have enough information.

P2: How can I know?

P3: We experienced enough? Don't get me started now (laughing).

P4: I cannot say that I know much, I do not have much experience. I live like this on my own. I don't know much about this.

P5: We only know how to have children.

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P11: It is sufficient, but if there is something we do not know, tell me. (laughing)

P19: I guess I know about sexuality. I mean I somehow know.

Most of the participants stated that they base their sexual knowledge on their own experiences as a source of information. Apart from their experiences, it was stated that they obtained information from friends and media (television). It has been revealed that the participants rarely choose intellectual methods (books, documentaries) in their sources of obtaining sexual information, and they usually acquire the information through traditional learning methods:

P1: So, I didn't do anything in particular. We learned what we heard and what we experienced. In addition, we used to watch such programs on TV. I sometimes watched on TV. How would I know? We would listen to doctors.

P19: I learned from books, from friends and experiences. I used to read books about this, books about health. But human life is something else. Of course, the best knowledge is experience.

P14: You learn from the circle of friends and you get married. It goes like this.

It was found that the participants were generally shy about talking about sexual matters, and they generally shared their views with their friends and spouses. It was also found out that some participants were able to talk about sexuality in public more comfortably than the other participants. In addition, the participants who did not talk about sexuality with other individuals found this type of conversations about sexuality wrong:

P3: It's not a shame. It is in our nature so if something happens, I will tell the person I am with because she understands me. You cannot talk to anyone else.

P5: I would not talk to my husband. How could I talk about it? How would you tell it anyway?

P7: I did not even talk to my wife. This is not traditionally okay.

P2: I used to talk with my husband after we got married. How else would it be? We got married and learned.

P9: I don't know. Such things go by word of mouth. I used to talk to my mother when I was little, then with my husband.

Considering the sexual education status of the participants, it was found that none of them received a sexual education. In addition, they were not sure whether there was a formal sexual education or not, and did not know how and in what form this education could be given:

P2: I do not know maybe there is somebody who can educate you. Nobody told us anything. But maybe there is.

P5: If I had known, my children would not be disabled. We are so ignorant that we have done this to both ourselves and our children.

Examining the statements of the participants, it was deduced that sexual education is important and should be given in the early stages of life. The participants did not directly focus on sexual education during interviews and generally talked about a general education approach.

P1: Education should be given to everyone. Everybody is equal.

P11: I am ignorant. You see what is going on with the news. We must explain especially to the young because nobody knows anything about this subject. You see, our people are strange.

P18: I was very scared when I was getting married. I didn't even understand what it was. Nobody would tell me about this at school. It is not a shameful topic, but everyone thinks so. We must explain this at schools.

P19: I worked in the public sector for 25 years. Such things are not discussed in schools. Nobody can do anything, but it would be better if it were done.

P23: Everybody needs to learn.

P6: I am a retired teacher. As someone who dealt with children for years, I believe that sexual education should be given starting from childhood. Sexual matters are relevant from infancy to old age. EIPD should also receive training because it is more difficult for them.

Sexual Experiences: Before and After

Regarding the sexual changes due to the disability and the age increase, it was found that generally the participants who continue sexual activities are married and some of the participants continue extramarital relations. However, there are significant changes in the sexual lives of the participants, especially those who have lost their spouses:

P16: There is tension, I don't know, there is something else, it is not the same as before. One should know the value of youth.

P18: It is not the same as before. I miss the old times, but we are still standing. Thank goodness for that.

P23: Sexual desire is always present.

History of Sexuality that Changes with Aging

Sexual changes are inevitable with old age. However, different reasons for experiencing change stand out. It was found that it is a process experienced especially as a result of the loss of sexual partners:

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P1: Generally, in old age, it is not time for sexuality, it is not the same as before. It's a matter of time.

P3: It's not like it used to be. I used to be very energetic. Women always loved me. But I know my wife was enough for me.

P11: I look back at my youth, I had a lot of experiences. But now that I am old, I have nothing to tell. The days are passing by.

P12: It is not easy. You see, we can't get up, we can't sit. It is not so easy like it used to be.

P15: It has been 15-20 years since my sexual life has ended. I did not get married after my husband. It didn't happen after that.

P22: Because of the health problems, you cannot deal with anything else.

