

Factors Influencing Dental Patient Participation in Biobanking and Biomedical Research

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Key Words

Biobanking · Oral tissues · Diseases · Biospecimens · Biomedical research

Abstract

Objectives: To study the willingness of dental patients to donate biospecimens for research purpose and to examine factors that may influence such a decision. **Materials and Methods:** A face-to-face interview was conducted using a pretested structured survey instrument on 408 adult dental patients attending a university hospital for dental care. Descriptive statistics were generated, and the χ^2 test was used to examine differences between groups. p values ≤ 0.5 were considered statistically significant. **Results:** Of the 408 participants, only 71 (17.4%) had heard of the terms biobanking/biospecimens, but 293 (71.9%) approved of the idea of using biospecimens for biomedical research, and 228 (55.9%) were willing to donate biospecimens and give personal information for research purposes. In participants who were unwilling to participate in biobanking, fear of information leakage was the most frequently reported reason, while in participants who were willing to donate biospecimens, the poten-

tial to provide more effective and less costly treatments was the most frequently reported reason. The preferences of the 228 participants who were willing to donate biospecimens were as follows: give a sample of removed oral tissues including extracted teeth ($n = 105$, 46.1%), donate a blood sample ($n = 52$, 23%), donate a sample of saliva ($n = 43$, 18.6%), and give a urine sample ($n = 28$, 12.3%). **Conclusion:** Dental patients had a generally positive attitude towards biomedical research and biobanking. The most preferred types of biospecimens to donate in a dental setting were removed tissues, including extracted teeth and blood samples.

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Introduction

A biobank is a facility where biological specimens are collected, stored, processed, and disseminated together with associated sociodemographic, clinicopathological, management, and follow-up data [1–3].

Recognizing their importance in biomedical research, several countries have developed their own biobanks at a national level and have become involved in international

collaborative research projects involving biospecimens from various parts of the world with diverse genetic and environmental backgrounds. Among the prominent biobanks are the UK Biobank, the Victoria Cancer Research Tissue Biobank (Australia), and the Canadian Tissue Network Repository [4]. The US is launching a national biobank as part of the President's Precision Medicine Initiative.

The success of biobank projects depends largely on public understanding and support. Previous studies have shown positive attitudes towards biomedical research and high rates of intention to participate in biobanking among Jordanians [5]. However, the success of a biobank also depends on active involvement and support from health care facilities across multiple disciplines, including dentistry. In fact, dentistry has been formally involved in the UK Biobank since 2002 and now constitutes an integral resource for biospecimens and clinical data [6]. Dental contribution to biobanking involves the collection of clinical and demographic data through questions included in the initial medical history questionnaires conducted by dental staff, and the collection of biospecimens including saliva, blood, urine, extracted teeth, and oral tissues. It is estimated that there are more than 120,000 saliva samples processed and archived in the UK Biobank [7], and more than 10,000 shed primary teeth stored in the Norwegian Mother and Child Cohort Study (MoBa Tooth) since 2008 [8].

The involvement of dentistry in biobanking could contribute to uncovering links between common oral and dental diseases and other more systemic diseases. Specific biobanks for oral diseases have recently been established, including the Malaysian Periodontal Database and Biobank System (MPDBS) and the Malaysian Oral Cancer Database and Tissue Bank System (MOCDBS) [4, 9]. Jordan is a developing Middle Eastern country with a relatively advancing health care system and a capacity for developing biomedical research. Patterns of oral and dental diseases in Jordan are similar to other countries in the Middle East due to similarities in risk factors and cultural and environmental backgrounds [10].

Previous studies indicated that dentists were generally willing to perform chairside medical screening, measure blood pressure, and collect saliva and finger-stick blood [11]. Similarly, studies conducted on dental patients indicated that the majority are willing to undergo chairside medical screening tests performed during their dental visits [12]. It is unknown, however, how dental patients would perceive the idea of donating their personal data and biospecimens, in a dental setting, for biomedical re-

search. The purpose of this study, therefore, was to examine the perception of dental patients toward biobanking and to study factors that might influence their decision to donate biospecimens and participate in biobanking.