P7: Everything is empty when one is old. I'm waiting for death. I don't even get the taste of food, let alone sexuality.

P8: It is not easy when you get older. My husband also passed. It has been 2 years.

The Effect of Physical Disability on Sexual Life

Physical disability directly affects sexual experiences. However, it is also among the experiences of individuals that they are restricted by the attitudes of the society and stereotypes:

P12: You cannot even stand up at times. Health is another thing!

P14: My wife took good care of me. If only my knees would hold! I would return to my youth. A disabled person cannot go anywhere on the street. Let alone experience his sexuality! It's hard to imagine. I don't have feet. Who would marry me?

P18: I can't see in one eye. In the past, men used to chase me. Now those days are gone.

P6: Disabled people cannot live the way they want. They suppress their feelings because of what society might say.

Perceptions, Attitudes and Behaviours regarding Sexuality

Perceptions, attitudes and behaviours towards the sexual life of EIPD are discussed in the subcategories of "Family and Close Environment", "Society" and "Elements of Faith and Culture":

Family and Close Environment

The existing attitudes of the families and close circles of the EIPD limit the individuals. The marriage demands of the individuals are not accepted. Besides, these attitudes have a restrictive effect on the sexual behaviour of the individuals:

P12: Youth was different. It is not like that now. Whatever I do, they judge me saying “what kind of a father”.

P15: How is my sexual life?! Sometimes I just want to walk around, and my daughters immediately ask my whereabouts.

P14: After my husband, there were people who wanted me. My children did not want me to be involved with somebody else. Me neither. One gets used to her husband and knows everything about him. Nothing like that ever happen again.

P19: Sometimes I say I love you to my husband. Even our children judge me for saying that. Everyone thinks that saying this type of thing is shameful, but I don’t think so. I think it is precious.

P9: After my husband died, a man asked me to marry him. My children did not want it. Now, none of my children are with me. A partner is a must.

Society

Social perspective towards the sexual life of EIPD is found to be marginalizing and they are exposed to discrimination referred to as ageism in the literature. Sexual behaviours are not welcomed by the society. The society generally has a negative perspective towards sexual behaviours (holding hands, hugging, kissing) especially in public areas:

P13: The other day, I heard someone saying “Look at this old lady! What she is doing is not appropriate for her age.” What I was doing was just laughing out loud. Even laughing out loud is forbidden to us.

P16: I travel with my husband, and sometimes we hug. The people around us look at us strangely. I would like to see them when they get old.

The findings indicate that society generally has a negative perspective on the sexual lives of EIPD. The participants with disabilities are affected by this. The participants who experienced disability later answered the questions in an indirect manner through other disabled individuals:

P1: I do not think that physical disability is an obstacle for sexual intercourse. It is very bad that people are excluded for this reason. Think about it, everything is the same, except you don’t have feet or your eyes. Why would people discriminate for this reason?

P18: We exclude the disabled. I understood that after I started losing my sight. Being disabled is difficult because everything is prohibited to you. They think something can happen at any moment. But it is actually normal.

P19: They think as if the old age of the person and their disability make them asexual. How wrong this is. It is only natural.

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P6: In our society, people think people lose their sexuality when they reach a certain age. For example, my husband and I kiss each other from time to time. They condemn us for this. Even if they do not say it out loud, it is clear from their behaviour and actions. However, there is no age for this. Since we are in a closed society, and because of the dominance of men, especially women cannot live this openly. In other words, feelings and desires cannot be experienced as we wish. Of course, these issues are blocked due to the fear of death as we age.

Elements of Faith and Culture

In Turkey, cultural and societal values determine the sexuality of the people. In terms of social roles, women are more affected by restrictions on sexuality. The perspective towards sexuality has improved in the modern society, however; sexual activities are not appropriate outside of marriage and talking about sexual matters is a significant taboo.

P1: People live as they wish. But when it comes to talking about it, it is a dead zone; I experienced that. Let me tell you as a foreigner. Especially men want a lot (laughing). But nothing when it comes to talking about it.

P13: We are in such a place and time that even when they see you leaving the house, they judge and gossip about it.

P2: Our opinion was never asked. It did not matter what I wanted. It was always what the man said. We didn't know anything.