Materials and Methods

The Faculty of Dentistry Research and Ethics Committee, University of Jordan, Amman, reviewed and approved this study which was conducted during the period of September 2014 to January 2015 in full accordance with the World Medical Association Declaration of Helsinki. Written informed consent was obtained from all participants.

Study Population

A total of 487 adult patients (>18 years) attending the Department of Dentistry at the University of Jordan Hospital for dental treatment during the period from September 2014 to January 2015 were approached to participate in the study. The University of Jordan Hospital is the main public teaching hospital in the capital of Jordan attended by patients from diverse socioeconomic backgrounds.

Interview

The study was conducted using a pretested questionnaire instrument [7]. A pilot study was conducted initially to ensure that the interview was easy to conduct and lacked ambiguity. Sample size was determined using the n-Query Advisor Software with oversampling to account for potential withdrawals. The interviews were conducted in Arabic by a trained coauthor (N.O.) and required 7–10 min to complete. The nature of the study was explained, and all participants formally consented. Then, demographic data were collected from respondents, including gender, income, and education.

The participants were asked whether they had ever heard of or read about the terms 'biospecimens' or 'biobanking'. A paragraph defining biospecimens and the concept of biobanking was read to the participants, and information about the potential operation of the biobank was explained. These included the absence of direct health benefit, lack of payment to the participant or cost for participation, access of health information, recontact by the research team, freedom to withdraw, availability of consent, availability of general research results (but not individualized data), participation of non-Jordanian researchers, indefinite storage of samples, imprecise research results (findings of unknown clinical significance), and religious approval of research (Appendix).

The participants were then asked about their willingness to donate biological samples and reveal personal and health-related information for research purposes. Responses were recorded as either agreed or disagreed, and participants were queried about the reasons behind their decision by asking them to choose from a list of potential reasons (the participants were told that they could choose more than one choice if applicable). Reasons for disagreeing to participate were compiled from literature review [5] and research team suggestions, and included the following 12 statements: (a) I do not trust medical research; (b) I think medical research is just a waste of time; (c) I do not think medical research

Table 1. Ranking of reasons behind the decision of participants to participate in biobanking

Willing to participate		Unwilling to participate	
Factor	Responses, n (%)	Factor	Responses, n (%)
Participation in biobanking would help to provide more effective and less costly treatment	88 (38.5)	Fear of information leak	45 (24.8)
Biobanking would provide new working opportunities	51 (22.4)	Recontact by research team	39 (21.7)
Religious beliefs	41 (18.6)	Fear of physical harm	37 (20.4)
Participation in biobanking makes me feel like a member of the medical team	22 (12.4)	Inability to access personal research results	34 (19.1)
Existence of signed consent	19 (8.1)	Existence of signed consent	32 (17.8)
Participation of international researchers	13 (5.8)	Indefinite storage of samples	25 (14)
		Fear of unethical research	24 (13.4)
		Religious beliefs	17 (9.6)
		No trust in medical research	15 (8.3)
		Lack of monetary benefits	15 (8.3)
		Participation of international researchers	15 (8.3)
		Waste of time	10 (5.7)

will benefit me; (d) I think giving biospecimens for research purposes conflicts with my religious beliefs; (e) I am afraid that medical research is unethical; (f) I am afraid (or do not want) to give my signature/consent; (g) I am afraid (or do not want) to keep my data/biospecimens for an undefined period; (h) I am afraid of a possible information leak; (i) I am afraid that donating biospecimens will cause physical harm to me; (j) I am afraid that researchers will keep contacting me in the future; (k) I want to know the results of tests done on my own biospecimens, and (l) I am afraid of (or do not want) the involvement of international researchers. Reasons to agree to participate in biobanking were similarly compiled from literature review [5] and research team suggestions, and included the following 6 statements: (a) I think my participation in biomedical research would help to provide more effective and less costly medicines; (b) biomedical research might offer new work opportunities; (c) participation makes me feel like a member of the research team; (d) my religious beliefs encourage me to participate; (e) I feel comfortable with the presence of signed consent, and (f) I feel comfortable with the participation of international researchers.

The final part of the interview involved asking the participants about the type of biospecimens (blood, saliva, urine, extracted teeth, and oral tissues) that they would be willing to donate in a dental setting. The participants were also asked whether they would agree to use donated specimens for nondental/oral research.

Data Analysis

Statistical analysis was performed using SPSS for Windows release 16.0 (SPSS Inc., Chicago, Ill., USA). Descriptive statistics were generated. The χ^2 test was used to examine differences between groups. Results were considered significant if p values were ≤ 0.05 .

Results

Demographic Characteristics

Of the 487 adult patients who were approached, 408 (83.7%) agreed to participate and completed a face-to-face interview about biobanking. Of the 408 participants, 170 (41.7%) were male and 238 (58.3%) were female. The mean age of the participants was 36.2 ± 14.2 years (range: 18–85). Regarding education, 199 (48.8%) participants had a university education, 183 (44.9%) had high school education, 20 (4.9%) had elementary education, and 6 (1.5 %) were illiterate. In terms of monthly income, 208 (51%) participants had less than JOD 400, 120 (29.4%) between JOD 400 and 800, 42 (10.3%) JOD 800, and 38 (9.3%) did not report their income (JOD 1 = USD 1.4).

Awareness about Biobanking and Attitudes toward Biospecimen-Based Research

When asked about their knowledge of the terms biobanking and biospecimens, 71 (17.4%) participants had previously heard of the terms. Female patients were more aware about biobanking compared to male participants ($p < 0.05$), and participants with a university education were more aware about biobanking compared to those with less than university education ($p < 0.05$). No significant association was found between biobanking/biospecimen awareness and the age or monthly income of the study participants ($p > 0.05$). A total of 293 participants

(71.9%) approved of the idea of using biospecimens for biomedical research, and 228 (55.9%) were willing to donate biospecimens and personal information for research purposes. No significant difference was found between age, gender, education, and monthly income and willingness to donate personal information and biospecimens for research purposes ($p > 0.05$).

Factors Influencing the Decision of Participants to Donate Biospecimens and Personal Information for Research Purposes

The reasons of participants for their decision regarding donating personal information and biospecimens for research purpose are listed in table 1. In participants who were unwilling to participate in biobanking, fear of information leakage ($n = 45$, 24.8%) was the most frequently reported reason for their decision, followed by physical harm ($n = 37$, 20.4%) and recontact by the research team.

As for participants who were willing to donate biospecimens, the potential to provide more effective and less costly treatments ($n = 80$, 38.5%) and new work opportunities ($n = 51$, 22.4%) were the main reasons behind their decision to participate (table 1).

When asked about their response regarding using their biospecimens for further research, most participants ($n = 135$, 59.2%) agreed unconditionally, 72 (31.5%) would agree after knowing more about the intended research, and 21 (9.2%) did not agree.

Sample Preference

The preferences of the 228 participants willing to donate biospecimens for biobanking were as follows: give a sample of removed oral tissues including extracted teeth ($n = 105$, 46.1%), donate a blood sample ($n = 52$, 23%), donate a sample of saliva ($n = 43$, 18.6%), and give a urine sample ($n = 28$, 12.3%). No significant differences were found between sample preference and the age, education, and monthly income of participants. However, female participants were less likely to be willing to donate saliva and urine samples ($p < 0.05$).

Discussion

In this study, a high response rate of 83.7% was obtained, which reflected the interest of this cohort of dental patients in the subject of biobanking and biomedical research as well as the brevity of the survey and the lack of other activities in the waiting room.

The finding that the terms biospecimens and biobanking were not known by most dental patients in the present study confirmed those of previous studies in both developed and developing countries [13–15]. The familiarity with the terms was not a major concern because, after it was explained to them, the majority of participants approved the idea of using biospecimens for research, and more than half were willing to donate biospecimens and give personal information similar to other studies [4, 16]. The 55.9% willingness to donate samples among dental patients of the present study was within the range of 40–96% reported previously [17–22] and close to 63% reported for the general public in Jordan [4]. It has been reported that more patients may be willing to donate samples for research than the general public, probably due to a need to reciprocate or because they find themselves as part of a social community [5, 23].