P4: Nobody says this, but this is the case. You cannot even love your child in front of your father let alone talk about what you are asking me now (referring to sexuality).

P12: It used to be worse and now it is good. More comfortable.

DISCUSSION

It is argued that the physical well-being of EIPD is affected by sexuality in a study conducted in Turkey. In this study, how EIPD experience sexuality and their level of knowledge about sexuality are discussed. In addition, society's attitudes and behaviours towards the sexuality of the EIPD in Turkey are discussed.

EIPD have limited opportunities to receive sex education in both public and other environments (Addlakha et al., 2017). In this study, EIPD have stated that they have not received any form of education on sexuality but some kind of education should be provided. Participants also stated that their knowledge of sexuality comes from previous experiences and that they benefit from their spouses and friends as sources of information as well as television programs. Regarding sexual issues, participants do not receive support from their surroundings. Married individuals share their

situation with their spouses, and some participants had talked about sexuality with their friends. It is difficult to argue that knowledge regarding sexual matters has a direct effect on the well-being of the individual because the participants consider the knowledge acquired as a result of sexual experiences sufficient. However, the participants emphasised that training on issues such as sexuality and sexual health is necessary. In a study conducted by Metz and Miner (1998), the participants stated that training is necessary to cope with the problems caused by disability and in changing situations depending on age.

In a study carried out by Blieszner (2001), it was determined that individuals who have a sexual partner are better and happier than individuals without any sexual partner. In this study, it has been observed that individuals who are still married and continue their sexual activities with their spouses have more positive feelings than other individuals. Since extramarital relations in Turkey are not widespread and the participants have underlined that sexual life did not continue after marriage ended, the observation is valid for married individuals who have an active sexual life. For individuals who have lost their spouses, the reason for avoiding sexual activities (except for health problems) is the individual's divorce or loss of spouse. Parallel to this, in the study of Gott and Hinchliff (2003), the most important reason for individuals to avoid sexual activities is reported as widowhood and the participants generally advocated for monogamy. In the same study, it was argued that dimensions of sexuality such as emotion and passion were more important for individuals, and sexuality should not be evaluated in one dimension. Similarly, in this study, it is evident that the emotional aspects of sexuality are considered to be more important by the participants, and behaviours such as holding hands, kissing and touching are experienced more frequently.

Individuals should not have diseases that prevent sexual activities in order to conduct sexual activities in a healthy way. Johnson (1998) revealed that healthy individuals engage in sexual activities more frequently than other individuals in his study, thus drawing a connection between sexual behaviour and health. In a similar research study, a significant link was reported between physical health and sexual activities (DeLamater & Koepsel, 2014). The results of this study also indicate that sexuality has a direct impact on the well-being of the individual. It has been inferred that individuals who see themselves positively are the ones who experience sexuality more frequently than other individuals. However, most of the participants who have illnesses that directly affect their sexuality avoid sexual activities. These participants have stated that their sexual life does not continue.

There are many studies arguing that sexual activities continue throughout life (Deacon et al., 1995; Pushkar et al., 2010; Schlesinger, 1996). In this study, EIPD are divided into two categories on this subject. Participants who supported this argument have specified that the feeling caused by sexuality keeps people alive and happy. Those who are not in favour of this argument have different priorities

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over sexual matters. This difference can be explained by religion and culture. In a study conducted by Trudel and Desjardins (2000), it was observed that individuals' sexual decision-making processes are based on religion and culture, while at the same time, they constantly experience emotional conflicts. This finding of Trudel and Desjardins (2000) is in line with the results of this study.

Societal attitudes towards the sexual life of IPD are generally negative. In a study, the participation rate of EIPD in sexual matters was found to be 20% (Evans et al., 2009). In another study, members of family and close environment think that individuals are more sensitive and vulnerable due to their disability. Due to this attitude, families display insensitive behaviours in issues related to sexuality and try to avoid discussion of the subject. (Aunos & Feldman, 2002). Some of the participants stated that the wishes of IPD to marry after the loss of their spouses were rejected by their family members for various reasons. This indicates that overprotective and defensive behaviours are exhibited by the family and the environment.

The freedom of expression of IPD on sexual matters is restricted and is not tolerated by society. It has been observed that especially the behaviour of married individuals in society is judged and that these individuals do not have freedom of sexual expression. In a study conducted by DeLamater and Koepsel (2014), it was found that the expressions and thoughts of individuals on sexual issues are limited and not welcomed due to old age. It is also argued that this situation is experienced differently in different locations because of cultural differences. In a study by Johnson (1998) about the investigation of the relationship between sexual expression and life satisfaction, the life satisfaction of individuals with negative attitudes and thoughts in relation to sexual issues was found to be lower than elderly individuals with positive attitudes.

There is a consensus in the literature that physical disability affects sexual activities negatively. Physical disability and related problems limit sexual activities and cause individuals to avoid sexual activities. Since all participants have confirmed that they have become disabled later in life, they may experience the effects of physical disability differently from individuals who have experienced the effects of disability since birth (McCabe et al., 2003). They were more socially and sexually active before they had a disability. At this point, there emerges a need for trainings to support these individuals and ease their adaptation to new conditions and attitudes (Minihan et al., 2011).

CONCLUSION

Participants have stated that they consider themselves sufficient or partially sufficient in terms of sexual knowledge. It is evident that the knowledge of the EIPD is based on their experience. Since none of the participants received sexual education, it is difficult to say that their knowledge was sufficient. The sources of information for the matters on sexuality were generally their spouses and

friends, and some participants obtained the information from television programs and books. However, most of the participants stated that they did not talk to anyone about sexual issues and they found it wrong that these issues are not discussed.

The participants generally acted hesitant to share their sexual experiences. They think that sexual issues are intimate subjects and gave short answers when conveying their sexual experiences. The majority of the participants stated that their first sexual experience was after marriage. It was observed that sexual experiences are important in the lives of individuals. Especially love, being loved and being attached keep individuals alive. Almost all of the participants agreed that sexual activities should be within the framework of marriage. The participants focused more on the emotional outcomes of sexuality, and it is observed that with age emotional attachment replaces sexuality.

Regarding the sexual preferences of the participants, it was discovered that both physical characteristics and personality traits were equally important to them. While female participants mostly focused on personality traits, male participants gave more importance to physical characteristics. Generally, it can be stated that attractiveness is attributed to youth and with aging it is replaced by respect and devotion. This indicates a change in the attitudes towards a partner with age. In old age, individuals support each other and share their loneliness independent of physical characteristics. In addition, cultural and social contexts in Turkey support this change in attitudes and perceptions of partners in old age.

The family and society have negative attitudes regarding the sexual life of EIPD who are married and continue to partake in sexual activities. Sexual behaviours are not welcome by the society. It was stated that the sexual expressions of the participants were limited since they were supressed by the negative messages of the family and society. EIPD refrain from discussing sexual matters and exhibiting sexual behaviour.

Limitations

The aim of this study is to reveal the deep meanings and different experiences of sexuality. In this sense, the inclusion of individuals in Mersin province in the study limits the study in terms of reflecting the diversity of the participants. The fact that all participants receive care in a home environment is insufficient to convey the experiences of individuals residing in care institutions. In addition, the fact that all participants have become disabled at a later stage of life results in a limitation to revealing their innate sexual experiences. Failure to reflect the perspectives of individuals who chronically experience sexual problems is seen as a limitation to research. Finally, it is among the limitations of the study that the individuals may not fully share their own beliefs, attitudes and behaviours due to cultural and social structures where sexual experiences and freedom of expression are limited.

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Recommendations

In this section, considering the literature, and the experiences of the researchers, some suggestions to contribute to the multi-faceted and holistic regulations and policies for the sexual lives of EIPD are discussed in line with the research results.

It is thought that the number of studies on the sexual life of EIPD and supporting research on taboo subjects should be increased. Besides, it is recommended that the topic of sexuality of EIPD should be included in the education curriculum.

Ensuring that the sexual health histories of EIPD are taken and followed-up by healthcare workers as well as organizing sexual education programs for healthcare workers are thought to be useful. Moreover, developing institutional responsibilities that will enable IPD to receive training on “Sexual Health” and “Sexuality of the EIPD” and establishing centres where individuals can apply is highly recommended. At this point, it is also significant to broadcast accurate information on “Sexuality”, “Sexual Health” and “Sexuality of Elderly People with Physical Disabilities” through mass media and other media tools and routinizing sexual health programs.

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