In this study, the negative factors of fear from information leak, physical harm, and recontact by the research team that influenced the decision of dental patients to participate in biobanking confirmed those previously observed in Jordan [24].

Jordan is a predominantly Muslim country. The findings of our study showed some discrepancy with regard to the influence of religion. While 18.6% of participants were encouraged to participate in biobanking because of religious beliefs, 9.6% were discouraged for the same reason. Studies from the UK and Singapore showed that the opinions of Muslims toward biospecimen donation were negatively shaped by presumed religious beliefs [15, 22]. Clarifying the position of religious teachings regarding the donation of biospecimens could potentially improve the willingness to participate in biobanking.

In this study the inability of participants to access the outcome of their donated biospecimens negatively influenced their decision to donate samples for research. Returning research results to participants is a major incentive to participate in biobanking [24, 26, 27]. However, drawbacks for returning personal research results include the need for financial and logistical support, the fear of data misreporting, and the association of research data with negative psychological and social burdens without clinical benefits [28]. It has, therefore, been suggested that the dissemination of generalized research results in the form of periodic newsletters or via public forums and websites may be a satisfactory alternative [24, 25]. The availability of generalized research results displayed in dental offices may help to improve the willingness of dental patients to donate samples for research through showing respect toward participants, educating

them, and increasing their interest in biomedical research.

A sample of removed oral tissues, including extracted teeth, was the preferred type of biospecimen to donate by the dental patients in our study, possibly because there are no additional procedures to be performed since tissue will be removed anyway as a part of their dental treatment. Around a quarter of the participants preferred donating a blood sample, possibly because the procedure of venipuncture is familiar and easy to accept for most participants. Although the collection of saliva samples is simple and noninvasive, only 18.6% of the participants were willing to donate saliva; this may be because participants were unfamiliar with the procedure or felt embarrassed to give a sample of their saliva. The willingness of dental patients to donate various types of biospecimens in the dental clinic, including blood and urine, indicates that dental staff should be trained to collect and store these samples. The willingness of dental staff to perform such procedures needs to be examined since additional costs and extra time and effort might be needed.

An inherent limitation of the present study is the fact that it used a self-report interview; participants therefore might be reluctant to explicitly disclose their views and rather provide biased and socially acceptable answers. In addition, we assessed the future intention to participate in biobanking which may not reflect actual behavior. In fact, Johnsson et al. [29] (2010) reported that surveys assessing willingness to participate in biobanking predict actual behaviors poorly. Furthermore, the present study was conducted in a teaching hospital, a setting that might influence the responses of participants and might not necessarily reflect the responses and attitudes of dental patients attending private dental clinics. The influences

of other factors, such as the declared purpose of the research or its perceived significance, on the willingness of patients to donate biospecimens were not addressed in the present study. Patients in a dental setting might be more willing to donate samples for research studies addressing oral or dental diseases, but might feel uncomfortable donating their biospecimens for research studies addressing issues other than dental/oral diseases. Further studies are needed to test this assumption.

Conclusions

In this study, dental patients generally had a positive attitude and a willingness to donate biospecimens and give personal information in biobanking and biomedical research. The most preferred types of biospecimens to donate in a dental setting were removed oral tissues, including extracted teeth, and blood samples.

Appendix

Biospecimens were defined to participants as samples of material, such as urine, blood, tissue including teeth, cells, DNA, RNA, and protein from humans. Biospecimens are stored in a biorepository and are used for laboratory research. Medical information may also be stored along with a written consent to use the samples in laboratory studies.

Biobank was defined to participants as a place where biospecimens are collected, stored, processed, and analyzed.

Personal information was defined to participants as gender, date of birth, social status, family history and circumstances, medical history, current medications, occupation, and place of residence. Participants were informed that collected information is only used for research purpose.

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